

# Interventions to Enhance Social Inclusion of Older **Adults with Dementia in Saskatchewan**

# **Windup Summit Report**

June 2024







The Dementia Supports in Rural Saskatchewan project team is made up of the Backbone Management Group, the Advisory Committee & Collaborating Organizations.



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## Acknowledgments

We thank everyone for attending the Dementia Supports in Rural Saskatchewan Windup Summit in Yorkton, SK, on Thursday, June 20, 2024. Witnessing the level of engagement and interaction among those in attendance was wonderful. The discussion groups produced valuable feedback. The Collaborating Organizations' sustainability plans also provided much to take away. We express our sincere gratitude to every one of you for your presence, your feedback, and your significant contributions throughout the day and the project. Your involvement has been instrumental in making this event a success.

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## Introduction

*Dementia Supports in Rural Saskatchewan* is a five-year initiative (2019-2024) undertaken by the Saskatchewan Population Health and Evaluation Research Unit (SPHERU), University of Regina. The project objectives are to improve public awareness of dementia, to reduce stigma, and to improve the feeling of social inclusion of older adults living with dementia and their care partners.

Dementia Supports in Rural Saskatchewan

### Dementia Supports in Rural Saskatchewan

1. To improve the feeling of social inclusion of older adults with dementia and their care partners residing in Yorkton, Melville and surrounding rural areas (individual programs)

2. To improve public awareness about dementia (community programs)

3. To reduce level of public stigma about dementia (community programs)

4. To improve supports for customers, clients and employees who are living with dementia or their care partners residing in Yorkton, Melville and surrounding areas (organizational programs)



Windup Summit Report June 2024



### Windup Summit Overview

As the 5-year (2019-2024) federally funded project comes to an end on August 31, 2024, the DSRS Backbone Management Group and Collaborating Organizations facilitated a Windup Summit on the initiative's progress, a brief discussion of evaluation findings, and a discussion on the plans for sustainability. It took place on Thursday, June 20, 2024, at the Gallagher Centre in Yorkton, SK, from 10:00 a.m. to 3:00 p.m.

A total of 36 individuals from the Advisory Committee, Collaborating Organizations, artists, community members, people with lived experience, the Mayor of Yorkton, the City of Yorkton, Yorkton Public Library, Yorkton & District Nursing Home, and several employees from the Saskatchewan Health Authority attended the summit.

The summit was recorded for educational and promotional purposes.





## **Small Group Discussion**

### Introduction

The summit participants were presented with a summary presentation of the Evaluation Findings that highlighted five "key lessons":

- 1. There is a need for direct supports to people living with dementia (PLWD) close to their home community.
- 2. There is an interest and willingness for organizations (both public and private) to make their facilities more dementia-friendly.
- 3. There is a need for greater public awareness about dementia.
- 4. Local CBOs are one avenue for providing direct support interventions.
- Sustaining local initiatives remains a challenge for those community-based organizations (CBOs).

Dementia Supports in Rural Saskatchewan

## Background

- Over 350 people are diagnosed with dementia everyday in Canada
- Caregivers spend an average of 26 hrs/week caring for someone with dementia
  - They can experience financial hardship, burnout, depression and isolation
- Canada's home care, long-term care and primary care systems are under increasing stress
  - All of which adds to the strain of accessing services for PLWD & care partners

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• And this is made even worse if you live in a rural area where services and supports are even harder to find

As part of the evaluation, the collaborating organizations made the following observations about dementia-friendly services and supports:



### Limited Services

- What services exist tend to be concentrated in larger urban centres
  - This leaves PLWD and care partners isolated or forced to travel
- Long term care facilities often not equipped for caring for PLWD who remain active and have specific interests
- Accessing healthcare providers hardest in rural communities



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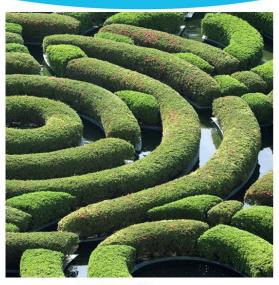
- 1. There was a limited availability of services.
- 2. There were challenges accessing those services that did exist.
- 3. There were challenges getting information about those services.
- 4. Limited awareness about dementia within the general public, but also within

organizations and within the health care system.

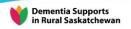
Dementia Supports in Rural Saskatchewan

#### **Accessing Services**

- Care partners often have to learn how to navigate through complex processes to access services
- There are no specific supports to assist PLWD or care partners in finding needed services
- Collaborating organizations often stepped into the breach, but their capacity to assist is limited



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### Information on Services

- There is inadequate information on the next steps after a dementia diagnosis
  - If true in Yorkton, Melville & surrounding areas then likely true in other rural areas as well
- Projects observed that there was no specific resource they could recommend to families that needed further information on existing supports
- Need to find ways to leverage existing information networks to provide locally relevant information



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### Dementia Awareness & Literacy

- Beyond the most basic information, there is a general lack of knowledge about dementia in society
  - Confirmed by SPHERU survey in Yorkton and area in 2021
- This extends to those working in the healthcare system
  - They cannot provide information on 'next steps'
  - Not trained on having PLWD as patients
- Collaborating organizations noted the need for dementia training for docs, nurses, LTC staff & others in the system





### Concluding Thoughts

- We know (A) the state of dementia services in rural Sask
- We know (B) there's a need for more services & a willingness of communities to be part of delivering them
- But we don't know the pathway to get from A to B ...
- And even if we get to (B) there are still issues that need to be confronted
  - Resources and capacity within CBOs to design and deliver services
  - Sustaining those services over time
- Are initiatives like this one, a possible vehicle to overcome those challenges?
  - We don't have a definitive answer to that, but it is something to be considered

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Following the presentation, the summit participants were given two questions to consider in facilitated small group discussions. These questions were:

- We have real issues with a lack of training in health care organizations, businesses and governments for personnel dealing with PLWD. How can we better incorporate dementia awareness in these organizations?
- 2. Even the most well-designed health care system requires navigation (by patients, care partners and health care personnel). What is required to make accessing dementia care easier to navigate?

#### What We Heard

After the discussion in small groups, each group reported back in turn on each of the questions and those responses are summarized below.

#### Question 1: Promoting Dementia Awareness

The groups consistently came back to redoubling efforts to undertake public education campaigns that could include both broad-based education campaigns and more focused activities like the ABCs of Dementia presentations undertaken by the Alzheimer's Society. These need to go hand in hand with putting information into the hands of health system professionals so that

they can assist patients and their families. Physicians especially can play an important role in the one-on-one transfer of knowledge, but they have to be better informed about what dementia is, how it manifests and what services are needed/available.



More and better dementia training needs to be incorporated into the education of health professionals, especially within the primary health care system and the longterm care system so that there is consistency in the messages delivered to

patients. This is especially true as the baby-boom generation ages and the need for appropriate dementia care and support grows.

Groups also spoke about the need for greater levels of political and social activism in order to spark action on the part of governments and organizations, especially local governments, to pay more attention to dementia-friendly initiatives.

Another consistent theme that came through was the idea that being "dementia-friendly" needs to be consistently and substantively incentivized. Some of the training requirements could be regularized in regulations and curricula, but there needs to be incentives for private organizations to undertake efforts to make themselves dementia-friendly.

#### Much of this comes down to two things:

- 1. Making dementia awareness/training a priority within civil society institutions
- 2. Making resources available to support that awareness and training

Changes to professional training curricula and/or making dementia training part of health care workers' professional development will only occur if those in charge of the training of health care

workers see it as a priority. Similarly, regulations around health care facilities, and in this case especially long-term care facilities, can and should speak to the need for facilities to be able to provide appropriate care to PLWD and support to their care partners.

And this will require the commitment of both human and financial resources to accomplish. Those resources need to be focused:

- 1. At the provision of the direct services to individuals by individuals who are appropriately trained and regulated.
- 2. At organizations in the public, private and not-for-profit CBO sectors to both deliver direct services but to transform their organizations themselves.
- 3. At the broader public to increase its awareness of what dementia is and how it manifests and to make the public more confident that, as individuals, they would know how to interact with PLWD and their care partners.

#### Question 2: Improving System Navigation

In an ideal world a person receiving care would be able to navigate their way through the health care system on their own. But even the most transparent and supportive health care system will need to provide those who are ill with supports to assist them moving through the system and ensuring that the right service is available at the right time in the right place. This is particularly true for those PLWD whose cognitive capacity is going to inevitably decrease over time.

The key to successful navigation of the health care system is ensuring that the right information is available in the right place at the right time and in the right form. This was emphasized in all of the small group discussions.

There are a host of institutions where individuals come face to face with the health care system, or with those adjacent to it in varying degrees – doctors' offices, clinics, hospitals, pharmacies, long-term care facilities, etc. – that could be venues for disseminating information of dementia services. Social service CBOs, especially those dealing with an older clientele, are also prime candidates for providing access to the necessary information.



But behind that there needs to be resources allocated to ensure that the information is current, comprehensive and understandable. And it has to be in a form that is useful. A list of websites is of little use to someone in a community

that has no or very poor broadband service – they will need phone numbers and, preferably, the names of people to whom to reach out.

In other words, there is no single best way to access information or single best place to keep that information. The internet can be useful, but it can also be overwhelming and filled with as much bad information as good. The groups clearly wanted information that had been curated by those with knowledge and expertise and packaged in a way that considers the context in which it will be used.

Further, groups noted that it was not just the medical aspects of dementia care and treatment that needed navigating. There were the social and community aspects as well – access to support

groups, recreational services, home support services and the like – are every bit as much a part of dementia-care as any medically focused care-plan. But repeatedly, the groups spoke about how much their own access to information and their own knowledge about navigating the system relied on happenstance, being in the right place at the right time and the kindness of strangers.



## Conclusion

The conversations at the summit provided a clear confirmation of much of what we heard in the evaluation of the projects that were undertaken in this initiative. With appropriate resources and support, it should be possible to better improve the knowledge and training of health professionals and those other organizations with whom PLWD interact. And, again, the expectation is that the aging of the baby boom generation is going to increase the overall need for qualified personnel and for organizations to provide appropriate services both in terms of medical and social care. Though rural Canada and rural Saskatchewan continue to decline as an overall proportion of the population, rural areas consistently skew older than urban areas, and the potential for them to be ignored when thinking about how to organize and deliver services is significant. As the discussion groups repeatedly said, there is no 'one size fits all' approach that is viable. The specificities of how to do this in rural communities has to be taken into account.



## **Evaluation Findings**

### Impacts at the Individual Level

Providing individuals living with dementia and their care partners an opportunity to participate

in activities that build social connections.

Dementia Supports
in Rural Saskatchewan
Increased Social Interaction and Feelings of Inclusion
<ul> <li>Persons living with dementia and care partners engaged with other persons and activities (games, museum, cooking, painting, craft, quilting, and beading) beyond immediate family, home, and vicinity</li> </ul>
<ul> <li>Found a safe space, supportive framework, and sense of community for families</li> </ul>
<ul> <li>Cooking and baking familiar foods and flavours, is calming and connects older adults living with dementia (and their caregivers) to their past and their identity (IleX)</li> </ul>
<ul> <li>Art activities reduce stigma by focusing on personhood and the diverse abilities of individuals</li> </ul>
Dementia Supports in Rural Saskatchewan
Enhanced Quality of Life
<ul> <li>Persons living with dementia and care partners explored creative talents</li> </ul>

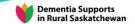
- Increased coping ability for care partners by reducing burnout through respite and preparing healthier easy meals that support their health
- Easier access to existing supports (referrals, LTC) reduced the time and effort care partners would have required to navigate these services
- Ease of access to health professionals for dementia diagnosis and management (memory clinic)



### Impacts at the Community Level

Supporting communities with tools to engage those living with dementia and their care

partners to participate fully in community life.



#### Partnerships

- More partnerships established with SK Health Authority leadership/management for the implementation of memory clinics
- Partnerships developed with the Saskatchewan Health Authority Medical Social Work departments in Yorkton
- Memory Clinic Team consists of health professionals from Primary Health Care services in different cities, Community Pharmacist and the Alzheimer Society of Saskatchewan (ASOS) First link Coordinator
- Collaboration between Cos and other stakeholders: City of Yorkton, The Saskatoon Council on Aging (SCOA), and Alzheimer Society Saskatchewan promoted Cognitive Kitchen programs via social media and e-news
- Collaboration between SaskAbilities Dementia program and staff in the health sector including occupational therapists and training of staff in nursing homes

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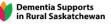


#### Increased Dementia Awareness

- Increased willingness by businesses to adjust to create dementia-friendly atmospheres for persons living with dementia and care partners- some restaurants consistently provided quiet and accessible spaces for group outings
- Several organizations have requested for ABCs warning signs presentation, staff orientation and examined dementia-friendly considerations for their programs and services

#### Example: The East Central Newcomer Welcome Centre and Anytime Fitness:

 Hosted a staff orientation, facility reviews, and received resources to implement dementia-friendly considerations in services and physical environment



### Community Support and Advocacy

- PLWD and Care Partners are encouraged to challenge the stigma about dementia and be more willing to share and engage with others in their dementia journey
- SIGN Family Resource Center collaborated with Kamsack Public Library and ASOS to organize a Dementia Friendly orientation for community organizations in Kamsack
- Three pharmacies sponsored the the ABCs presentation at the Golden Jets Senior Center which had 70 persons in attendance
- The Community Well in Foam Lake offered vouchers for transportation for participants of the Cognitive Kitchen and advertised the project
- Quilting, painting, and beading provide a community of support, building awareness and passing on traditions to younger generations

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#### Increased Media Coverage

Project news shared in the media generated interest in various projects:

- Three printed newspaper articles about the Cognitive Kitchen: the Foam Lake Review, the Preeceville Progress, and the Canora Courier
- Publications in *Yorkton This Week* and the *Preeceville Progress* about the Alzheimer Society of Saskatchewan Public Awareness campaign
- Dr. Debra Morgan (RaDAR) granted 03 interviews to the media (650 CKOM, CBC and Global Regina
- Videos (SaskAbilities promotional video, RaDAR Esterhazy video, Godfrey Dean Art Gallery Belong Where You Find Yourself Documentary film)
- Ile-a-la-Crosse podcast on dementia awareness through a Metis community lens\*

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### Impacts at the Organizational and System Level

Engaging businesses and organizations to adopt policies and practices that facilitate those living with dementia and their care partners to fully access their services.

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#### Organizational Adjustments to Enhance Dementia Inclusivity

Institutions implemented recommended changes to enhance dementia inclusivity.

The Yorkton Public and Saltcoats libraries made changes for spaces to be more inclusive and accessible:

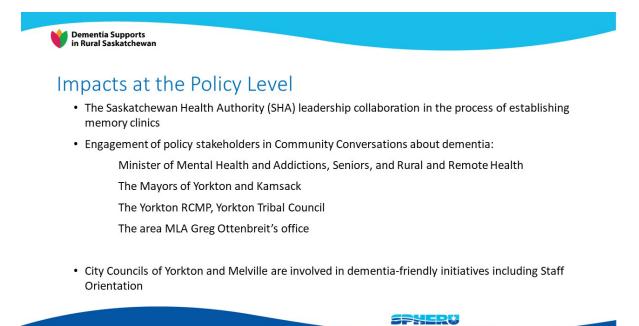
- Quiet space designated for patrons
- · Larger print keyboard and books provided for guests
- Upgraded visual signs (signage for washrooms, parking)
- Yorkton Pharmasave adapted fonts to be more visually accessible on medication sheets provided with dementia care prescriptions
- Continuous collaboration across DSRS Collaborating Organizations (COs) through referrals and promotion of other DSRS projects

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The Collective Impact Approach can provide a framework for policy reform in addressing and

implementing appropriate dementia supports in rural Saskatchewan.



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## Sustainability Plans

Collaborating Organizations' plans for sustaining their initiatives once the 5-year (2019-2024) federally funded project comes to an end on August 31, 2024.

### **ASOS Dementia Friendly Community Project Sustainabilty**

The ASOS began DFC work in 2016, the DSRS project has been an asset to this work.



DFC initiatives will continue to be an ongoing focus in our public awareness work.





Alzheimer Society



### Dementia Friendly Life Enrichment Program

#### Sustainability Plan

- Secured 3 months of additional funding through the University of Regina to extend our current program (April 1st to June 30th, 2024)
- Successful in securing funding through Healthcare Excellence Canada - Enabling Aging in Place Initiative
- Successful in securing funding through Saskatchewan Seniors Mechanism- Facilitating Independence Grants in The Support to Age Well at Home
- Successfully secured a grant from the Government of Canada - New Horizons for Seniors
- Submitted a request for multi-year funding to the Ministry of Health and waiting for a response.

#### Programming

- Continue providing one on one services to people living with dementia and their care partners
- Expand our services to support a Peer Support Model
- Begin offering some Supported Living Services (ex. Grocery shopping, meal preparation).
- Increase group programming, specifically within rural communities



## Belong Where You Find Yourself

Looking forward...



#### **Documentary Film:**

A series of film screenings have been confirmed in May - June 2024 with future plans to share this hour-long documentary in educational and cultural settings.

#### Catalogs:

A 36 page, full colour catalog containing documentation of the exhibition and artists, and an essay will be distributed hard copy and digitally.

#### **Resource Kits:**

50 resource kits will be distributed to people living with dementia across the province. Kits contain a copy of the project catalog, art supplies, and instructions for engaging in an art-game with people living with dementia.

#### **Future Partnerships:**

A partnership with Remai Modern in Saskatoon has been established, with outreach events planned for fall 2024. Future partnership opportunities will be pursued by project team at other cultural institutions.

#### **Online Archive:**

GDAG is creating an online archive for the entire project so that it can be accessed by the general public through their website



#### Sustainability Plan for RaDAR Memory Clinics

#### First Year of Memory Clinic

- **Operational guidance** is provided on-site at every memory clinic by a RaDAR research assistant who offers tailored recommendations (e.g., on patient flow, scheduling assessments, and identifying space for assessments).
- Clinical guidance is provided via opportunities for team members to connect with professional counterparts and shadow memory clinics in other communities.
- Regular team workgroup meetings are held every 1-2 months with all clinic team members. The purpose of workgroup meetings is to debrief after memory clinics and identify strategies to resolve problems with the aim of improving the clinic process. The meetings support team-building as members reflect on the benefits of the clinics for patients/families and discuss quality improvement strategies.

#### After First Year

- Check-in meetings with SHA Primary Health Care (PHC) managers and facilitators are held every 3-4 months across the current memory clinic teams. Check-in meetings were implemented in 2019 and engage SHA management in sharing information and best practices across clinics and health networks.
- Dementia Working Group meetings are held every 3 months with SHA PHC directors and managers and Alzheimer Society representatives. We initiated the Working Group in 2013 to support our research partnership in southeast SK. The Working Group now serves to identify and share dementia care gaps and areas of growth across health networks, and supports sustainability and spread of memory clinics.
- Continuing education events on dementia-related topics are offered on an ongoing basis by the RaDAR team. Memory clinic teams are invited to participate in all events including the annual RaDAR Summit of the Knowledge Network in Rural and Remote Dementia Care hosted by Dr. Morgan since 2008.



#### SUSTAINABILITY PLAN

#### **PARTICIPANT-Level:**

- · Participants report using the program workbook (themed material/recipes, additional recipes/resources):
- e.g., re-made recipes that were prepared within the program, prepared the additional recipes
- In the last class of each 6-week program, participants discuss their key takeaways from the program and contribute ideas on how to continue practicing elements of the program they found most valuable (personal goal-setting):
  - e.g., continuing with their own weekly cooking gathering independently, exploring new foods, borrowing library books for new meal ideas to keep cooking exciting
- · Some participants have exchanged contact information to stay in touch and participants from one virtual group have continued to gather via Zoom for regular cooking/socialization

#### **PROGRAM-Level:**

- Additional funding for the research component of the program will allow for more virtual offerings to take place over the next year
- Plans are in place to approach different agencies to secure funding for future programming
- Further development of the program has been requested:
  - e.g., for healthcare providers to support clients, train-the-trainer model with videos

### UNIVERSITY OF SASKATCHEWAN Sustainability - Addressing dementia in the community of Île à la Crosse

#### University orRegina

Sakitawak Elders Group Inc., University of Saskatchewan, University of Regina

#### 1. Métis-driven programming Dementia awareness and support initiatives and programming have been designed with and

- by Métis community members living in Île à la Crosse (IleX) in culturally relevant ways that integrate Métis knowledge, perspectives, lived experience, and ways of doing
- These community-driven programs are responsive to current dementia awareness and support needs unique to IleX and will be expanded upon by the community with sustainability in mind

#### 2. Translated Dementia resources to Michif & Cree

- Alzheimer's Society of Saskatchewan documents were translated to Michif and Cree
- These documents will be printed out for use at various IleX businesses, homes, organizations, and schools

#### 3. Sakitawak Elder's Group Inc. (SEG) Podcast Creation

A 'season 1' podcast series is being developed and dedicated to Métis experiences and perceptions of dementia and dementia awareness, thus building content that is informed by a Metis community lens.

#### 4. Dementia Awareness in community

- Dementia awareness activities have initiated important conversations within the IleX community, creating opportunities to reduce stigma around dementia
- Creating spaces to openly discuss the unique lived experiences of dementia in IleX will drive further discussions and programming essential to creating a dementia-friendly community









## Concluding Feedback from the Participants

We asked our participants from the Advisory Committee, City of Yorkton, Yorkton Library, and Godfrey Dean Art Gallery for their feedback regarding the day's Windup Summit as we wrap up the Dementia Supports in Rural Saskatchewan initiative.



"It's been great. I've seen people I haven't seen for a while... it's nice to be able to connect. We've been meeting over Zoom for most of the time, and so it's nice to see people, person in person and to connect back and to see how people are doing and hear about their projects and it's been a good report... it's a sad day... because there's a wind up. The project has come to an end. And while it's been a very successful and an amazing project...sad to see it end, but... good to see that things are going to continue." (Edna Parrott, Advisory Committee)

Our experience today? It's been terrific. It has been really good...meeting people that I hadn't met before, even on the online components of these meetings over Covid or even for the collective impact meetings when we were getting together... it was nice to have an inperson... gathering because, even though zoom and the virtual world is sometimes okay, I'm getting to a point where I still think we have to deepen community by getting together, and this is helping. (Lisa Washington, City of Yorkton)





"It is a celebration to kind of reflect on the last five years of the project and how all the pieces together of being involved and what that involvement looked like, from a library perspective, learning more about the partners and celebrating all the projects...So it's nice to be able to come together, especially in person, as a lot of the communication throughout the project was all virtual." (Amber Harvey, Yorkton Library)

"Today has been really special in that being an artist and being part of a research project is really unique. Seeing how art has such an impact on research, and that it's a tool that can be underutilized and can be utilized more in research, is really important. (Alana Moore, Godfrey Dean Art Gallery)





For more information, visit: ruraldementiask.ca