UNIVERSITY OF CALGARY

Innovation for Indigenous-led Dementia Care to Enhance Safety (VOICES)

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Background & Rationale:

The primary outcome of this project is an implementation-ready approach to Indigenous-centred dementia care that will be co-developed with Indigenous communities to enable national and international grant funding opportunities for future implementation and evaluation. CIHR project grant funding is critical to expanding a successful and competitive research programme in this area that will facilitate rapid training of highly qualified research staff. It will allow an immediate start to community-based research, bridging the research-community divide and ensure truly participatory research such that the knowledge gained is directed by, and useful to, Indigenous communities.

Based on current population-level data, dementia is a priority in Canadian healthcare (Public Health Agency of Canada 2019; Canadian Academy of Health Sciences 2019), particularly for Indigenous populations where data show the age-standardized prevalence of dementia in First Nations persons as 34% higher than in non-First Nations individuals (Jacklin et al. 2013). Other countries experiencing colonization also show this trend, with data from Australia showing higher incidence rate ratios of dementia for younger Indigenous males and females (27.3 cases per 1000 person-years) between the ages of 45–64 years in comparison to the non-Indigenous population (10.7 cases per 1000 person-years) (Li et al. 2014). This same research on the epidemiology and pathophysiology of young onset dementia experienced by Indigenous people in Canada, Australia, and the United States has helped provide more insight into the prevalence, incidence, and risk factors (e.g., childhood trauma, colonization) of dementia (Li et al. 2014).

In 2015, the Truth and Reconciliation Commission of Canada (TRCC) released 94 Calls to Action compelling Canadian institutions across service sectors (i.e., education, child welfare, criminal justice, healthcare) to acknowledge that colonization is the principal driver of population-level health disparities experienced by Indigenous people (TRCC 2015), including dementia and brain health. However, detailed information on the needs of Indigenous people living with dementia, and those of their families and communities, remains sparse. This is particularly true for subpopulations such as younger people living with dementia (Roach et al. 2012; Roach et al. 2008). The quality of dementia care delivery across all ages for Indigenous people in Canada is uncertain, and outcomes are undocumented. This current paucity of information with regards to the experience of dementia within Indigenous populations makes planning for and responding to health issues difficult (Jacklin et al. 2013). Canada's National Dementia Strategy (2019) and the Public Health Agency of Canada (2015) also call for additional work to improve dementia care provision and health care services in general for Indigenous people as a priority, as do the communities and organizations included in this proposal.

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Anti-Indigenous Racism in Health Systems

The direction to incorporate environments of cultural safety in existing systems, services, and interactions while working to improve access to safe healthcare to all Indigenous people including those who live off reserve and in urban centres (TRCC 2015) also applies to dementia care. There is irrefutable evidence that Indigenous people living in Canada experience racism in the healthcare system (McLane et al. 2019; Leyland et al. 2016; Allan and Smylie 2015), and that this is associated with direct impacts to health outcomes including reduced access, increased emergency visits, comorbidity, and mortality (McLane et al. 2019; Paradies et al. 2015). In addition to interpersonal experiences of racism, the pervasive systemic racism present throughout the Canadian healthcare system includes services and structures that are inappropriate and culturally unsafe which exacerbate existing health conditions and deepen inequities. Previous work with Indigenous people demonstrates that self-determination is an important factor in maintaining well-being and contributes to positive health outcomes (Chandler and Lalonde 2008). Continued devastating harms happen against Indigenous people within the health care system with ongoing public reports of mistreatment, harm and death caused by systemic racism (Allan and Smylie 2015; Leyland et al. 2016; Turpel-Lafond 2020). The need for healthcare services designed by and for Indigenous people is outlined in health-related Call to Action #22 from the TRCC (2015) and aligns with refined definitions of person-centred care (Vernooij-Dassen and Moniz-Cook 2016) and principles of relationship-centred care (Nolan et al. 2004) that form the central tenets of ethical dementia service design.

Culturally Safe Dementia Care

The current model of dementia care is woefully unsafe and inadequate and continued inaction will only lead to continued harm. Existing services must begin to incorporate aspects of cultural safety to better respond to the needs of Indigenous people, especially Indigenous people living with dementia, their families, and their communities (TRCC 2015). Recent work with ethnic minority populations living with dementia in the UK has demonstrated that commonly used dementia reminiscence therapies are inappropriate and culturally unsafe for Black, Asian, and Minority Ethnic (BAME) groups (Truswell 2020). Likewise, in Canada, ongoing work that has been undertaken by members of the Canadian Consortium on Neurodegeneration and Aging (CCNA) Team 18: Issues for Older Indigenous Adults shows that common dementia and cognitive assessment tools are not appropriate, nor culturally safe, for Indigenous populations.

Work is underway to develop screening and assessment tools that are culturally safe to assess cognition and activities of daily living for Indigenous people living with dementia (Walker et al. 2021), given that current widely used assessment tools are not relevant or safe for Indigenous people. This is important, yet without parallel work to develop culturally safe supports and services, Indigenous people living with dementia will continue to be harmed and underserved by current models of care. Dementia supports and services that are not cognizant of intergenerational trauma, the legacy of colonization on lived experience and cognition, and Indigenous ways of knowing are unsafe for Indigenous people living with dementia. Providing dementia care that is strengths-based and trauma-informed, while also being grounded in Indigenous knowledge systems and experiences is an urgent priority in Canadian health systems and plays an important part in enhancing patient safety and closing gaps in health inequities.

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Foundational Work by NPA and Team: Systems Understandings and Experiences of Care

Throughout the dementia journey family care partners, and communities more broadly, are often excluded from a systems and service design approach (Hutchinson et al. 2020; Hutchinson et al. 2018; Roach et al. 2012), such that the person living with dementia is treated apart from the family and community (Roach et al. 2012). Yet, the complex interplay of family systems and relationships are known to impact effectiveness and efficacy of interventions (Roach et al. 2008). This is particularly important in Indigenous communities where the individual and the community must be centered in the care, rather than the disease entity focus utilized in the western, biomedical model (Cornect-Benoit 2020). The evidence substantiates that the disruption in biographical continuity experienced while living with dementia creates further disruption in family systems (Roach et al. 2014; Roach et al. 2012; Roach et al. 2008; Rolland 1994; Rolland 1988). When applied to the health benefits we see in other contexts experienced by Indigenous people as a result of connection to culture and community self-determination (Chandler and Lalonde 2008; Oster et al. 2014) it is reasonable to assume that a disruption in biographical continuity predicated by a dementia diagnosis also causes disconnection to culture and the resulting negative impact to individual and community health outcomes. There are currently no tools to measure a lived Indigenous experience of dementia care. Understanding the family experience of early onset dementia was unexplored in a way that could be measured in clinical settings, which led the NPA (Dr. Roach) to co-develop a strengths-based family experience tool (Family-AiD) in previous research (Roach et al. 2014) (also see Appendix: questionnaires). More recently, she has led CIHR-funded research to co-develop Indigenous patient experience tools for virtual experiences of primary health care (see Appendix: questionnaires). This gap in current, dominant western ways of providing care and assessing lived Indigenous experiences of dementia can be addressed by co-developing an Indigenous-centered dementia care approach, which this team have the experience and expertise to do.

Additionally, the literature recommends that a shift away from pharmacological to non-pharmacological treatment for dementia is effective in all populations (Watt et al. 2019; 2020; 2021). Reminiscence therapy and other person-centered approaches to care are key interventions that are ranked highly by families living with dementia for managing symptoms (Watt et al. 2019; 2020; 2021). However, there is no prior work to adapt these approaches in partnership with Indigenous people, despite the observable link between person-centered care and tangible connection to past memories, culture and community. With limited progress on pharmacological treatments for dementia conditions and a more holistic understanding of health held by many Indigenous communities reaching beyond the biomedical model to include spiritual and emotional health, it is imperative to understand the effectiveness of non-pharmacological approaches to dementia care and lived experience. It is also important to consider this work with Indigenous people living with dementia through a shifted gaze from a person-centered to a community-centered orientation.

Models of Dementia Care: The Need for an Indigenous Way of Doing

The experiences of intergenerational trauma or adverse childhood events can make typical western approaches to dementia care retraumatizing due to the lack of inclusion of trauma-informed care principles and approaches (Truswell 2020). Strengths-based non-pharmaceutical dementia interventions including sensory therapy, reminiscence therapy and arts-based therapeutic supports might offer better alternatives for Indigenous well-being and quality of life. Programming that is connected to culture and incorporates traditions such as storytelling and intergenerational teaching are potential ways to develop Indigenous led and culturally safe dementia care services. Recent work has also emphasized the importance of intergenerational

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engagement within Indigenous communities to find meaning in living with dementia, and indeed, the care provided with communities (Cornect-Benoit 2020). It is evident in the literature that person-centered care approaches can be a highly acceptable and critical component of high-quality dementia care but are unsafe for Indigenous people living with dementia in current forms and structures within western models of care. It is with these principles of intergenerationality and community relationships that trauma-informed and Indigenous-led approaches to dementia care can be developed in an ethical way to co-create an Indigenous led dementia care approach grounded in culture and Indigenous worldviews to enhance cultural safety.

Aims & Objectives

The aim of this work is to develop and pilot an innovative, culturally safe approach to Indigenous-centered dementia care that integrates proven person-centered approaches and structures (Watt et al. 2019; 2020; 2021) with Indigenous-led components that are grounded in the experiences of Indigenous people living with dementia, families, and Indigenous communities. This research facilitates understanding how these approaches can be adapted to support Indigenous people living with dementia and families/communities at various points in the dementia journey. The proposed study will address the three research questions below (also see Figure 1).

1. How can the needs of Indigenous people living with dementia be met with culturally safe and trauma-informed approaches to Indigenous-centered dementia care?

Figure 1: Project Plan

- Objective 1: C ompletion of a qualitative emancipatory project with Indigenous people living with dementia, family members, and community members to establish a co-constructed Indigenous understanding of culturally safe dementia care and to adapt the published Family-AiD dementia (Roach et al. 2014) experience tool to an Indigenous context.

2. What are the key components and format of an Indigenous led dementia care approach that can lead to improved experiences for Indigenous people living with dementia?

- Objective 2: Engagement and Nominal Group Technique with Indigenous community members, health system stakeholders, and experts in the development of an Indigenous-centered dementia care approach based on the outputs from objective 1 that could be adapted and made freely available to individual Indigenous communities and Nations.

3. How does an Indigenous-centered approach to dementia care meet the needs of Indigenous people living with dementia and their families?

- Objective 3: To complete a small-scale pilot and evaluation of the Indigenous-centered approach to dementia care developed in objective 2, incorporating the adapted Family-AiD dementia experience tool developed in objective 1.

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Indigenous Ways of Knowing & Research Ethics

In order to understand the conceptualization of culturally safe dementia care services for Indigenous people, extensive engagement is necessary while adhering to Indigenous ethical research principles. Due to the potential diversity within urban Indigenous populations, these principles include: OCAP (First Nations Information Governance Centre 2014; Schnarch 2004); the Principles of Ethical Métis Research as outlined by the National Aboriginal Health Organization (NAHO) (NAHO 2010); and the National Inuit Strategy on Research (Inuit Tapiriit Kanatami 2018) (see attached table in supplementary material). In addition to these guiding principles which set out ethical engagement for research with distinct Indigenous communities (Inuit Tapiriit Kanatami 2018; FNIGC 2014; NAHO 2010) the proposed work respects the principles of sovereignty, self-determination and reciprocity (Wilson 2008) and will build understanding of how the factors of colonization, adverse childhood experiences, and intergenerational trauma impact cognitive development, as well as cognitive decline, later in life. This sets the foundation for understanding: how Indigenous peoples have experienced colonization; and the related Indigenous-derived solutions and strengths to address the resulting direct impacts to health outcomes as a result.

To ground ourselves in the concepts of ethical space (Ermine 2007), we will come together as a research team with cultural humility in partnership with the Indigenous people and communities working together on this project. A reference group of advisors and co-researchers will come together at the outset of the work, including people living with dementia, family care partners, Indigenous community members, Elders, and health care providers/researchers. The reference group will direct all objectives and components (including planning, data collection, analysis, and knowledge sharing) of the work utilizing an integrated knowledge translation approach, to ensure relevance to Indigenous communities and to people living with dementia and families, and to ensure the work is being undertaken in an ethical way to achieve better outcomes for Indigenous people living with dementia. This reference group will be comprised of representatives from all participating communities to ensure that discussions are relevant to specific communities (see below and letters of support), geographic areas and related ways of knowing and being. The reference group will be formed at the start of the research project and will meet twice annually (at least one meeting/year in person and other meetings held virtually) to provide guidance on the direction and progress of the work; communication with reference group members may also occur throughout the study on an ad-hoc basis. All reference group members will be compensated with honoraria and Elders provided with Elder honoraria and traditional protocol. Our overarching ethical approach also embeds integrated knowledge translation into the development and implementation of the dementia care intervention so that the research outcomes are directly applicable and useful to communities and are developed and adapted throughout the process in response to culturally appropriate direction.

Methods

Objective 1 – Developing an Understanding of Indigenous-centered Dementia Care

Objective 1 of the proposed study will be undertaken using a qualitative emancipatory methodology informed by Indigenous paradigms (Wilson 2003) and the Métis theoretical way of knowing of Keeoukaywin (The Visiting Way) (Glaudet 2019), guided by the group of advisors and Elders. Though Keeoukaywin (Glaudet 2019) is a relational methodology specific to Métis and Cree Ways of Knowing, Being, Doing and Connecting, the emphasis on relationality, reciprocity, and self-location to challenge colonial western ways of relationship building and

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community engagement is appropriate to working with the Indigenous communities involved in the project. In this way, Keeoukaywin will guide the use of storytelling, including narrative interviews (Riessman 1993, 2008; Williams and Keady 2008; Haydon and van der Riet 2017) with key Indigenous community members and people living with dementia to understand Indigenous constructions of dementia and the key components of a culturally safe and Indigenous-centered approach to dementia care. Interviews are a commonly used research method within health care settings and are proven as a way of obtaining in-depth accounts of personal experience and when used incorporating narrative approaches can align with Indigenous storytelling (Drawson et al. 2017). Narrative prompts will be developed into an interview guide with consultation with the project team and using the Family-AiD tool (Roach et al. 2014). Such in-depth interviewing techniques have advantages when exploring how people make and attach meaning to events in their lives, as they allow for 'guided' conversations in order to elicit responses through a natural setting (Atkinson 2001; Johnson 2001; Warren 2001). The project team has extensive experience including people living with dementia in ethical ways in research and inviting conversation in ways that are inclusive and safe. The inclusion of the voice of people living with dementia is critical to engaging in rigorous and inclusive ways. It is expected that approximately 15-20 participants will be recruited through communities and organizations (Bent Arrow Healing Society in Edmonton; The Alex in Calgary; the Métis Nation of Alberta; and potentially the Métis Nation of British Columbia) to gain an in-depth understanding of what culturally safe dementia care services look like. Participants will be provided with honoraria for their time and contributions. The team will use purposive sampling to recruit people with diverse experiences including Elders, Indigenous people living with dementia, family and/or care partners, with a diversity of dementia diagnosis or severity of dementia. Data will be transcribed verbatim and qualitative interviews will be analysed using Indigenous approaches to reflexive thematic analysis (Braun et al. 2016; Clarke et al. 2019; Drawson et al. 2017), which is consistent with our theoretical approach, to co-develop an Indigenous framework of dementia care grounded in lived experience and to adapt the Family-AiD dementia experience tool to Indigenous contexts (Roach et al. 2014). NVivo software will be used to organize and manage data (QSR International 2020). Member checking, peer debriefing and triangulation of the patient and provider data will enhance rigor (Lincoln and Guba 1985). Further, the Indigenous reference group and Indigenous team members will be closely involved in the analytical process.

The team recognizes that exclusion from health services and systems research can be problematic for underserved populations represented less frequently and/or inequitably within the health care system. Our research will actively promote inclusion of women, Two Spirit, and other individuals with diverse gender identities within Indigenous populations in the recruitment, data collection and analysis throughout the project. Recruitment strategies will be tailored based on these needs by talking to gender specific groups as needed, and we will be considerate of factors in data collection and analysis such as the sex or gender expression of the research team member undertaking interviews or synthesizing results.

Objective 2 – Co-creating an Indigenous-centered Dementia Care Approach

Objective 2 will begin with the development of an Indigenous-centered dementia care approach. The team will engage with participating Indigenous communities to understand local context and the most appropriate content and structure to be included in the co-development of the care approach based on the understandings from objective 1. As there is rich diversity between Indigenous communities, the developed approach will be specific to the communities that are participating, and part of the work will be to create guidance in how to adapt the approach for

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other communities and Nations through local community engagement. To strive to maintain ethical and decolonial research approaches we will use sequential focus groups (Jacklin et al. 2016) with Indigenous community members and Elders when designing the Indigenous-centered dementia care approach, in order to align our team with equity-focused and consensus building methodologies. Focus group guides will be used to propose content and methods of delivery that have been determined through the understanding of Indigenous care developed in objective 1 and based on the current literature, with a visiting approach (Keeoukaywin) used during the groups to allow for the emergence of new themes. We anticipate we will recruit 8-10 participants to take part in 3-4 sequential focus groups in order to explore these concepts but may require more based on the iterative process. Participants will include Indigenous community members living with dementia, families, and Elders recruited using the same methods as above (see objective 1) and likewise provided with honoraria. Data will be co-analysed using Indigenous approaches to thematic qualitative analysis (Braun et al. 2016; Clarke et al. 2019; Drawson et al. 2017) to draft a preliminary plan and structure for the Indigenous dementia care approach. The draft plan will be circulated back to sequential focus group participants to ensure it is representative of their vision and ethics. When the sequential focus group participants are ready for the draft co-created Indigenous-centered dementia care model to move forward, a modified Nominal Group Technique (NGT) (Harvey and Holmes 2012) will be held with a group of decision makers including health systems collaborators, models of care scientists, Indigenous community members, people living with dementia, and knowledge translation experts to undertake a consensus process that will lead to agreement on the pilot Indigenous-centered dementia care model content and design, as well as the development of training materials for facilitators. The specific components and structure of the care model will emerge from objective 1 but it is anticipated based on previous literature that it will include a series of in-person group activity sessions with a focus on various cultural activities in each session such as music, drumming, story-telling, crafts (e.g. beading, working with hides), and food, organized with community-based and intergenerational principles in mind. When the pilot plan is finalized, a designer will be hired to design hard copy and electronic materials that can be hosted on a website and made freely available, along with training materials for facilitators.

<u>Objective 3 – Indigenous-centered Dementia Care Approach: Pilot Delivery</u>

Objective 3 of the study will be a small-scale pilot of the Indigenous-centered dementia care approach developed in objective 2 with 6-10 people living with dementia and 6-10 care partners or community members to support intergenerational relationships. Participants will be recruited through community networks with the partner organizations (see letters of support) and participant driven sampling. These organizations again include: Bent Arrow Healing Society in Edmonton who work with urban Indigenous seniors to incorporate healing activities into day to day life; The Alex, a community-based health service provider that serves a large urban Indigenous population; the Métis Nation of Alberta, the provincial Métis governing body in Alberta; potentially the Métis Nation of British Columbia, who have expressed initial interest; and the Indigenous Wellness Core within Alberta Health Services. We will design evaluation strategies using one-group pre-post-test methods (Bowling 2002) of key functional and satisfaction measures to use as pilot data for future CIHR grant applications. A facilitator will deliver the sessions with the project team including NPA and the evaluation of the Indigenous-centered dementia care approach will include key functional measures to indicate feasibility, such as attrition throughout the sessions, participant satisfaction (specific questions to be developed after the finalization of the dementia care plan), Indigenous experiences of dementia care (adapted from Family-AiD as part of objective 1) and qualitative participant interviews after

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completion of the program. Qualitative interviews will be completed in order to synthesize lived experience of the Indigenous dementia care approach using qualitative description (Green and Thorogood 2018) to identify areas for improvement and modification, and to inform future grant application for wide scale implementation or adaption to other communities and contexts. All participants will be invited to take part in an interview and participants will be provided with honoraria at the completion of the program and/or interview.

Timeline
The proposed research can be completed in five years. Activities will begin immediately with the recruitment, hiring and training of a full-time research coordinator (1.0FTE). A Masters student (Meagan Ody) who is already working for the NPA and is familiar with the field and previous research will also be hired and begins her program in September 2022; internal funding has been secured for Ms. Ody's first year stipend which will support part of year one/objective one of this work. Recruitment of other staff and graduate students will continue as needed with a PhD student being recruited to lead the development phase (objective 2) and undergraduate summer students recruited to complete literature reviews and descriptive statistical analysis. Part-time research assistant salary is also requested for Michelle Padley, a Métis student to assist with some of the data collection for objectives 1 and 2. In-kind support for partial funding of the postdoctoral fellow salary for years 4-5 is provided from the O'Brien Institute for Public Health and the Hotchkiss Brain Institute.

Research Activity	Year 1				Year 2				Year 3				Year 4				Year 5			
Quarter	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Ethics application & staff recruitment	X	X																		
Obj 1 recruitment			X	X																
Obj1 data collection				X	X	X														
Obj1 data analysis					X	X	X													
Obj 2 recruitment: focus groups								X	X	X										
Obj2 data collection – focus groups									X	X										
Obj 2 analysis – focus groups										X	X									
Obj 2 data collection and analysis – NGT												X								
Obj 3 preparation, training													X	X						
Obj 3 delivery															X	X	X			
Obj 3 evaluation																X	X	X		

Research Activity	Year 1				Year 2				Year 3				Year 4				Year 5			
Quarter	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Indigenous reference group meetings	X		X		X		X		X		X		X		X		X		X	
Knowledge Sharing (Integrated and End of Grant)				X	X				X		X	X						X	X	X

Material costs in year one will be primarily related to project supplies and honoraria for Indigenous participants to ensure that local protocols are adhered to (protocol costs will also be included throughout all years). There are expected travel costs to enable the NPA and study team to engage in integrated knowledge translation activities, but meeting costs will be lower as it is anticipated that many meetings will continue to be held in virtual or hybrid formats. The project reference group will meet in the first quarter of year one and every six months thereafter, alternating in-person and virtual meetings. Virtual data collection will be undertaken if public health restrictions continue, and the team is confident of their ability to do this. Ethics applications, protocols, and data collection procedures will be finalized and submitted by end of the second quarter of year one. Participant recruitment for objective 1 will occur as soon as ethics approval is obtained. This is anticipated in the third quarter of year one. Data collection will begin as participants are recruited, with transcription and analysis also occurring alongside data collection. Data collection, transcription and analysis will continue into year two, with anticipated completion by the third quarter of year two. During the second half of year two and throughout year three the reference group and project team will finalize the structure and content of the Indigenous-centered dementia care approach. Facilitators for the intervention pilot will be recruited at the start of year four, while an Indigenous artist designs materials and the website where the materials can be hosted. An implementation working group will be formed during year two and will continue meeting throughout year three to develop the evaluation plan and pilot the care approach with a small group of participants. In the first half of year three the facilitator will receive training in the care approach from the project team and participants will be recruited into the pilot program, which will be delivered and evaluated throughout year four and into the first quarter of year five. End of grant knowledge dissemination and mobilization will be planned for and initiated in the final months of year four and will continue throughout year five with the finalization of the care approach and website. Knowledge mobilization activities and engagement with all participating or interested Indigenous communities will occur throughout the five years.

Pathways to Impact & Knowledge Dissemination

Our research not only adheres to the principles of self-determination as outlined by the United Nations Declaration on the Rights of Indigenous People (2008), it also directly addresses systemic racism in the Canadian healthcare system. Developing culturally safe dementia care approaches for Indigenous people living with dementia is relevant to the ongoing improvement of the ways in which we provide care for people living with dementia and their families. The involvement of service users, including the Alberta Health Services Indigenous Wellness Core and Indigenous community members throughout the work embeds integrated knowledge translation in the methodological approach. Moreover, this work and the ethical, strengths-based, and Indigenous-centered approach that adheres to ethical principles is highly applicable

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to other contexts and other underrepresented groups in dementia care settings. This work will impact numerous populations that need culturally specific approaches to dementia care policy and planning by informing an ethical process to engaging with diverse populations, thus contributing toward the goal of eliminating systemic racism in the Canadian healthcare system by creating safer spaces for racialized people living with dementia and their families.

This work will develop a model of culturally safe dementia care approaches and provide a framework for content, methods, and delivery of such approaches. The development of the Indigenous-centered dementia care approach will be guided by community need and will include the principles of intergenerationality and cultural connection, alongside established dementia care programming. Working with national partners from CCNA Team 18, the work will be developed to facilitate spread, scale and adaption to local Indigenous contexts. Additionally, the principles and methodology may be applied internationally to develop locally driven and culturally specific dementia care intervention for Indigenous populations or other underrepresented populations. The NPA and collaborators have networks and research partners in the United States, Australia, and the United Kingdom whereby further work can be developed. The team is ideally and uniquely positioned to complete this important work as they have an extensive background in co-developing work with people living with dementia, narrative and storytelling methods, experience in developing dementia care training for health care professionals, in-depth understanding of the impact of systemic anti-Indigenous racism in the Canadian healthcare system, and personal and professional connections to Indigenous communities. The sustained community relationships will maintain important connections in order to facilitate integrated knowledge translation throughout the study while iteratively adapting the dementia care approach content and model of delivery through ongoing feedback processes. End of grant knowledge dissemination will also occur in the final year of the study through community presentations, gifting of the materials back to participating communities through ceremony, academic journal articles (e.g., Aging & Society; Dementia: the International Journal of Social Research and Practice) and conferences (e.g., PRIDoC; The Canadian Association on Gerontology; The Gerontological Society of America) and other knowledge exchange events.

Expertise and Experience

As already described, the Public Health Agency of Canada has repeatedly called for additional work to improve dementia care provision, including for Indigenous people as a priority (2019; 2015) but to date this work has not been undertaken. Our uniquely positioned team brings together the needed expertise and relationships to successfully lead and undertake this research. Individuals from CCNA Team 18 who are applicants on this proposed study (Roach, Crowshoe, Henderson, Walker, Bourque Bearskin, Hogan) are currently leading a scoping and a realist literature review on the social, political, and cultural drivers of dementia and brain health for Indigenous people. These reviews are imperative to inform the development of culturally safe interventions and treatment models and seek to understand the implications of colonization, adverse childhood experiences and intergenerational trauma on cognitive decline later in life. Additionally, multiple co-investigators have been involved with recent work over the past two years to complete a qualitative interview project to understand the lived urban Indigenous experience of young onset dementia (manuscript in press with the Journal of Neurology Research) and the team is further supported by the substantial expertise in dementia health services research at the University of Calgary.

Pamela Roach, NPA, is an early-career Métis Assistant Professor (member of the Métis Nation of Alberta) and Tier 2 Canada Research Chair in Indigenous Health Systems Safety. She

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currently works with Indigenous community partners to develop Indigenous sensory/tactile interventions (interventions using sensory items to reduce behavioral or psychiatric symptoms of mental health or cognitive disorder) for individuals living with anxiety to create an evidence base for physical items to be used to impact clinical healthcare measures. She has extensive experience working with families living with dementia to understand and improve quality of life, including working with health care professionals to create a strengths-based clinical decision support tool to improve the provision of relationship-centered care (Family-AiD) and a recent strengths-based Indigenous patient experience of virtual primary care tool. She will be leading the work from a content and methods point of view. Lynn Jackson is a member of the Métis Nation of British Columbia and lives with dementia. Lynn brings her lived experience and expertise to the team as an Indigenous person living with dementia. Lynden Crowshoe is a Piikani First Nation family physician-scholar with extensive experience leading large multi-disciplinary provincial, national, and international research teams focusing on chronic disease and social equity within areas of primary health care, public health, and health education. He is successful in bringing together and bridging multiple disciplines of knowledge including health, clinical, social sciences and Indigenous Ways of Knowing. He is the co-lead of CCNA Team 18. Jennifer Walker is a Haudenosaunee member of Six Nations of the Grand River and Associate Professor in the Faculty of Health Sciences at McMaster University. She is the second co-lead of the CCNA Team 18 and a Tier 2 Canada Research Chair in Indigenous Health and will contribute to the design and evaluation of the dementia care approach. Rita Henderson is an early-career non-Indigenous models of care scientist with experience working ethically with Indigenous communities to implement new health services models of service provision and a member of the Department of Family Medicine at the University of Calgary. Dr. Henderson is a co-PI of the AIM-HI Mentorship Network and current Faculty Chair for the O'Brien Institute for Public Health's Group for Research with Indigenous People (GRIP) and will inform the development of the proposed service model. Lisa Bourque Bearskin is a Cree/Métis member of Beaver Lake Cree Nation and Associate Professor at Thompson River University in the School of Nursing. She holds the inaugural CIHR Chair in Indigenous Health Nursing. She is a leader in reconciling parallel pathways of traditional Indigenous health in community wellness and will bring an important nursing perspective to the work. David Hogan is a non-Indigenous geriatrician who is academic lead of the Brenda Strafford Centre on Aging (University of Calgary), co-author of the CAHS report on dementia that included a commissioned report on Indigenous issues and CCNA Team 18 member. He will contribute knowledge of dementia care services and health systems. Jayna Holroyd-Leduc is a non-Indigenous academic geriatrician and implementation scientist and holds the Brenda Strafford Chair in Geriatric Medicine. As Professor and Head of the Department of Medicine at the University of Calgary she brings both a clinical and health services implementation lens to the work and can advise on project direction and implementation considerations. Dallas Seitz is a non-Indigenous neuropsychiatrist and health services researcher with funded research underway to examine the effectiveness of nature-based interventions for dementia care and can help to inform the development of a service for people living with dementia. Zahra Goodarzi is a non-Indigenous health services researcher and implementation scientist who works as a geriatrician. She has extensive expertise in non-pharmacological treatments for people living with dementia and current models of care. Jeffrey Proulx is Mohawk of the Six Nations of the Grand River and Assistant Professor at the Brown University School of Public Health and Associate Director of Diversity and Inclusion at the Mindfulness Centre. His work focuses on the development of mindfulness programs using traditional activities and teachings and will inform the development and evaluation of the dementia care approach. Vivian Ewa is a non-Indigenous physician and Assistant Professor in Family Medicine at the University of Calgary. She has leadership roles in

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long term care and is section chief for Seniors Care, Family Medicine and plays an important part in education and training of future seniors' health physicians. Her direction and guidance as a care provider will be invaluable to the project design and outcomes. Richard Oster is a non-Indigenous health researcher and Scientific Director at the Alberta Health Services Indigenous Wellness Core. He provides crucial health systems guidance and extensive experience working in community-based settings to improve the health of Indigenous people. Meagan Ody is a Masters student already working with the NPA to develop Indigenous patient experience tools and has a first-author paper describing urban Indigenous experiences of early onset dementia in press with the *Journal of Neurology Research*.

In addition to the team and community collaborator strengths, the University of Calgary is well positioned to support this work. The Indigenous, Local and Global Health Office, in which Drs. Crowshoe and Roach have leadership positions, supports a Traditional Knowledge Keepers program to connect to Elders from the various Treaty areas within the province of Alberta and Métis Nation of Alberta. The Hotchkiss Brain Institute (HBI) is an internationally recognized centre of excellence in neurological and mental health situated in the medical school. Dr. Roach's active membership on the HBI's Cognitive Disorders and Dementia Brain and Mental Health Team provides an outstanding opportunity for collaboration in diverse areas of brain and mental health, neuroscience, social health systems, and Indigenous healthcare services. Moreover, the O'Brien Institute for Public Health is located within the Cumming School of Medicine and encompasses more than 500 members with a range of academic and professional backgrounds. The O'Brien Institute is also home to the Group for Research with Indigenous Peoples (GRIP), currently chaired by Dr. Henderson, and the Alberta Indigenous Mentorship in Health Innovation Network (AIM-HI). This offers students and trainees high quality training in research methods and ethical ways of working with Indigenous people, as well as necessary skills for reconciliation and health systems transformation.

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