# Family care partner perspectives:
Phase 2 of an environmental scan of programs and services for older adults in rural memory clinic communities and surrounding areas

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Background & Objectives

- **In collaboration** with primary care teams in southeast Saskatchewan, RaDAR rural memory clinics (RMCs) evolved in four geographical areas.

- **This study** is the second phase of an environmental scan of programs and services available in and around those four areas, that RMC patients and families might use.

- **Our goal** was to gain a deeper understanding of service-user experiences with those services, from their perspective, in their own voice.
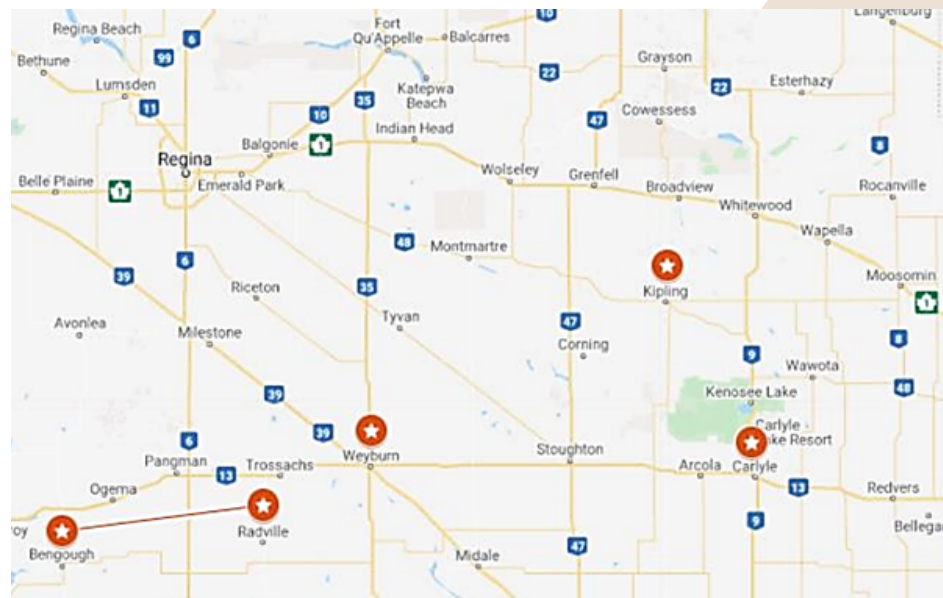
Four communities where RMCs were first developed and implemented:

- ✪ Kipling (pop. 1,076)
- ✪ Weyburn (pop. 10,870)
- ✪ Rural West (Bengough/Radville) (pop. 1,110)
- ✪ Carlyle (pop. 1,524)

Geographic areas explored in this study covered an area of approximately 5666 km^2

Phase 1 Findings – a brief review *- reported on previously at Summit 2021!*

Data collection involved focus groups with health care providers and managers along with secondary source review, and a systematic internet search.

43 Programs & Services Across 7 Categories

Program & Service Types (n)	Available remotely	Available in-person in rural communities						TOTALS
		*Kipling	*Weyburn	*Radville	*Bengough	*Carlyle	Wawota, Kennedy, Kenosee Lake, Manor	
General Support & Referrals (n=13) • counselling, relationship/behaviour management, support groups, referrals	n=12	nil	nil	nil	nil	nil	n=1	N=13
Respite (n=2) • in-home, overnight, day centres	nil	n=1	n=2	n=1	n=1	n=1	n=1	N=7
Home & Personal care (n=2) • medical or non-medical care in the home such as Home Care, house cleaning/laundry, gardening/lawn mowing, showering, meal prep	nil	n=1	n=2	n=1	n=1	n=1	n=1	N=7
Transportation (n=7) • such as volunteer driver programs, Handi-vans	nil	n=2	n=1	n=1	n=1	n=2	n=3	N=10
Information & Education (n=4) • education/information sessions, leaflets/flyers, awareness events	n=4	nil	nil	nil	nil	nil	nil	N=4
Safety (n=1) • MedicAlert® Safely Home® - Canada-wide medical identification service	n=1	nil	nil	nil	nil	nil	nil	N=1
TOTALS (n=43)	N=20	N=7	N=7	N=5	N=5	N=6	N=11	N=61
		N=41						

*Total N's in this column include some duplicate service types offered in-person within multiple communities (e.g., Regional Public Libraries)
*Locations of RaDAR memory clinics

Referral Process	Programs n
Self	2
Self, other	25
Self, other, Health Care Provider	6
Health Care Provider	1
Primary Care Physician, Nurse Practitioner	1
RaDAR Rural Memory Clinic team	1
Missing	7

Service Level	Programs n
Local	24
Provincial	17
National	2

Cost	Programs n
Free	20
Fees per service provided	9
Membership fees	5
Missing	9

Education/Training of Program Providers	Programs n
Geriatric Psychiatrist, FP/NP, OT, Pharmacist, Continuing Care Consultant, Social Worker	1
Neurologist, Neuropsychologist, Nurse, Psychometrist, PT	2
PhD in Psychology, grad students, neuropsychologist supervision	3
RaDAR Rural Memory Clinic team (FP/NP, Home Care Nurse, OT, PT, Dietician; composition varies by team)	1
Nurse, Social Worker, Counselor	5
Certified Fitness Instructor	1
Volunteer-based	8
Missing	22

Most were:
- social/leisure activities or general support/referrals
- referred by self or other
- provided locally

Nearly half were:
- free to access
- available remotely

Less than 20% were volunteer-based.

17 were were related to dementia, mostly (10/17) by the Alzheimer Society.

Each RMC community offered:
- more than one social/leisure program
- in-home care
- respite
- some sort of transportation

Phase 1 findings informed development of the family caregiver interview guide in Phase 2.

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Phase 2 - Family care partner perspectives

- **Semi-structured phone interviews with 5 family care partners** of people living with dementia in and around locations of 4 RMCs.

Findings:

- **Home-care services and the Alzheimer Society programs** were most frequently used and played a key role in connecting to other available services.

- **Program providers and participants were** an equal mix of females and males, and **content was** typically gender neutral.

Response	Service Category						
Yes	General Support & Referrals	Respite	Home & Personal Care	Transportation	Education, Training, Information	Social & Leisure Activities	Safety
Aware of	4/5	5/5	5/5	3/5	4/5	5/5	5/5
Used	3/5	2/5	4/5	0/3	2/4	4/5	3/5
Group service	1/3	0/2	0/4	n/a	1/2	4/4	0/3
Female provider	3/3	1/2	2/4	n/a	1/2	2/4	0/3
Provider sex impact	0/3	0/1	0/2	n/a	0/1	0/2	0/3
Helpful	3/3	1/2	4/4	n/a	2/2	4/4	3/3
Recommendations	3/3	0/2	2/4	n/a	1/2	3/4	0/3
Difficulty	2/3	1/2	1/4	n/a	1/2	2/4	1/3
Workaround	2/2	0/1	1/1	n/a	1/2	2/4	1/1
Made it easier	3/3	1/2	2/4	n/a	2/2	4/4	1/3

- **Key themes** reflected the **need for locally available, accessible services** that offer:
  i) individualized, flexible needs-based approaches
  ii) continuity of care, and in-home care options
  iii) both formal and informal supports

- **Key gaps** reflected a **range of factors** including:
  i) locally accessible available services and resources in general
  ii) dementia-related training and education for service providers
  iii) awareness of what services were currently available, particularly among service providers

Care partners identified both positive and negative aspects:

Rurality
- more personalized care, familiar providers
- more isolated

Pandemic
- more remote services available, mask-wearing lowered risk of illness
- even more isolated

Negative effects of gaps:
- delayed assessment/Dx/treatment, advanced disease, and care crises
- moving to larger center

Recommendations to address:
- ✓ expand formats and schedules
- ✓ link current available programs and services to dementia stages

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Conclusions and Implications

- **This environmental scan identified unmet needs and access barriers** for people living with dementia and their families in and around 4 rural primary care memory clinics.

- **Drawing on the voices of family care partners** was a key step in highlighting the service experiences, needs, and concerns, along with recommendations to address existing gaps.

- **Findings may inform** decision-makers and guide future service delivery and interventions in similar rural areas.

Questions? Comments? Let us know!

We appreciate your interest in this study update and,
look forward to hearing your thoughts and any questions you might have!