

Outcomes Report of Activities Supported by Campus Alberta HOPH Meeting Grant

Please provide brief responses below, expanding as necessary to not exceed 2 pages.

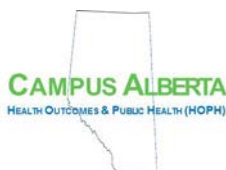
Date of Report	2021, for 2019 award
Date of Meeting	March 4, 2020
Title of Meeting	Tailored, Community-Based Intervention Program For People Living With Dementia And Their Family Caregiver
Team Lead(s)	Dr. Gwen McGhan
Amount of Award	\$4,000

- Please append the program/agenda for your HOPH-sponsored meeting.**
See Appendix 1
- Meeting attendance** (total number of attendees, affiliations represented, etc):
See Appendix 2 for full attendee list with affiliations. Total attendance was 22 people not including organizing committee.
- Outline the meeting expenses covered by the awarded funding:**
Catering – \$1,656.27
Participant parking and transportation - \$259.45
Research associate (planning, coordination, environmental scan, literature review, data analysis, report writing) - \$2084.28
- List, link, provide, or explain existing or planned products from the meeting** (reports, publications, etc):
See Appendix 3 for white paper prepared from meeting proceedings.
We intend to prepare a publication from the data gathered at the meeting in Summer 2021.
- List (with projected timelines and names of participants) what activities or next steps are ensuing from the meeting** (follow-up meetings, etc):
As with so many activities in 2020, our work in this area has been delayed by the pandemic. As vaccination rates increase and it becomes possible and safe to offer community programs, we are working with The Vecova Centre to launch a new Tailored Community Program for People Living with Dementia. This will provide a launching off point from which to work with meeting participants to advocate for similar programming province-wide.
- Please provide any additional commentary on the benefits or unexpected consequences arising from the meeting:**
The pandemic has been our main unexpected consequence, making it impossible to offer in-person programming and leaving our partners dealing with many pandemic-related issues, and without bandwidth to address to this project.



Faculty of Health Sciences





Meeting Agenda

Meeting Date: Wednesday, March 4, 2020

Time: 8:00 am – 3:00 pm MDT

Location: Multi-Purpose Room: W21C (TRW Building, Foothills Medical Campus)

Map & Parking: See last page

Project: Tailored, Community-Based Intervention Program For People Living With Dementia And Their Family Caregiver

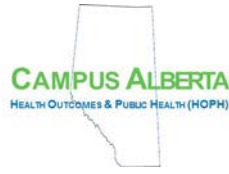
Participants: See page 3

Agenda

8:00 – 8:30	Breakfast
8:30 – 9:30	Welcome Session
8:30 – 9:00	Meeting Overview and Introductions
9:00 – 9:30	Family Caregiver Experiences
9:30 – 10:30	Group Discussion
	<ul style="list-style-type: none"> • What programs or resources are currently available for people living with dementia and their family caregivers? • What are the key ingredients for a successful program?
10:30 – 10:45	Refreshment Break
10:45 – 11:30	Group Discussion
	<ul style="list-style-type: none"> • Where are the gaps in programs or resources? • How are the needs of the different segments of the dementia community best addressed?
11:30 – 12:15	Lunch
	Research team debrief - W21C Boardroom
12:15 – 1:30	Break Out Sessions: Addressing the Identified Gaps and Developing Potential Partnerships
12:15 – 12:30	Break Out Session Orientation
12:30 – 1:30	Break Out Session Discussion
1:30 – 1:45	Refreshment Break
1:45 – 3:00	Afternoon Group Session
1:45 – 2:45	Break Out Sessions Report Back
2:45 – 3:00	Next Steps & Adjournment

Organizers Contact Information:

Gwen McGhan	587.892.2801
Kristin Flemons	403.210.9257



Meeting objective:

The goal of the meeting is to bring together key groups of healthcare and community leaders to discuss community resources and identify gaps for people living with dementia and their family caregivers.

Additionally, we are seeking your input on interventions that promote quality of life for the caregiving dyad, as well as potential avenues for achieving spread and scale across diverse communities within Alberta.

We seek to understand:

- What programs or resources are currently available in the community for the caregiving dyad?
- What/where are the gaps in community interventions for the caregiving dyad?
- How do we best address those gaps and develop potential partnerships for delivery?

Wednesday, March 4, 2020 Campus Alberta Stakeholder Meeting Attendee List

Stakeholder Name	Affiliation
Ali Cada	Club 36
Dr. Anne Toohey	O'Brien Institute for Public Health, University of Calgary
Beth Mansell	SAGE, Tusk
Catherine Laing	Brenda Strafford Foundation
Charlene Retzlaff	AHS Family Caregiver Centre
Christene Gordon	Alberta Alzheimer's Association
Christine Sparrow	Family Caregiver
Cindy McCaffery	YouQuest
Cynthia Watson	Vivo
Dr. Dave Hogan	O'Brien Institute for Public Health, University of Calgary
Dr. Heather Hanson	Seniors Health Strategic Clinical Network
Jessica Power Cyr	The Glencoe Club
Johnna Lowther	Caregivers Alberta, Tusk, Life With Dementia Podcast
Karen McDonald	SAGE
Katharina Zacharias	Kerby Center
Kim Brundrit	Dementia Network Calgary
Laura Forsyth	Ministry of Senior Services
Mary Sangha	Family Caregiver
Dr. Meghan McDonough	Faculty of Kinesiology, University of Calgary
Dr. Myles Leslie	School of Public Policy, University of Calgary
Navjot Virk	Brenda Strafford Foundation
Shannon Janewski	Calgary Seniors Resources Center
Stephanie Chrumka	Family Caregiver

Wednesday, March 4, 2020 Campus Alberta Stakeholder Meeting: Research Team

Research Team	Affiliation
Gwen McGhan (PI)	Assistant Professor, Faculty of Nursing, University of Calgary
Deirdre McCaughey (Co-PI)	Associate Professor, Division Lead – Health Systems, Department of Community Health Sciences, University of Calgary
Jasneet Parmar (Co-PI)	Associate Professor, Medical Lead, Department of Family Medicine, University of Calgary
Sharon Anderson (Co-PI)	Research Coordinator, Covenant Health Network of Excellence in Seniors' Health and Wellness
Kimberly Shapkin (Co-PI)	Nurse Practitioner, Faculty of Nursing, University of Calgary
Lisa Poole (Co-PI)	Family Caregiver, Calgary Dementia Network Strategic Council and The Alberta Seniors' Health Research Priority Setting Partnership Steering Group
Kristin Flemons	Research Associate, W21C, University of Calgary



Paid Parking

The **TRW Parkade** (\$20.00/day) is directly across the road from the TRW Building, and is accessed via the ramp to the underground lot. The elevator from this lot will take you up to the Ground floor of the TRW building. Turn left out of the elevator, and turn left again directly after the Information/Security desk, before you exit through the main building doors. W21C is at the end of the hallway.

The **Lot 10**, McCaig Parkade (\$14.25/day) is immediately south of the TRW parkade and across the road from the McCaig Tower, also underground. Proceed to the parkade entrance, down the ramp and find yourself a spot to park on one of the public parking levels. Take the elevator or stairs and come back to the TRW building. The W21C door is between the main doors and the Information desk on your right. Proceed to the door at the end of the hallway.

Please note – if you have requested a parking pass: you **must** park in Lot 10, not the TRW parkade. You will need to display your pass on the dash of your car. We will have the passes for you at W21C when you arrive Wednesday morning.

Map

<https://maps.google.com/?q=3280+Hospital+Dr.+NW,%0D+%0D+%0D+Calgary,+AB,+T2N+4Z6&entry=gmail&source=g>

APPENDIX 2 - Attendees

Stakeholder Name	Affiliation	Attended?
Ali Cada	Club 36	Yes
Dr. Anne Toohey	O'Brien Institute for Public Health, University of Calgary	Yes
Beth Mansell	SAGE, Tusk	Yes
Catherine Laing	Brenda Strafford Foundation	Yes
Charlene Retzlaff	AHS Family Caregiver Centre	Unable to attend
Christene Gordon	Alberta Alzheimer's Association	Yes
Christine Sparrow	Family Caregiver	Yes
Cindy McCaffery	YouQuest	Yes
Cynthia Watson	Vivo	Yes
Dr. Dave Hogan	O'Brien Institute for Public Health, University of Calgary	Yes
Dr. Heather Hanson	Seniors Health Strategic Clinical Network	Yes
Jessica Power Cyr	The Glencoe Club	Yes
Johnna Lowther	Caregivers Alberta, Tusk, Life With Dementia Podcast	Yes
Karen McDonald	SAGE	Yes
Katharina Zacharias	Kerby Center	Unable to attend
Kim Brundrit	Dementia Network Calgary	Yes
Laura Forsyth	Ministry of Senior Services	Yes
Mary Sangha	Family Caregiver	Yes
Dr. Meghan McDonough	Faculty of Kinesiology, University of Calgary	Yes
Dr. Myles Leslie	School of Public Policy, University of Calgary	Yes
Navjot Virk	Brenda Strafford Foundation	Yes
Shannon Janewski	Calgary Seniors Resources Center	Yes
Stephanie Chrumka	Family Caregiver	Yes



Campus Alberta Health Outcomes & Public Health Meeting Grants Award Stakeholder Report

Tailored, Community-Based Intervention Program for People Living with Dementia and their Family Caregivers

Project Goals

The goal for our *Tailored, Community-Based Intervention Program for People Living with Dementia and their Family Caregivers*, 2020 Campus Alberta Meeting Grant was to assemble a group of key healthcare and community stakeholders to examine available community resources and identify critical gaps for people living with dementia and their family caregivers. Additionally, we sought the guidance and feedback of our stakeholders on strategies to increase the availability and quality of community resources across diverse Alberta communities.

The purpose of the meeting was to develop a guide for existing community-based resources; highlight the critical gaps in available resources; and strategize approaches and partnerships to best address the current gaps.

Project Processes

Research team members (see Appendix A) conducted biweekly conference calls from Fall 2019 to Spring 2020. The team discussions focused on:

1. Identifying key stakeholders to invite to the March stakeholder meeting (Appendix B)
2. Compile a preliminary environmental scan
3. Determine meeting focus group discussion topics
4. Review meeting logistics.

Stakeholder Identification & Engagement

Key stakeholders were purposefully identified to ensure a variety of perspectives across the care continuum. Provincial stakeholders with diversity in geographic location, employer and/or organization, range of roles (frontline staff to senior leadership roles), and family representatives were invited to participate. Having diverse representation facilitated the exploration of multiple perspectives when addressing the purpose of the meeting.

Process of the Meeting

The meeting consisted of an overview and introduction (by the team's lead investigators), followed by facilitated morning group discussions and afternoon breakout sessions, concluding with a breakout group report back. Each stakeholder was assigned to one of three breakout groups, which were led by experienced facilitators.

The Core Questions of the Project

The following questions generated a fulsome discussion around available resources in Alberta for people living with dementia and their family caregivers (caregiving dyads):

1. What programs or resources are currently available in the community for the caregiving dyad?
2. What/where are the critical gaps in community resources and/or interventions for the caregiving dyad?
3. How do we best address those gaps and develop potential partnerships for delivery?

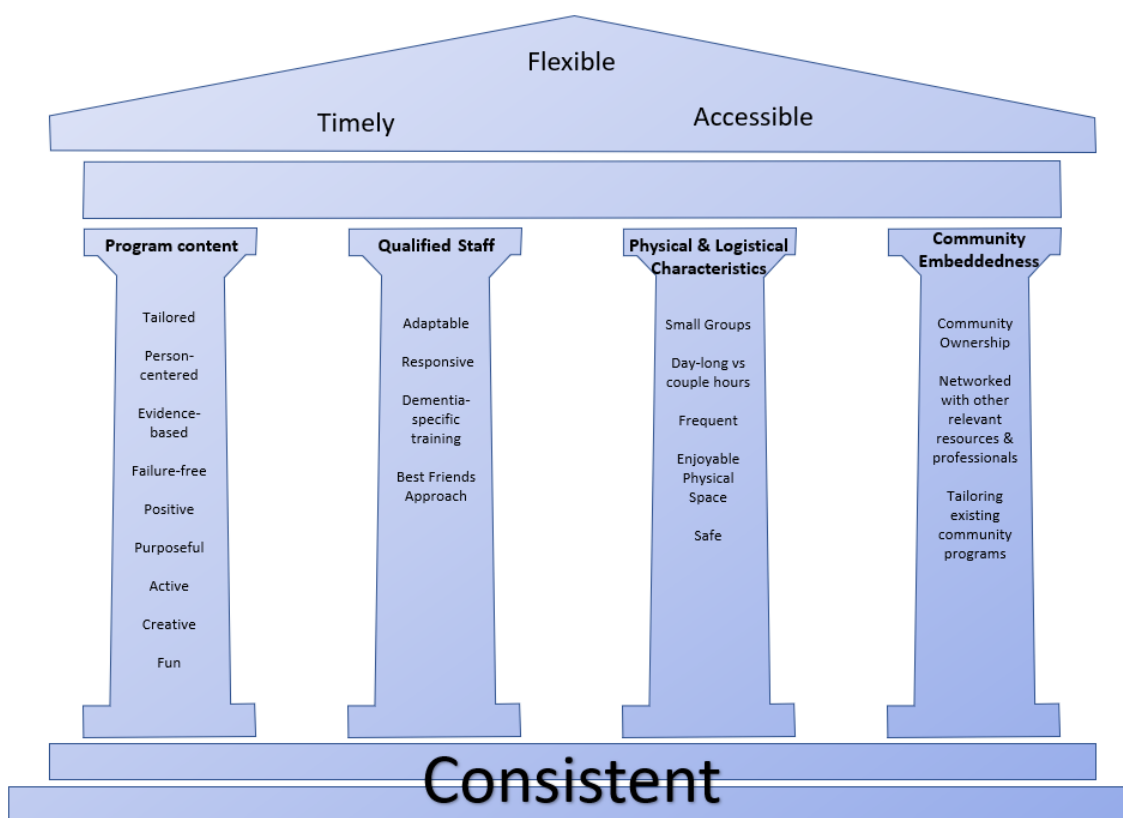
Morning Group Discussion 1: The Current Landscape

1. What programs or resources are currently available for people living with dementia and their family caregivers?
2. What are the key ingredients for a successful program?

Stakeholder Findings:

Existing Resources: See environmental scan for resources

Key Ingredients:



Morning Group Discussion 2: Identifying Gaps Across a Diverse Landscape

1. Where are the gaps in programs or resources?

2. How are the needs of the different segments of the dementia community best addressed?

Stakeholder Findings:

- Identified gaps can be broadly grouped into five categories:
 - Systemic gaps
 - Gaps between communities of practice
 - Underserved populations
 - Program content and delivery gaps
 - People living with dementia (PLWD) and family caregiver support gaps
- See Table for a breakdown of the points raised under each of these categories:

Systemic Gaps	Gaps Between Communities of Practice	Underserved Populations	Program Content & Delivery Gaps	Caregiver & PLWD Support Gaps
<ul style="list-style-type: none"> • Funding Gaps <ul style="list-style-type: none"> ◦ How do we route funding? ◦ Sustainable & non-directive? • System navigation <ul style="list-style-type: none"> ◦ Single Point of Contact is needed • Lack of 'system planning' approach <ul style="list-style-type: none"> ◦ Strategic planning and sustainability • Between healthcare and social care <ul style="list-style-type: none"> ◦ Lack of interprofessional approach ◦ Joint health/social services ◦ Integration of services • Geographic gaps/program deserts • Duplicative efforts, working in silos <ul style="list-style-type: none"> ◦ Need knowledge base or hub • Defining Value: Monitoring & 	<ul style="list-style-type: none"> • Between healthcare and social care • Research translation into community based programs (knowledge integration, communication, translation) • Gap between leadership and front line staff <ul style="list-style-type: none"> ◦ Availability of training, access to new knowledge and approaches • Duplicative efforts, working in silos <ul style="list-style-type: none"> ◦ Program leaders unaware of similar programs 	<ul style="list-style-type: none"> • PLWD living alone • Young children of young onset dementia • Young onset dementia <ul style="list-style-type: none"> ◦ can't access services directed at seniors • Early stage dementia <ul style="list-style-type: none"> ◦ Opportunities for employment, volunteerism • Multicultural communities <ul style="list-style-type: none"> ◦ Not recognizing dementia as an issue ◦ Stigma ◦ Needs of newcomer and immigrant communities • People with developmental disabilities <ul style="list-style-type: none"> ◦ Guardianship and trusteeship services • Rural & Remote communities 	<p>Program Content:</p> <ul style="list-style-type: none"> • Programming that includes physical exercise • Dietary & nutritional needs of PLWD & Caregivers • Input from PLWD • Choice and tailoring - person-centered programming • Meaningful programming <p>Program Delivery:</p> <ul style="list-style-type: none"> • Consistency in care, appropriateness of care <ul style="list-style-type: none"> ◦ Continuity in formal caregivers ◦ Formal caregivers require appropriate training • Lack of training for home care workers • Palliative and End of Life care <ul style="list-style-type: none"> ◦ Make it dementia-specific 	<p>Caregiver Support:</p> <ul style="list-style-type: none"> • Communication with caregivers <ul style="list-style-type: none"> ◦ Provide anticipatory guidance for resources and supports • Lack of information/access to information <ul style="list-style-type: none"> ◦ Updated info ◦ Trusted sources ◦ Methods of sharing • Social isolation <p>PLWD Support:</p> <ul style="list-style-type: none"> • Isolation • Accessibility <ul style="list-style-type: none"> ◦ Noise level, visual stimulation, lighting • Support with home maintenance

<p>Evaluation for iterative improvement</p> <ul style="list-style-type: none"> • Input from people living w dementia • Lack 24/7 care • Critical transition points across care continuum 		<ul style="list-style-type: none"> • First Nations communities • Young Caregivers • Homeless, unstably housed • Mild and moderate dementia <ul style="list-style-type: none"> ◦ Programming that maintains continuity w their lifestyle, interests, identity • LGBTQ communities 	<ul style="list-style-type: none"> ◦ Supporting staff in long-term care to guide and support families, answer questions, make decisions • Cost - free programming vs valued programming 	
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Breakout Session: Addressing the Gaps

1. What are pragmatic ways to address the identified gaps?
2. What are appropriate interventions? What partnerships would enable a sustainable approach to address the identified gaps?

Stakeholder Findings:

- Models identified fit into four categories:
 - System navigation
 - System planning
 - Program design and content
 - Meeting the needs of marginalized communities

System Navigation	<ul style="list-style-type: none"> • Key Worker navigation model • Link Worker model (UK) • 211 network (potential model and partnership) • Oncology Care navigation model • Ontario's Alzheimer Society Care Navigators • Fraser Health Authority's Social Prescribing Model
System Planning	<ul style="list-style-type: none"> • BC Model (see below)
Program Design and Content	<ul style="list-style-type: none"> • Memorial Lodge (Victoria, BC): Arts programming • South Health Campus "loud" and "big" programs for Parkinson's: client matching, all-day, multi-day comprehensive networked support • Win/wins - Ontario golf program
Meeting the Needs of Marginalized Communities	<ul style="list-style-type: none"> • Promoting dementia-friendly communities in rural areas • Roving/popup programs for smaller or more isolated communities • Increasing access to virtual programming (Should be appropriate to the community - perhaps children of young onset dementia; risks must be addressed) • Co-ownership and co-management of care facilities to ensure appropriate care and cultural fit • Work-share or volunteer programs; i.e. a workplace program that provides guidance and information for workplaces/volunteer organizations to continue employment of people in early stages; support them in adapting to disease progression; identify when an individual should stop working or volunteering.

- BC Model:
 - Community based senior service sector that advocates for the value of the work happening in the community

- Department of Healthy Aging within the Ministry of Health; funding is centralized
- Data and evaluation that is consistent throughout the province for key outcomes
- Shared funders table
 - Includes community and research groups
 - Groups streamline info, inform, prevent duplication, and address gaps
- CORE: hub for sharing resources and skills virtually
 - ongoing support to build a capacity of local organizations to work collaboratively
- Healthy Aging reference group including academia, policy makers, older adults, government and nongovernmental organizations
- Municipal government representatives meet pan-provincially to advance work aimed at helping older adults age-in-place
- Regional groups and task groups that are topic based (i.e. dementia, assisted transportation, affordable housing)
- Therapeutic Activation Program for Seniors (TAPS) – supports and promotes recreation and social connectedness

Potential Partnerships Identified:

- Caring companion and assisted transportation
- 211 Network
- City of Calgary and Edmonton Recreation
- Long-term Care facilities
- Community Centers across Alberta
- Medical mentorship programs: pair medical students, nurses, other health care aids with people living with dementia

Meeting Conclusions:

With the input of our key stakeholders, we highlighted the need for consistent resources for both people living with dementia and their family caregivers that are flexible, timely and accessible. This includes programs and interventions tailored to the needs of the caregiving dyad, embedded in the community and led by qualified and trained staff.

Key outcomes from the meeting include:

- 1) A repository of community-based dementia resources that will be distributed to our stakeholders and other interested parties
- 2) Suggestions for sustainable resources and interventions, highlighting the identified key elements for success and critical gaps
- 3) Potential partnerships for future collaboration on the development and refinement of interventions for people living with dementia and their family caregivers, including knowledge dissemination and funding opportunities.

Appendix A Investigator Team

Team Member	Affiliation
Gwen McGhan (PI)	Assistant Professor, Faculty of Nursing, University of Calgary
Deirdre McCaughey (Co-PI)	Associate Professor, Division Lead – Health Systems, Department of Community Health Sciences, University of Calgary
Jasneet Parmar (Co-I)	Associate Professor, Department of Family Medicine, University of Alberta Medical Lead, Home Living and Transitions, AHS EZ Continuing Care
Sharon Anderson (Co-I)	Research Coordinator, Covenant Health Network of Excellence in Seniors' Health and Wellness
Kimberly Shapkin (Co-I)	Nurse Practitioner, Faculty of Nursing, University of Calgary
Lisa Poole (Co-I)	Family Caregiver, Calgary Dementia Network Strategic Council and The Alberta Seniors' Health Research Priority Setting Partnership Steering Group
Kristin Flemons	Research Associate, W21C, University of Calgary

Appendix B

Stakeholder Meeting Attendee List

Stakeholder Name	Affiliation
Ali Cada	Club 36
Dr. Anne Toohey	O'Brien Institute for Public Health, University of Calgary
Beth Mansell	SAGE, Tusk
Catherine Laing	Brenda Strafford Foundation
Christene Gordon	Alberta Alzheimer's Association
Christine Sparrow	Family Caregiver
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Dr. Dave Hogan	O'Brien Institute for Public Health, University of Calgary
Dr. Heather Hanson	Seniors Health Strategic Clinical Network
Jessica Power Cyr	The Glencoe Club
Johanna Lowther	Caregivers Alberta, Tusk, Life With Dementia Podcast
Karen McDonald	SAGE
Kim Brundrit	Dementia Network Calgary
Laura Forsyth	Ministry of Senior Services
Mary Sangha	Family Caregiver
Dr. Meghan McDonough	Faculty of Kinesiology, University of Calgary
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