# Knowledge Network in Rural and Remote Dementia Care

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

## 1st Annual Summit

### November 20 - 21, 2008
### Saskatoon, SK

# FINAL REPORT



CCHSA / CCSSMA

Saskatchewan Health Research FOUNDATION

Rural Dementia Care

*Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas*

UNIVERSITY OF SASKATCHEWAN

CIHR IRSC

**Save the Date!**

**October 2009**

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Mark your calendars now for the 2nd Annual Knowledge Network in Rural and Remote Dementia Care Summit

**October 29th & 30th 2009**

# Contents

Dear Decision Maker Advisory Council members:


Thank-you for your participation in the first annual Summit of the Knowledge Network in Rural and Remote Dementia Care, held in Saskatoon in November, 2008. On behalf of the research team members, I want to express my appreciation for your time and input, as we work together to develop the research, education, and knowledge exchange program of the Applied Chair in Health Services and Policy Research that was recently funded by the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation. The title of the Applied Chair program is *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia.*

This report summarizes the activities of the meeting on Friday November 21st, 2008. A separate report was created with copies of the posters presented at the wine and cheese reception on Thursday November 20th.

The second annual Summit will be held on October 29th and 30th, 2009, in Saskatoon. We plan to follow a similar format to this year's meeting, and we have reserved space at the Sheraton Hotel for both the Thursday evening and Friday sessions. We encourage you to mark these days in your calendars.

As I mentioned at the meeting, I will be in the UK on a sabbatical trip in January and February 2009. I will take up funding for the Applied Chair program in March, 2009. Once again, thank you for helping to launch this "new" research endeavour, which will allow our team to continue its work to improve dementia care in rural and remote areas, with your guidance.

Sincerely,

Debra Morgan

## Preamble and Summit Summary

This report summarizes the activities of the 1st Summit of the Knowledge Network in Rural and Remote Dementia Care held in Saskatoon on the 20th and 21st of November 2008.

The summit was held as an opportunity for Decision Makers and researchers--from a variety of disciplines--to meet and exchange ideas and identify future priorities for further inquiry in the delivery of healthcare for rural and remote seniors with dementia in Saskatchewan. Hosted as an integral part of the activities of the Canadian Institutes of Health Research (CIHR) Applied Chair in Health Service and Policy Research Program, the summit provided an arena to foster research, knowledge translation and exchange between participants. Attendees included researchers linked to the CIHR New Emerging Team (NET) on Rural and Remote Dementia Care, and Decision Makers who work "in the field" to plan and provide care to people affected by dementia, their families and communities. The Decision Maker Advisory Council will provide ongoing guidance to the research team.

Before the summit, the group of decision makers were provided with orientation materials to prepare them for the meeting, and were asked to identify the top three issues that they see in rural and remote dementia care (participant responses are listed in appendix A of this report).

Anchored at the Sheraton Cavalier Hotel in downtown Saskatoon, the first day of the Summit included an informal wine and cheese reception and poster session (a document with copies of the posters is available, please see page ten for information on how to request a copy). An opportunity for the researchers in attendance to discuss research progress with the decision makers, the evening also provided some background context for the discussions that would take place the next day. The conviviality of the evening was enhanced by the announcement that the proposed Applied Chair research program in rural and remote dementia care was funded by CIHR and the Saskatchewan Health Research Foundation (SHRF). The award will be taken up March 1, 2009.

During the second day of the summit, meals and meetings were held at Saskatoon's TCU Place. The morning began with opening remarks and a presentation from Dr. Debra Morgan outlining the CIHR Applied Chair program, and the team research program and activities to date. Dr. Morgan then introduced five priority areas in rural and remote dementia care for further discussion. These five priority areas had been identified by the summit organizing team as common themes present among the "top three issues in rural and remote care" submitted earlier by the decision makers. Some discussion was had among the large group about these five priorities, and then participants self-selected into one of five groups for further small group discussion of the priority which most interested them. The events for the day were scheduled with a desire to provide opportunities to nurture informal conversations between decision makers and researchers, and therefore the group paused for an ample lunch break. After lunch, a representative of each small group reported back on the discussion and identified important themes and potential areas for further research from their priority area. The discussions in the small groups were captured by both a 'secretary' and a flip-chart note-taker for each group. The themes from each group discussion are contained in this report.

After an opportunity to collect some evaluation information about the event, the day finished with participants excited about the experience, and looking forward to another opportunity for the group to meet to exchange information.

**Five Priorities: Discussion and Elaboration**

As the summit organizing team reviewed the "three top issues" in rural and remote dementia care submitted by participants prior to the event, they were able to identify five thematic areas from all of the responses collected. These five themes were presented as priority areas for discussion at the summit. The five priority areas are:

1. Expertise and Specialized Care
2. Best Practices and Client-Centred Care
3. Access Issues
4. Education of Formal and Informal Caregivers
5. Supporting Patients, Caregivers & Communities

After the morning opening remarks and presentation of the five priority areas the entire audience had the opportunity to discuss these, assisted by a number of PowerPoint slides with example issues or discussion points for each priority area. The room then broke into five small groups. Each group spent the rest of the morning discussing their chosen priority area. After a lunch break, each small group was able to report their findings to the larger group.

The small discussion groups were provided with objectives as a guide to help them in their discussion. The objectives were as follows:
1. As a decision maker, what benefits do you see from involvement in knowledge exchange events such as this?
2. For your priority area, was anything missed from the discussion so far?
3. What research would you find most useful in this priority area?

Each group discussion was recorded both by an appointed 'secretary' for the group, and a note-taker who tracked group comments on a flip chart. The following five pages summarize and condense issues identified in the group discussions on that day. Verbatim copies of group notes have been retained and are available from Debra Morgan (please see page ten for contact information and additional documents available).

As you read this report please keep in mind that due to time constraints and the vibrancy of discussion, not every group was able to fully address each of the three objectives listed above. A lack of a summary of one of the three objectives indicates that the group discussions focused more strongly on the other objectives.

Please also note that the italicized text in the following summaries indicates discussion points presented to the groups during the morning plenary. These discussion points were chosen from the responses participants provided prior to the summit (appendix A).

## Discussion Group 1 - *Expertise and Specialized Care*
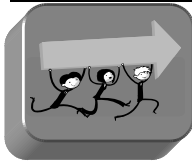
-tools and supports    -education

-interventions    -multidisciplinary    -turnover

-behaviour management    -barriers

The participants in group one included: Tom Smith Windsor, Andrew Kirk, Debra Morgan, Moira Remmen.

1. Group one's **identified benefits** they see in knowledge exchange events such as this summit included:
*-Exchange of ideas and knowledge between individuals working in the same field is valuable.*
*-There is a usefulness and added learning that comes from an interdisciplinary approach.*
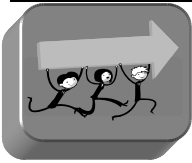
2. The group discussed the following points which had so far been **missed in the discussions:**
 (The points in italics were collected prior to the summit and discussed during the morning plenary)
*-Fewer clinicians in rural areas providing dementia care.*
*-Hard to even get a diagnose; wait lists for services are long.*
*-Specialist services and referrals not as common post-diagnosis or once a person is admitted to LTC.*
*-No established mechanisms in place for connecting different care providers or levels of care.*
*-Impacts of clinician turnover: in rural communities many practising physicians do not plan to stay long-term. This creates concerns for continuity of care, relationship development between patient and physician, and historical understanding of patient behaviour when making diagnoses.*
*-Multidisciplinary approaches: other health care professionals participation in the decision making process is very helpful to individual physicians. Needs change during the course of dementia, and a multi-pronged approach can best respond to changing needs. It is important to include families; they see what is needed, and how needs are changing. As well, more communication between family doctors and specialists at the end of the day, and utilizing one-stop appointments and TeleHealth are processes which will only improve dementia care.*
*-Behaviour management: behavioural issues are the biggest problem, and behaviour management expertise is needed in rural settings. This would help both physicians and family.*
*-Tools needed for professionals: family doctors are often uncomfortable making a diagnosis of dementia, how can we increase comfort? What is family doctor role in managing dementia as often they are only accessed when a particular problem manifests. Providing dementia care requires time; how can doctors be supported to provide longer appointments.*
*-Tools for education: there are a variety of new technologies (Web based interactive learning platforms, telephone, tele-video) which could be utilized to deliver interactive education for rural professionals.*
*-Education and awareness: education is needed for family doctors and 1st degree health care workers, some referrals do come from home care workers. Can we increase education about dementia for health care workers in general? There also exists a need to educate family members and the public: not only in an understanding of dementia, but also as to what services are available.*
*-Overcoming barriers: in rural dementia care language and cultural differences between physicians and patients can impact care.*

3. In discussing **research that would be most useful in this area**, group one identified the following:
*-Comparing the referral diagnosis from family doctor to the clinical diagnosis from specialists.*
*-Examine the outcomes from early versus late intervention in dementia. Is there an advantage?*
*-Research to show what behaviour management is effective.*

## Discussion Group 2 - *Best Practices and Client-Centred Care*

-support systems          -Communication
-Consistency              -Cultural shift
-leadership               -diverse population

The participants in group two included: Leslie Holfeld, Taylor Bassingthwaite, Dave Gibson, Hazel Crosson, Anita Bergen, Carol Gregoryk, Carol Dyck, Charlene Chipeur, Elizabeth Waterer.

1. Group two's **identified benefits** they see in knowledge exchange events such as this summit included:
*-A need to do this all the time, front line staff and decision makers agree that Knowledge Translation is necessary.*

2. The group discussed the following points which had so far been **missed in the discussions:**
(The points in italics were collected prior to the summit and discussed during the morning plenary)
*-Important to focus on therapies that optimized quality of life for those living with dementia.*
*-Culturally appropriate care is essential:* we are a diverse population and cultural sensitivity cannot be reductionist. We need to consider the needs of Aboriginal residents and other cultures. Languages spoken can create barriers between residents and staff, as well as dietary needs, or cultural practices.
*-Evidence, outcomes, and best practices need to be communicated to front line staff in LTC and home care in ways that are 'hands-on':* change to improve quality of care cannot happen without strong **communication** and **leadership** on multiple levels from Ministry down to hands-on staff. Leaders need to lead and need to understand the experiences of front line staff; focus attention on the people in the system.
*-We need to provide quality care, but in a way that gets beyond schedules, routines, etc.*
-Cultural shift in care delivery: shifting to a client/patient-directed care model with family input is a shift from the current model of staff directing what care is appropriate. Routines are very ingrained, and without buy-in from staff, are difficult to change. Changes not implemented well create chaos, which discourages care staff from accepting "best practices".
-A common definition: we all speak of "Best Practices", but what does it mean? Do we all understand this term in the same way?
-Physical space that is conducive to best care: many now LTC centres were not constructed for dementia care, or are very old. It's important to respect a balance between public space and residents' living environment.
-Education and knowledge exchange: providing training to caregivers to deepen their knowledge of dementia would help them understand the variety and effects of dementia. Opportunities for information sharing between facilities would also be valuable. Funding to educate staff, host workshops, and support good mentoring programs is needed.
-Consistency of care: we need a provincial-level care standard or a senior's strategy. The province needs to provide leadership by setting baseline care standards, and then allow enough flexibility for individual regions to tailor care.
-Support systems: support needs to be holistic. LTC system can respond of the needs of the patient in the context of their family and community. As well, LTC systems can fulfill their mandates while fostering support for individual staff members, patient family concerns, and community.

3. In discussing **research that would be most useful in this area**, group two identified the following:
*-Examining mortality rates/level of relocation stress/delirium caused by current policy of LTC placement.*
*-Developing LTC best practices in Saskatchewan, and examining standards of care.*
*-Physical environments that are conducive to dementia care/client-centred care.*
*-Effects on client and family with the first bed first served policy in Saskatchewan.*

## Discussion Group 3  - *Access Issues*
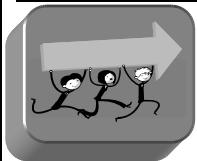
-the "personal touch"
-context
-vast geography

-balancing care with cost
-ageing in place
-appropriate access

The participants in group three included: Carl D'Arcy, Leslie Holfeld, Julie Kosteniuk, Turner Goins, Heidi Schmaltz, Diania Daigneault, Glenda Montgrand, Lesley McBain, Chandima Karunanayake, Rob Beever.

1.  Group three skipped the **discussion of benefits** they derive from participating in knowledge exchange events such as this summit to spend more time on the other discussion points.

2. The group discussed the following points which had so far been **missed in the discussions:**
 (The points in italics were collected prior to the summit and discussed during the morning plenary)
*-Geographic, financial, and distance/travel related burdens limit access.*
*-Fewer services/ resources within rural/remote communities; the smaller the community the fewer services available.*
*-Awareness of services and supports within community or outside of community often complicates reduced availability.*
-Access, what does it mean: is access an umbrella issue that affects the other four discussion groups, or is it an issue itself? Access can mean not only getting into a service at a level appropriate to the need of the client, it can also be access to education and access to supports.
-Increasing specialist access across vast geography: travel to visit urban centres to access specialists is expensive for people living in northern SK. Can we further expand and utilize TeleHealth services to cost-effectively provide access to specialized care. In the U.S. tele-home-health is utilized with much success to provide care to people in remote areas.
-Balancing quality care with cost efficiency: TeleHealth saves travel costs, but incurs technology costs. It also means we lose some context, and 'the personal touch'. Expecting patients to travel long distances in poor weather is a risk – we need to balance patient safety with fiscal considerations. Sometimes a simple phone call can be just as effective too.
-What already exists in the community: are there chronic or acute care services already in the community? Pre-identifying what is available to a community is really important, often when people have a problem it manifests as a 'crisis' situation.
-Access to language services: because of vast geography and infrequency of need it can be difficult for policy makers to justify translation costs, but access to translation affects care.
-Ageing in place: policy makers need to focus on balancing the needs of the individual, the community, and funding to support people accessing and receiving care in their community. Pressure on First Nations communities (due to shifting cultural practices which result in fewer First Nations people living in large family groups who provide support and direct care to elderly family members) means that First Nations leaders are calling to build LTC centres specifically to support elderly community members to continue living in the community.
-Appropriate access to care for episodic and chronic needs: consistent, flexible care which balances the safety and risk needs of the client with the resources available to the community.

3. In discussing **research that would be most useful in this area**, group three identified the following:
-There needs to be research evidence on "what is the appropriate level of service in rural and remote communities".
-What can we do remotely? Are there limits to TeleHealth? Do we need human contact?
-What do informal caregivers need? Sometimes the people who don't use the services can tell you the most about what the barriers to those services are.

## Discussion Group 4 - *Education of Formal and Informal Caregivers*
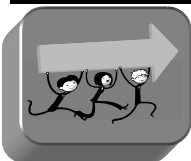
-public awareness          -engaged leadership
-access                    -different models
-decrease stigma           -continuing education

The participants in group five included: Morley Hewison, Janet Keim, Beverly Greenwood, Brenda Walsh, Diania Daigneault, Cynthia Shelstad.

1. Group four skipped the **discussion of benefits** they derive from participating in knowledge exchange events such as this summit to spend more time on the other discussion points.

2. The group discussed the following points which had so far been **missed in the discussions:**
 (The points in italics were collected prior to the summit and discussed during the morning plenary)
*-Many people with dementia and their caregivers do not understand their diagnosis or have basic information that will help them live their life to the fullest with [dementia].*
*-Lack of qualified, trained staff providing dementia-care in rural areas.* This is partially due to the fact that many SCAs in rural communities were 'grandfathered in' without specialized education.
*-Knowledge transfer, education, and on-going support for people working/living with individuals with dementia.*
-Continuing education for LTC staff is a priority: it is important to keep LTC staff up-to-date and well trained, but currently it is difficult to find funding support to make continuing education for SCAs possible. Nurses need education too, can we explore different models: Train the Trainer, story-telling to illustrate good approaches to dementia care, etc. One of the newer models being explored in Alberta is a competency-based approach with the following principles for LTC staff: Path of least resistance, No means no, So what?
-Variety of peoples in long term care requires a variety of education: the shifting demographic towards more older persons in long term care means an increased need to focus education on geriatric and dementia related care. As well, older mental health clients affected by drugs and or alcohol, crystal meth, etc present needs that are different than the typical focus of SCA education.
-Access to education in remote areas: for staff in remote areas how can we use technology (TeleHealth, stored presentations, access to computers) to bring education to them?
-Engaged, learning leaders: leaders in LTCs need continuing education too; they need to set an example for all staff in making education a priority. They also need to share decision-making and leadership tasks to empower SCAs to make decisions.
-Informal caregivers are a diverse group and need a variety of educational opportunities: not only do they have varying levels of knowledge, and require varying levels of further education, informal caregivers often require education about what services are available in their community. Can we engage family physicians to start the process of educating informal caregivers? Providing handouts/pamphlets which can serve as a 'roadmap' to services has proven to be useful, but they need to be made available to family doctors to distribute to community.
-Increasing public awareness and involvement: we are a complex society facing a number of issues such as ageing, a variety of mental health issues, children with special needs, and diverse peoples. We need to educate our children to decrease stigma, and offset the effects of media attention which often portrays a negative picture of people in LTC. Programs such as intergenerational activities, a 'buddy' program, or adopt a family can help to raise awareness.

3. In discussing **research that would be most useful in this area**, group four identified the following:
-Research that informs policy – providing specific recommendations that can be applied in the field.
-Advocate research results to the province to impact funding. Research can support the policy-maker's work, and help to change practices (ie: funding for education programs should be consistent funding)
-Research focus to target the SCAs and help to change the culture of care. Exploring MAREP versus Carewest, for example.

## Discussion Group 5  - *Supporting Patients, Caregivers and Community*
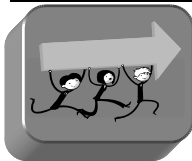
-collaboration
-advocacy
-holistic care

-culturally relevant
-northern communities
-1st nations Peoples

The participants in group five included: Dorothy Forbes, Barbara Church-Staudt, Peter Butt, Heather Dyck, Stephen Britton, Allison Cammer, Vanina Dal Bello-Haas.

1. Group five's **identified benefits** they see in knowledge exchange events such as this summit included:
-exchange of ideas and knowledge between individuals with various levels of expertise
-learning from each other which helps each person move forward in their advocacy and professional roles.
-an appreciation for inclusion of Aboriginal peoples in the discussions and the process
-an appreciation of the opportunity for collaboration; value of having service users, providers, and researchers working together.

2. The group discussed the following points which had so far been **missed in the discussions:**
 (The points in italics were collected prior to the summit and discussed during the morning plenary)
*-Isolation of caregivers and of people living with dementia is a real concern.*
*-Limited support available to assist people in living independently in homes/communities, to help to age in place.*
*-Respite care is a help but there is difficulty in planning for respite; sometimes it is needed on short-notice.*
-Continuity of care is important: different staff every day affects the care a patient receives. They cannot attend to the nuances of the patient's needs, or develop a plan for therapies if care providers change from day to day.
-Building care relationships: focusing on client-centred care. Can we create a common definition of "Client-Centred"? Can we provide training and skill development programs to empower Special Care Aides to be more involved in decision making to improve client care?
-Considering Aboriginal and northern communities: focus on collaborative, culturally relevant and holistic approaches to help improve care. Supporting patients, caregivers, and community is complex, we need time/support/training to 'delve in' to issues and explore the context. We also need to support informal caregivers to avoid burn-out.
-Navigating the health care system: informal caregivers and families need a "coach" or advocate to provide assistance and support. The vocabulary and conventions of the health care system can be daunting and opportunities can be missed by informal caregivers who are unaware of the services available.

3. In discussing **research that would be most useful in this area**, group five identified the following:
-An annotated bibliography of what's been done to date regarding supporting caregivers and client centred care. What are the best practices?
-Client-perspective research: test what clients identify as their needs; best-practice and intervention research; the role of "coach" or intermediary within the healthcare system.
-Research to application of ideas, how to change the system. How can we work with Aboriginal communities to facilitate ant tailor solutions to address needs? How can we address local needs?
-Research to investigate the financial cost of implementing best practices.

**Following up and Supplemental Resources Available**

After the afternoon session, during which each group reported back to the entire audience, 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-to-face on an annual basis. We have already secured meeting space and hotel bookings for the **second annual summit, to be held October 29th & 30th, 2009**. As well, more communication between decision makers throughout the year was indicated as valuable. This report is one such tool for further communication among group members. Further communication opportunities include appendices C and D of this report which provide contact information for all decision makers and researchers who attended. We will also be sending a mid-year 'newsletter' via email in April 2009 to provide an information and progress update.

If you did not attend the event this year, or if you did attend but would like more resources, you may contact either Dr. Debra Morgan (email: debra.morgan@usask.ca or phone 966-7095), or Duane Minish, Research Assistant (by phone: 966-4098 or email:duane.minish@usask.ca) to request additional materials.
Supporting documents and supplemental information available includes:
- Verbatim content of small-group discussion and flip-chart notes
- Biographies of Decision Makers and Researchers
- Bound copy of all the posters from Thursday's poster session
- The slideshow presented during the morning plenary as a prelude to the small group discussion
- Any of the documents provided to attendees of the summit
- You may also contact us if you were not able to attend in 2008, and would like to be a part of the 2nd summit.



Mark your calendars now for the 2nd Annual Knowledge Network in Rural and Remote Dementia Care Summit

**October 29th & 30th 2009**

## Event Evaluation Feedback Response Summary

### *CIHR Applied Chair in Health Services & Policy Research:*
### *Decision-Makers' Summit*
*November 21st, 2008*

| EVALUATION RESULTS |
|---|

Were you able to attend the **Reception & Poster Session** last night?     Yes = 27     No = 4

If Yes, did the event:
a) Provide you with an opportunity to **learn** about what has been
   happening with the Rural and Remote Memory Clinic Research?     Yes = 26     No = 1
   (already knew about it)
b) Provide you with an opportunity to **meet** Research Team members
   you had not met before?     Yes = 27     No = 0
b) Provide you with good **value** for your time (e.g., worth travelling the
   night prior to the meeting)?     Yes = 25     No = 0

**Comments on the Reception & Poster Session:**

- Very informative
- Very interesting. I would have appreciated having the presenters there to talk about their poster. Some were but not all
- Very Nice!
- I learned about a number of research projects I was not aware of
- Very interesting to see what research has already been done
- Well-organized
- Good to see that the RRMC project can generate a tremendous amount of research projects that involve collaboration from individuals with different academic backgrounds
- Very informative, nice meeting new people who face the same challenges as us
- Very informative & interesting. Good to see all the work being done to address this issue
- Well organized. Would like a copy of the poster presentations for follow up.
- The format was excellent particularly because of the interest level (passion) of the researchers/people there. Food great.
- Very informative. The casual setting was appreciated.
- Good venue to meet people we haven't met
- Lots of fun and good exchange of information
- A wonderful networking opportunity. I don't always get a chance to attend all NET related activities so it provided me with an opportunity to catch up with what people are doing
- Great information
- I liked the chance to connect the night before. It then lets us "get to work" on the Friday
- Lots of overlap between posters from memory clinic. Layout with posters at circumference was great. Abstracts of posters might be helpful in meeting package.

**Today's Summit** - Please rate your satisfaction with the following *(check appropriate box)*:

| | Very Satisfied | Somewhat Satisfied | Could be Better | Definitely not Satisfied |
|---|---|---|---|---|
| **Time Allotment for Agenda Items** | 30 | 2 | | |
| **Time Allotment for Breaks** | 29 | 1 | 1 (shorter for shorter day) | |
| **Venue of Summit** | 27 | 2 | 2 | |
| **Flow of Day's Activities** | 30 | 2 | | |
| **Opportunity to voice your opinions** | 29 | 1 | | |
| **Accomplishment of Day's Objectives** | 24 | 5 | | |

**It was worth my time to attend and participate in this Summit** *(please circle one):*

Strongly Agree = 22    Agree = 9    Neither Agree/Disagree=0  Disagree=0    Strongly Disagree=0

**What, if anything, should be done differently for the next Decision-Makers' meeting?**
- More detailed agenda
- Please provide microphone for speakers (good in PM).
- October, September, or Jan – April are preferred meeting months
- Binder should have a content page. Binder tabs are not properly placed.
- Perhaps a guest speaker
- Meeting at the host hotel instead of a different venue.
- I would appreciate the notes from the breakout groups (summary)
- Perhaps ½ longer so we could have participated in 2 groups. Hard to decide
- Clear focus in small groups
- At the next meeting it would be great to have an update to see if any proposals were pursued and the results
- Great event. Very meaningful to have front-line staff, family, managers and government all in one room.
- A bit long for unstructured discussions.
- I think it was a great opportunity to discuss and share issues. Great information presented. Important to be part of research project and to get our concerns addressed and talked about. I think process is very effective. No changes.
- I really appreciated hearing from the range of "positions": researcher, policy, SaskHealth, frontline, families
- Better acoustics to facilitate discussion. Long lead time for planning.  Subgroup discussions ?
- Would like access to all of the selected research team publications on the purple sheet in the handout.

**How often should the Decision-Makers meet face-to-face?** *(please circle one):*
        Quarterly = 3                    Twice a Year    = 10                    Yearly = 18

**By what other means would you find useful to communicate with the team?** *(check all that apply)*
- emailed newsletters/updates=23
- videoconferencing (e.g. Telehealth) = 16
- teleconferences = 12
- interactive online meetings (e.g. WebEx; Illuminate) = 12
- online community  (e.g. Sharepoint; Timeless) =8

## Appendix A – Top Three Issues as Identified and Submitted by Decision Makers Prior to the Summit - Updated

1. Lack of knowledge/education on the use of appropriate medications for residents with dementia. For eg. Sk is showing a very high incidence of having depression without anti-depressive therapy, there seems to be hesitation from docs to provide antidepressants and treat the dementia with psychotropics
2. Lack of knowledge transfer in outcomes based care and best practices to support staff in long term care home and home care
3. Lack of education and ongoing support for staff working with individuals with dementia

1. Culturally appropriate and community accessible accommodation.
2. Access to comprehensive care: physical therapy, speech therapy, home care etc.
3. Access to specialized services (physiatry) and diagnostics.

1. Access to Geriatrician specialist services (often find that once client is admitted to LTC there is often not the attempts made to direct to a Geriatrician for ongoing consultation and follow up)
2. Behavior Management consultant availability/access and follow through
3. Mandatory specialized training for staff

1. Accessibility of diagnosis and support for dementia clients and their families
2. Funding cutbacks possibly causing closures of facilities sending
 clients to larger centers away from their local support group (family and friends)
3. Funding cutbacks for care staff resulting in minimal care or less time one on one.

1. Restricted access due to financial constraints
2.  limited awareness/knowledge, fewer clinicians in rural areas providing dementia care,
3. Travel difficulties if going into urban areas for the service.

1. Access to accurate and timely diagnosis and treatment - probably due to a number of sub issues, lack of recognition of warning signs, not relating symptoms to family doctor due to stigma attached to a diagnosis of dementia, lack of recognition of dementia by family physicians.
2. Lack of programs, services and supports to help people remain independent and in their homes as long as possible. This could be due to a number of sub-issues as well ranging from lack of awareness of programs that exist, programs lack the flexibility required to meet the needs of caregivers, lack of continuity of services.  This would also include services available from the Alzheimer Society - we have offices in the two major cities - we need to look at expansion and/or models to serve people in rural communities more adequately.
*(cont'd next page)*

3. Education - Many individuals with the disease and their primary caregivers do not understand their diagnosis and have basic information that will help them to live their life to the fullest with their diagnosis.  A Chronic Disease Management model may be a way to help support people with the disease and their caregivers to cope with the effects of the disease.  Some research studies indicate that informal caregivers that access information, on average, admit their family members to LTC one and one half years later that a caregiver who does not receive or attend education session. Professional caregivers also require core competencies related to dementia in their undergraduate training and as part of their on-going education requirements.

1. Access to, and availability of, specialty services that are aimed at client and support for family and client.  As well to what extent are
specialty services meaningful in terms of First Nation languages,
values and social norms. Cultural relevance and appropriateness is a
part of the access/availability issue.
2. Community home care has limited capacity
3. Access to, and availability of, respite care, assisted living and long term care. (again, there is the simultaneous concern regarding cultural appropriateness)

1.  Continuity of Care from agency to agency.  There are many gaps in
the bigger "system".
2.  Support staff within the facility.  It is hard to keep on top of best practice when we have few people with the expertise in house. For instance, it would be great to have funded positions for wound care, social work, physiotherapy, palliative care, pastoral care etc. We have access to some resources in the region, but few are
in-house, and it never seems to be enough.
 3.  Staff funding.  Our staff to resident ratio is probably as good as it gets in the region, but it still doesn't feel like enough.  SCAs and nurses are stressed
at work.

1. Access to services due to geographic barriers
2.  Financial burden for seniors on fixed incomes that live in rural areas
3. Continuity of care - local care providers (family doctor, homecare, etc) being involved in the dementia patient's treatment and follow-up. This could also include lack of support systems at home.

1. Access to timely diagnosis/treatment
2. Ability of support services (eg. Transportation, respite care, supported living, day programs, meals on wheels) in home community.
3. Training for rural healthcare workers

Top 3 issues.  Supportive Pathways offers a framework of empowering concepts and tools for all involved in the resident's care. It involves the entire facility from professionals to paraprofessionals.  It is the most holistic I have come across with a
focus on frontline staff.
1.  Lack of Model/Framework that connects
paraprofessionals, professionals, DOCs etc. (Supportive Pathways more than met  participant and organizer expectations).  My facility is moving on with it and we have FHHR buy-in. Least restraint, pain management, etc. are included.
2.   Education that provides hands on tools for frontline workers. Supportive Pathways did this
3. Client centered care.  How to make existing institutions into homes for the
elderly; get beyond schedules, routines, etc...

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1. Available respite care. Respite care is available in rural Saskatchewan when it can be booked ahead of time. However, often caregivers need respite on short notice to help them for short periods of time to manage crisis situations. This respite can be for a week end, during an evening or even overnight. This is not available.
2. Isolation is a very real concern for caregivers. This takes several forms: Family members are often far away. Our area of the Province has the highest percentage of seniors and the lowest percentage of caregivers between the ages of 20 and 64. The younger adults have moved away to pursue their careers and to be nearer the
job markets. People in the community often do not understand dementia and feel uncomfortable around those suffering with it. They tend to stop visiting these people. In smaller communities there is no public transportation or taxis. There are limited services and resources in smaller communities. For instance there is no dedicated dementia wards in smaller nursing homes.
3. There are limited affordable accommodations for those who are unable to live independently, especially when they are on a fixed income. We need to have subsidized private care homes for those who do not qualify for the nursing home beds in the region but still need 24 hour care. Private nursing homes can meet their needs but these people cannot afford the cost.
4. Accessible expert care is not readily available. The Rural and
Remote Memory Clinics are excellent and provide this care in rural
Saskatchewan. However, there is a large waiting list for this
service. This program needs to be expanded.

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1. Ability to access expertise in dementia (GP &/or specialist)
2.  Availability of support services (eg. transportation, respite care,
supported living, day programs, meals on wheels) in home community
3.  Caregiver support and education (whether institutional or at home.

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1.  Hard to even get diagnosis.  If not part of the rural study I don't know how family, caregivers would have access to follow-up evaluations etc going forward.
2.  Lack of qualified trained staff in care facilities.  Possibly trained but not really understanding of the need for good quality of life especially in early stages.
3.  Lack of some sort of qualified people in the home care support
system.  There seems to be a lack of support system to assist in
keeping people living at home in their small towns. If no family or
good neighbors, very difficult to remain at home when probably still
able to look after themselves.

1. Regarding those living at home and/or with family – what are the needs and how to meet them so that this is a quality experience
2. Accessible and efficient means of diagnosis and follow-up
3.Therapies which optimize the quality of life of those living with dementia – improve quality of life, improve function and/or slow deterioration. And how to make these available to the clients and families.

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1. Lack of resources for diagnosis of different forms of dementia
which impacts management.
2. Delay in/lack of use of Acetycholinesterase Inhibitors.
3. Lack of skills in LTC (Long Term Care) to manage BPSD, (behavioural and psychological symptoms of dementia) in an effective, best practice manner.

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1.  Diagnosis: As appropriate therapy is dependant on accurate diagnosis, and to some extent time is an important factor; It would be helpful for Family Physicians to have aids to help us diagnose the type of dementia the patient is afflicted with. This would more positively impact treatment outcomes. Although the remote memory clinic is a relatively rapid referral resource, I think it would still be advantageous for family docs to be able get on the right track with treatment as expeditiously as possible.
2. Treatment: A quick guide to the most effective treatment options for the various forms of dementia would be helpful. Rx Files I think, might be looking at this, but again it is my understanding that the correct diagnosis is the key.
 3. Placement: We need more suitable places for these people to live. Generally, family members sooner or later become unable to care for them, and there is a shortage of appropriate placements available.

## Appendix B – 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

Kulig, J., Stewart, N., Forbes, D., Morgan, D., & Emerson, P.  (accepted Sept 23, 2008).  Community attachment and satisfaction: Perspectives of rural and remote registered nurses.  *Public Health Nursing.*

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.   Improving Access to Dementia Care: Development and Evaluation of a Rural and Remote Memory Clinic. *Aging & Mental Health.*   Accepted for publication March 2008.

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## Appendix C: Decision Makers Contact Information - Updated

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|------|---------------------|--------------|

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.

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|------|---------------------|--------------|

| Name | Position & Location | Contact info |
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| Name | Position & Location | Contact info |
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*Supplemental Materials*

To request additional documentation from the Summit (listing on page 10)
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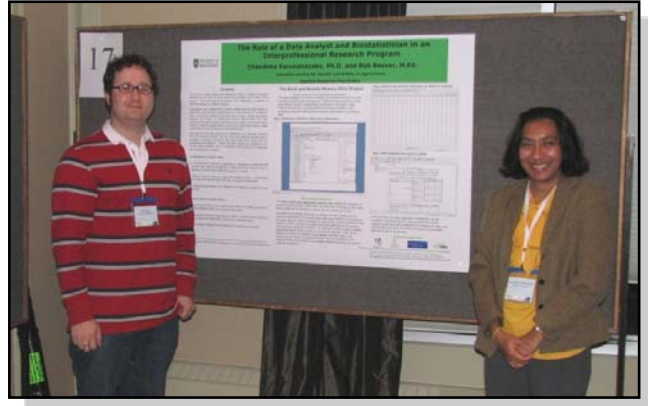*Report of the 1st Annual Knowledge Network in Rural and Remote Dementia Care Summit – November 20 – 21, 2008*