

INTERNATIONAL INDIGENOUS DEMENTIA RESEARCH NETWORK MEETING REPORT



11/13/2012

Ancillary Meeting of the Alzheimer's Association
International Conference July 16, 2012

PREPARED BY: DR. KRISTEN JACKLIN

ACKNOWLEDGEMENTS

Our sincerest thanks to Elder Larry Grant for welcoming us to the Coast Salish territory, for his opening prayer and for remaining with us throughout the meeting to guide our work. We would also like to thank the Indigenous Health Research Development Program (www.ihrdp.ca) and the Canadian Dementia Knowledge Translation Network for providing funding for this meeting. Finally, thank you to all of the participants who took time during the conference to come and meet and share your knowledge and ideas concerning dementia in Indigenous populations.

With gratitude from the organizers

Kristen Jacklin, Elana Brief & Wendy Hulko

PARTICIPANTS

Larry Grant (Elder) – Musqueam & University of British Columbia
Flamine Alary – Canadian Institute of Health Research (CIHR), Institute of Aging
Deborah Benczkowski – Alzheimer Society of Canada
Jennifer Bethell – Alzheimer Society of Canada
Jean Blake – Alzheimer Society British Columbia
Elana Brief – University of British Columbia
Leon Flicker – University of Western Australia
Dorothy Forbes – University of Alberta
N. Gouda – Alzheimer Society of Canada
David Harvey – Alzheimer Society Ontario
Neil Henderson – University of Oklahoma
Carson Henderson – University of Oklahoma
Wendy Hulko – Thompson Rivers University
Kristen Jacklin – Northern Ontario School of Medicine
Dina LoGiudice – Melbourne Health
Jennifer Mackie – University of British Columbia
Lesley McBain – First Nations University
Heather Moquin – Thompson Rivers University
Michelle Peel – Canadian Institute of Health Research (CIHR), Institute of Aging
Emily Thiessen – University of Alberta
Sandra Thomson – University of Western Australia
Wayne Warry – Centre for Rural and Northern Health Research, Laurentian University
Danielle Wilson – Interior Health British Columbia

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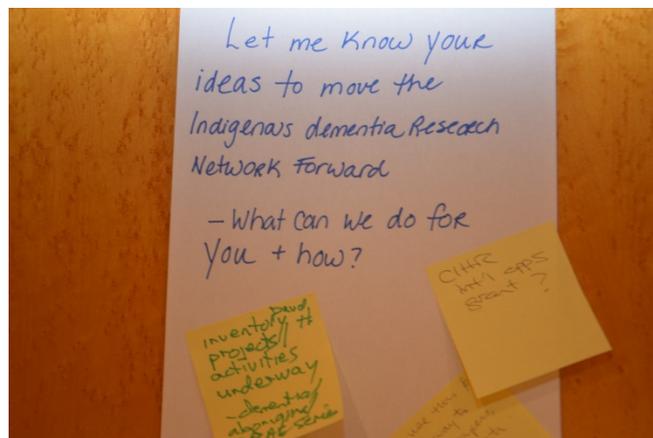
International Indigenous Dementia Research Network Meeting Report

ANCILLARY MEETING OF THE ALZHEIMER'S ASSOCIATION
INTERNATIONAL CONFERENCE JULY 16, 2012

OVERVIEW

In July 2012, researchers from across the globe gathered in Vancouver for the Alzheimer's Association International Conference (AAIC). Drs. Kristen Jacklin (Northern Ontario School of Medicine), Elana Brief (University of British Columbia) and Wendy Hulko (Thompson Rivers University) organized and hosted the International Indigenous Dementia Research Network (IIDRN) meeting – an ancillary meeting of the Alzheimer's Association International Conference. Funded by the Indigenous Health Research Development Program (www.ihrdp.ca) and the Canadian Dementia Knowledge Translation Network, the IIDRN meeting attracted interested researchers from Canada, the United States and Australia as well as delegates from the Alzheimer's Society Canada, the Alzheimer Society of Ontario, Alzheimer Society of British Columbia, and CIHR's Institute of Aging. The group was welcomed to the Coast Salish territory and was guided in their discussions by Elder Larry Grant. The exciting networking meeting involved a structured mingle where participants posted written information requests ("asks") concerning Indigenous dementia research on the walls. Everyone then took time to read the "asks" or respond with "offers" of assistance, answers or statements of mutual interest. The subsequent discussion highlighted the research needs surrounding dementia in Indigenous peoples and the synergies between the researcher's questions and the knowledge users' needs for information. The success of the event is evidenced in the newly expanded IIDRN membership, multiple researcher-knowledge user grant proposal developments initiated during these discussions and on-going dialogues between many of the attendees.

Example of an "Ask and Offer" sheet



HIGHLIGHTS

The participant's questions, or "asks", focused broadly on six key themes: knowledge gaps, clinical assessment/screening, caregiving, networking, research methods/tools and knowledge translation. Table 1 provides a breakdown of the "asks" categorized by thematic areas as well any responses that were provided at the meeting or thereafter through our network online discussions.

Roundtable Discussion



(left to right) Dr. Carson Henderson, Dr. Neil Henderson, Dr. Kristen Jacklin

In the area of knowledge gaps participants identified a need for information concerning incidence and prevalence of dementia in Aboriginal populations; genetic studies; research concerning connections between historical trauma and post-traumatic stress disorder in Aboriginal people and dementia; and, information on culturally relevant or sensitive screening tools and care models. There was a noticeable overlap between the knowledge gaps and clinical assessment and screening theme where participants in the session were looking for information on screening tools that were culturally relevant and sensitive for Aboriginal clients who had additional difficulties communicating (e.g., post-stroke). In the area of caregiving the knowledge requests were diverse. Attendees were interested in better understanding the specific issues faced by caregivers in Aboriginal communities and if culture in any way mediated the challenges. Cultural sensitivity training for workers caring for Aboriginal people with dementia was also asked about as were appropriate methods of programming and communication cross-culturally for Aboriginal people with dementia.

Questions and 'asks' focused on networking included requests for collaborative international research programs between universities as well as requests and offers to improve researcher – end-user/knowledge-user interactions. Interest was expressed in Australia-US-Canada research partnerships concerning Indigenous dementia screening and interventions and offers were made to work with Alzheimer's societies and chapters to allow for research tailored to user needs. Participants were also interested in topics concerning research methods for Indigenous health research specific to dementia. Queries were made about partnership

approaches to research, theoretical orientations and research tools such as acculturation scales. Some interest was expressed in areas related to knowledge translation (KT) such as strategies to incorporate traditional knowledge while respecting ethical issues relating to sharing this knowledge and innovative and appropriate mediums for knowledge translation such as using theatre.

Within these themes it is possible to identify at least two cross-cutting themes. For example, **communication** is identified as a topic of interest or a knowledge need in relation to clinical assessment/screening, caregiving, networking and KT. Another cross-cutting theme is **cultural safety** which comes across in relation to culturally sensitive and appropriate screening tools, communication, knowledge gaps, research methods, KT, and caregiving.

Meeting Organizers



(left to right) Dr. Kristen Jacklin, Dr. Wendy Hulko, Dr. Elana Brief

LOOKING FORWARD

Participants at the meeting had a common interest in building capacity in dementia research concerning Indigenous peoples. Several knowledge gaps were highlighted ranging from the need for basic epidemiological tracking to culturally tailored tools and interventions. The energy and momentum at the meeting was fueled by the possibility of international knowledge sharing and collaborations as well as by the support and interest from Alzheimer's Societies from across Canada and Interior Health, British Columbia. Since the meeting occurred discussion with knowledge users have continued and at least one CIHR planning grant application has been submitted. We believe the outcomes of this meeting provides some evidence of the potential benefits of both international and researcher-knowledge user collaborations and that this approach should be encouraged.

The “ask and offer” exercise aided the group in identifying the key areas of interest and a sister document to this report has been produced and distributed to the attendees that identifies particular individuals with information or interest in the common questions. This report highlights two cross-cutting themes that warrant special consideration moving forward: issues of communication and cultural safety. Based on the work coming out of this meeting and report we would encourage all researchers looking at dementia in Indigenous populations, to give special consideration to the integration of these two issues into their own work.

The International Indigenous Dementia Research Network (IIDRN) first established in 2009 is committed to working together to foster research that will lead to better understandings of dementia in Indigenous populations and to improving outcomes for those affected by this illness. Our network is open to anyone with similar interests and goals. To join the network please email Dr. Kristen Jacklin (kjacklin@nosm.ca) and request membership to our shared web-space.

TABLE 1: RESULTS OF ASK AND OFFER EXERCISE

| Thematic Area | Question/Ask | Offer/Answer /Resources |
|----------------|--|--|
| Knowledge Gaps | Does anyone have an idea of the prevalence of dementia/cognitive impairment in an Aboriginal community | <p>In Canada only administrative data for British Columbia is available</p> <p>Pathways to Healing (2009) Government of British Columbia</p> |
| | What are the research gaps and opportunities in aging and Alzheimer’s disease in Aboriginal peoples? | <p>impact of residential schools (intergenerational trauma/PTSD on dementia</p> <p>Language revitalization and intergenerational story telling</p> <p>Epidemiological profile including prevalence, incidence, type - Canada</p> <p>Culturally appropriate community care models</p> <p>Development of appropriate screening tools – Canada</p> <p>Prof Kim Scott at Australia has interest in language revitalization, storytelling and health and education http://www.celebratewa.com.au/pages/4945/professor-kim-scott</p> |

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| | <p>Is anyone doing research on cultural trauma and dementia?</p> <p>Is there research on Post-Traumatic Stress Disorder and/or intergenerational trauma in the context of dementia in Indigenous nations/communities?</p> | |
| | <p>Do you know of any other Indigenous communities who have a genetic risk for Alzheimer’s disease?</p> | |
| <p>Clinical Assessment/Screening</p> | <p>Has anyone any tips or experience for assessing cognitive function in Indigenous people post stroke in the presence of communication difficulties?</p> | |
| | <p>How do you assess cognition in First Nation/Indigenous peoples? What kind of tools are used? Which principles are followed? What do you find difficult in this process?</p> | <p>Alzheimer’s Chapter in London Ontario (Robin Shawana adapted MOCA)</p> <p>Grasshopper and Geese test in Saskatchewan” Margaret Crosley, Psychologist, U of SK , Dorothy Forbes</p> |
| | <p>I would like to have access to culturally sensitive First Nation/Aboriginal assessment tools and outcome measurement tools, e.g., quality of life with dementia.</p> | <p>for remote Aboriginal Australia google ‘KICA WACHA’</p> |
| <p>Caregiving</p> | <p>What are the issues of caregivers in your community? Are the issues positively mediated by the culture of the community and if so in what ways?</p> | <p>Works in progress identified:</p> <p>K. Jacklin and W. Warry (Ontario)</p> <p>E. Brief (British Columbia)</p> <p>D. Forbes (Oneida of Thames – Ontario)</p> |
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| | <p>What are specific examples of creative methods or programs for communicating and working with Elders with dementia and/or memory loss (i.e., non-verbal, arts-based approaches).</p> | <p>Look at arts based approaches in healing for First Nations people http://www.ahf.ca/downloads/healing-through-creative-arts.pdf</p> |
| | <p>Need help identifying people and resources for training (a) health care workers in providing culturally appropriate care; and, (b) aboriginal health workers in building capacity in dementia care.</p> | <p>Provincial health services authority in BC – Indigenous cultural competency team</p> |
| <p>Networking</p> | <p>Is anyone interested in international collaborations concerning Indigenous dementia care interventions or screening?</p> | <p>Several researchers in Canada, United States, and Australia identified themselves</p> |
| | <p>How can a national organization in Canada contribute to the dialogue and body of knowledge about how Aboriginal people can access information about Alzheimer’s disease and support services? How can we learn from other countries?</p> | <p>More Indigenous First Link workers Alzheimer’s Australia has an Aboriginal resource person in each state Engage in collaborative research with us</p> |
| | <p>Let me know if your ideas to move the Indigenous Dementia Research Network Forward. What can we do for you and how?</p> | <p>Inventory of projects and activities underway – Aboriginal dementia CDRAKE series Could we collaborate on something that is culturally appropriate and sensitive to all? CIHR international operating grant? To use this forum as a way to share papers reports etc</p> |

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| <p>Research Methods</p> | <p>How do we best protect the identity of a small sample of research participants among Indigenous people?</p> | <p>There has been some work in WA around Aboriginal people and HIV and camouflage among a whole lot of other activity as one of the ways of not drawing attention to those affected. But the usual methods of de-identifying data and ensuring that information is written up in such a way that individuals are not identifiable.</p> |
| | <p>There is considerable research being conducted on cultural understandings related to dementia. Can someone provide further examples of their findings and/or how they go about “doing” research in this area?</p> | <p>British Columbia - W. Hulko Australia - D. LoGiudice Oklahoma – C. Henderson Ontario – K. Jacklin and W. Warry</p> |
| | <p>Learn from others about acculturation assessment among First Nations people</p> | |
| | <p>Learn what theoretical foundations are being used in current research</p> | <p>Decolonizing Health Post-colonial Theory Critical Theory “Linda Smith, Decolonizing Methodologies; Margaret Kovach, Indigenous Methodologies; Shawn Wilson, Research is Ceremony”</p> |
| | <p>Learn about interactive “native-researcher” projects (i.e., research that ‘teams’ with native people in the research design – analysis)</p> | <p>Willie Ermine “The Ethical Space” Marlene Brandt Castellano’s work Jacklin and Kinoshameg 2008 ‘only if it’s going to mean something’</p> |

Suggest contacting IPHRC (Indigenous Peoples Health Research Centre) or other NEAHR Centres

<http://ahrnets.ca/> (NEAHRs)

<https://tspace.library.utoronto.ca/handle/1807/17129>
(Ermine - Ethical Space)

<http://www.ncbi.nlm.nih.gov/pubmed/19385745> (Jacklin and Kinoshameg)

Knowledge Translation

Do you know of an Aboriginal theatre group with whom we could work to disseminate our findings?

How do you create 'new' stories to teach nurses while respecting traditional knowledge?