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Evaluating the Implementation of Three Integrated Care Programs for Older Adults with Major Neurocognitive Disorders

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Abstract

Federal and provincial governments in Canada have mobilized resources to address the challenges of care associated with the growing population of older adults with major neurocognitive disorders (MND), which include Alzheimer's and other related diseases. Researchers and practitioners in Québec, Ontario, and Saskatchewan identified a need for better integrated care for older adults with MND, improved capacity for assessment, diagnosis, and management of cases, as well as greater accessibility for those living in rural and remote regions. To this end, three distinct programs—the *Réseau de services intégrés pour personnes âgées en perte d'autonomie cognitive* (RSI-PAPAC) in Québec, the Primary Care Collaborative Memory Clinic (PCCMC) in Ontario, and the Rural and Remote Memory Clinic (RRMC) in Saskatchewan—were developed with the help of funding from provincial governments and federal research grants. The objective of this article is to compare and analyze the implementation and performance of these programs. Each program saw a large scope of services offered with the integration of community services and a great degree of coordination between these actors. The RSI-PAPAC was a roster program implemented in a collection of community health centres in Québec, while the latter two were clinical models that originated out of one central clinic. In Québec, while the specific program we analyzed is no longer active today, the ministry of health and social services has since adopted a comprehensive action plan rolling out services at a provincial scale (unrelated to the program we analyzed). In Ontario, with the help of interested organizations, the PCCMC has since been scaled up across the province, with over 100 clinics now active. It was easily adopted due to the quick training program offered to physicians and its reliance on patients' existing circle of care. Finally, in Saskatchewan, the RRMC has not scaled up to other clinics, likely due to the lack of existing collaborative primary clinics such as those in Ontario; however, provincial governments and other health organizations have mobilized to fund its continuation, and it currently operates out of one clinic in Saskatoon, serving as a node of care and research within the University of Saskatchewan.

Les gouvernements fédéral et provinciaux du Canada ont consacré des ressources à l'aplanissement des difficultés en matière de soins et services pour la population croissante de personnes âgées atteintes de troubles neurocognitifs majeurs, qui incluent notamment la maladie d'Alzheimer. Des chercheurs et des praticiens du Québec, de l'Ontario et de la Saskatchewan ont souligné la nécessité de mieux intégrer les soins aux personnes âgées atteintes; d'améliorer la capacité d'évaluation, de diagnostic et de gestion des cas; et de rendre les services plus accessible à ceux vivant dans les régions rurales. À cet effet, trois programmes distincts—le RSI-PAPAC au Québec, le PCCMC en Ontario et le RRMC en Saskatchewan—ont été créés avec l'aide de fonds des gouvernements provinciaux et de bourses de recherche fédérales. L'objectif de cet article est de comparer et d'analyser la

mise en œuvre et la performance de ces programmes. Chaque programme a offert un cadre de services intégrés aux organisations communautaires et avec un degré avancé de coordination entre ces acteurs. Le RSI-PAPAC a été mis en place dans un ensemble de centres de santé communautaires du Québec, tandis que les deux autres correspondaient à des modèles cliniques issus d'une clinique centrale. Au Québec, le programme particulier que nous avons analysé n'est plus en opération, mais le ministère de la santé et des services sociaux a depuis adopté un plan d'action pour orienter les services à l'échelle de son territoire. Avec l'aide d'organisations en Ontario, le PCCMC s'est, depuis, élargi à l'échelle de la province, atteignant plus de 100 cliniques actives. Il a pu s'étendre plus facilement étant donné le programme de formation rapide offert aux médecins et son recours au cycle de soins déjà existant pour les patients. Le modèle RRMC ne s'est pas étendu à d'autres cliniques en Saskatchewan, probablement dû au manque de cliniques en soins et services primaires de type collaboratif comme celles existant en Ontario. Toutefois, les gouvernements successifs de la province et autres organisations du secteur de la santé se sont mobilisés pour financer le maintien de ce programme. Ce centre opère actuellement dans une clinique de Saskatoon qui sert de centre de soins et de recherche à l'Université de la Saskatchewan.

Key Messages

- The *Réseau de services intégrés pour personnes âgées en perte d'autonomie cognitive* (RSI-PAPAC) in Québec, the Primary Care Collaborative Memory Clinic (PCCMC) in Ontario, and the Rural and Remote Memory Clinic (RRMC) in Saskatchewan each sought to improve accessibility in rural and remote regions, expedite time to diagnosis, provide a better continuum of care, and integrate the patients' community networks into the management of the case.
- The success of novel integrated care programs for older adults with major neurocognitive disorders depends on the extent of extant institutional support, including sources of funding and active collaborative primary care models.
- Key champions may be critically important to the implementation and persistence of a model, especially in its early years as it grows and develops. Premature departure of a champion may threaten the program's sustainability.

Messages-clés

- *Le réseau de services intégrés pour personnes âgées en perte d'autonomie cognitive (RSI-PAPAC) en Québec, les cliniques collaboratives de la mémoire en soins primaires (PCCMC) en Ontario, et la clinique de la mémoire en régions rurales et éloignées (RRMC) en Saskatchewan visaient l'amélioration de l'accessibilité dans les régions rurales et isolées, l'accélération du diagnostic, l'offre d'un meilleur continuum de soins et l'intégration des réseaux communautaires des patients à la gestion du cas*
- *Le succès des nouveaux programmes en soins et services intégrés destinés aux personnes âgées atteintes de troubles neurocognitifs majeurs dépend de l'ampleur du soutien institutionnel existant, y compris des sources de financement et des modèles de collaboration active.*
- *Les acteurs clés peuvent être d'une importance cruciale pour la mise en œuvre et la persistance d'un modèle, en particulier dans les premières années pour que celui-ci ait une chance de s'élargir: un départ prématuré peut menacer le maintien du programme.*

ACKNOWLEDGEMENT: *Policies and Program Innovations that Connect Primary Health Care, Social Services, Public Health and Community Support in Canada: A Comparative Policy Analysis* is a pan-Canadian comparative policies and programs analysis about the integration or linkages of medical and social services, public health, and community support services to primary health care. This project is an initiative of the Strategy for Patient-Oriented Research and the Primary and Integrated Health Care Innovations Network and is supported by more than 15 funding partners. It is led by Dr. Jeannie Haggerty, McGill University Chair in Family and Community Health Medicine along with a team of more than 50 Canadian investigators, clinicians, decision-makers, trainees, and patient partners.

1 BRIEF DESCRIPTION OF THE PROGRAMS

In 2015, for the first time in Canada's history, people aged 65 and older outnumbered those 14 years and under (Statistics Canada 2018). This growing population of older adults faces high risks of aging-related neurocognitive impairments, notably, but not exclusively, due to major neurocognitive disorders (MND)[1], such as Alzheimer's disease and other related diseases. This comparative health reform analysis contrasts and analyzes the implementation and performance of three distinct programs that sought to address the complex needs of older adults with MND through integrated and interprofessional care.

In Québec, the *Réseau de services intégrés pour personnes âgées en perte d'autonomie cognitive* (RSI-PAPAC), created in 2005, began in an integrated health and social services centre in Suroît, an area with a large population of older adults (Gervais *et al.* 2010). After rostering referred patients with MND to the RSI-PAPAC register, a clinic coordinator managed the intervention and community services offered to the client and additionally sought to assess and mitigate vulnerability factors that would put the patient at risk for hospitalization. The program was considered innovative (which is why it was selected by our team for analysis here) and singled out (though without any detail as to why) in the report of the expert committee that laid the foundation for the current provincial program on Alzheimer and associated diseases (MSSS 2009). Despite this initial success and favourable political context, the program ceased its operations by 2010, ostensibly as a result of the departure of several key "champions" and lack of continued funding (it was not possible for us to establish the temporality of these events). Nevertheless, it is important to note that, while this particular local program has not persisted or scaled up, Québec has since adopted an action plan to address MND. This has resulted in the funding of 13 pilot projects across 14 (of 16) health regions and in 40 family medicine groups in 2013, and the roll-out of a provincial program from 2016 to 2019 (MSSS 2017).

In Ontario, the Primary Care Collaborative Memory Clinic (PCCMC), first implemented in 2006, sought to reduce the need for specialist referrals for patients with MND by improving the capacity to care among family practitioners, who maintained a central role in the client's continuum of care (Lee *et al.* 2010). The project has since been scaled up and widely implemented across the province's family health teams (FHTs) into remote and rural areas.

In contrast, Saskatchewan's Rural and Remote Memory Clinic (RRMC) operated out of a single location in Saskatoon and has been active since 2005 (Morgan *et al.* 2009). It initially sought to streamline the diagnosis process for patients with MND and improve the continuity of care using telemedicine technologies. It has continued thanks to the long-term funding of federal and provincial partnerships and research grants but has not sought to expand its operation beyond the academic setting from which it still currently operates.

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[1] In this text, we have adopted the terminology recommended in the DSM-5, but it is important to note that the programs we analyze here used alternative terminology such as "Alzheimer's and other related diseases" or, more recently, "dementia(s)." The latter is no longer recommended by the Alzheimer's Society.

The experiences of these projects demonstrate the importance of stable funding for these pilot initiatives. Clinician support may be a necessary condition in a project's early years in order to advocate for its growth and development, but it is certainly not a sufficient condition, as threats of departure of "key champions" can cast uncertainty on the project's sustainability if scale-up is not ensured structurally or if funding is not secured for long-term development.

2 HISTORY AND CONTEXT

2.1 Canada's aging population and challenges to accessing care

Due to sustained low fertility and high life expectancy, Canada's population has been aging rapidly, a trend likely to accelerate further in coming years, as the population 65 years and over is projected to increase from 17% to 23% of the total population from 2019 to 2031 (Statistics Canada 2018). This changing demographic landscape means Canada will have to adapt how it delivers services in the future in order to appropriately meet the needs of this aging population. Older adults face higher prevalence of chronic diseases and multi-morbidities, and in particular cognitive impairment from neurodegenerative diseases leading to a loss of functional autonomy. Timely intervention and continuity of care must be provided to maintain the independence of older adults and provide a high quality of life for as long as possible.

Developing strategies for improving the quality of life for older adults with MND is of high priority. The *National Strategy for Alzheimer's Disease and Other Dementias Act* came into force in June 2017, requiring the Minister of Health and delegated officials of provincial and territorial governments to create a comprehensive national strategy for MND, including outlining national objectives to reduce the burden of these diseases in Canadian society; encouraging greater investment in MND research; and assist provinces in disseminating best practices, clinical diagnostic and treatment guidelines for people suffering from MND (Government of Canada 2018). The federal government has proposed to spend $50 million over the next five years to support these goals, and "A Dementia Strategy for Canada" was formally released June 2019 (Government of Canada 2019; PHAC 2019).

The obstacles to implementing a comprehensive strategy for addressing the increasing burden of MND are manifold. Issues with access to primary care in Canada are well-documented. Canada performs "below average" in terms of timely access to care, experiencing long wait times for both regular doctors and specialists (Vogel 2019). While 93% of Canadians have a regular doctor, waiting too long for an appointment is among the most commonly reported problems in terms of difficulty accessing services (Clark 2016; CIHI 2019). Rural and remote populations continue to experience substantial challenges in this regard as the distribution of primary health care services among large geographical areas is highly unequal (Shah, Milosavljevic, Bath 2017). While these barriers to access are not limited to care for adults with MND, they can exacerbate unmet needs, given that many family medicine practitioners have also expressed concern about their lack of knowledge and preparedness to appropriately assess and treat MND (Van Hout *et al.* 2000; CIHI 2018). Poor symptom recognition and uncertainty over diagnosis is detrimental to detection and subsequent care management for people with MND and can lead to unnecessary emergency room visits and high health care costs (Lee *et al.* 2010). Integrated care approaches that include multidisciplinary teams, comprehensive assessment procedures, and better case management are means by which many health systems have sought to address these issues (Briggs *et al.* 2018).

2.2 Factors specific to the Québec context

Québec underwent important changes in the organization of health care in 2004, with the creation of 94 local health service networks known as *Centres de santé et de services sociaux* (CSSS: Health and social services centres), offering home care and delivering social services with high level of professional integration (Bourque and Quesnel-Vallée 2014, Breton *et al.* 2017). Under this system (which was fundamentally reorganized again in 2015), older adults (65 years of age and older) receive primary care services through their local CSSSs or *Groupe de médecine de famille* (GMF: Family medicine group). GMFs, implemented in 2001, sought to reorganize primary care delivery to better facilitate collaboration between family physicians and other health professionals responsible for a roster of patients (Breton *et al.* 2011).

The province already had a history of innovativley addressing the integration of health and social care needs among older adults experiencing a loss of autonomy. Indeed, in 1999, the Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA), a new research program aimed at improving the coordination of care for older adults with dementia and other cognitive impairments, was launched (MacAdam 2015). Early evaluation indicated significant reductions in the number of emergency room visits and the incidence of functional decline. The PRISMA model was thus adopted by the province, albeit only partially. Starting in 2001, the *Ministère de la santé et des services sociaux* (MSSS: Ministry of Health and Social Services) mandated that all regions in Québec start implementing PRISMA features, with great flexibility in the implementation permitted. PRISMA no longer exists in its initial inception, but its component features have been integrated in a province-wide program called *Réseau de services intégrés aux personnes âgées*, or integrated services network for older adults. (MacAdam 2015).

In early 2005, three CSSS in the Montérégie health region identified 2-year wait times for the evaluation of loss of cognitive autonomy in older adults (Gervais *et al.* 2010). This geographic region is located to the southwest of Montréal and shares a border with the United States. The area is largely agricultural with a population just under 245,000 and has the second largest population of adults aged 65 and above in Québec, after Montréal (ISQ 2018). The CSSS of Suroît, the CSSS of Vaudreuil-Soulanges, and the CSSS of Haut-St-Laurent already had existing psychogeriatric teams in place; however, physicians underscored a need for a quicker, easier, diagnosis tool. Moreover, there was little continuity of care between interventions and little communication between members of the CSSS working with patients, thus putting patients in positions of greater vulnerability in terms of malnutrition and poor medication adherence. As a result, the three CSSS formed a committee and developed a new program, *Réseau de services intégrés pour personnes âgées en perte d'autonomie cognitive* (RSI-PAPAC), or integrated services network for older adults with a loss of cognitive autonomy, aimed at delivering better integrated care for older adults, thereby addressing these issues.

2.3 Factors specific to the Ontario context

Ontario's FHTs, implemented in 2005, evolved from earlier family health group pilots in the province (Rosser *et al.* 2011). Following a similar model to that implemented in Québec with the GMFs, FHT physicians are responsible for a specific panel of enrolled patients; however, they work with a much more multidisciplinary team to expand the scope of their practice and are largely funded by blended remuneration formulas (Breton *et al.* 2011). As of 2016, there are over 180 FHTs province-wide, many of which serve rural or northern communities, and populations with special needs under the direction of the Ministry of Health and Long-Term Care (MOHLTC) (MOHLTC 2016). As early as 2004, organizations in Ontario were calling for policy supports for more integrated, interdisciplinary systems of care for older adults, citing the lack of a provincial framework in the midst of a growing population of older adults (EHECC 2005).

In 2006, a family physician at the Centre for Family Medicine (CFFM) FHT in Kitchener recognized gaps in the care standards for older adults with memory problems, including underdiagnosis and undertreatment (ARTIC 2017). Due to a lack of knowledge of MND and their symptoms among family physicians, as well as a lack of familiarity with cognitive screening, up to 80% of patients with memory disorders were referred to a specialist. This high referral rate created a problem of timely access, given the existing shortage of specialists such as behavioural neurologists, geriatricians, and geriatric psychiatrists (Lee *et al.* 2010). Identifying a need for a better capacity to care in existing primary care settings, the CFFM established the first PCCMC to address these challenges.

2.4 Factors specific to the Saskatchewan context

Saskatchewan has the highest proportion of older adults in all of Canada, and this proportion is only expected to grow in the coming decades (Statistics Canada 2018). In contrast with the other two provinces analyzed here, the majority of residents live outside urban areas (Morgan *et al.* 2015). Older adults make up less than 15% of the population of cities compared to roughly 22% of townships and villages (Morgan *et al.* 2011). Being a largely rural and sparsely populated province poses many barriers to access to health services in Saskatchewan. Moreover, there is an identified lack of culturally-safe care for Indigenous communities, who face higher rates of many of the risk factors for MND, compounded by systemic poverty, lack of adequate funding, cultural and linguistic barriers, discrimination, and geographic isolation (Halseth 2018). Within the northern-most regional health authorities of Saskatchewan, over 80% of the population self-identified as Aboriginal according to the 2006 national census (Morgan *et al.* 2011).

Given these challenges, the province initially sought to improve access to health care in remote and rural areas through the use of telemedicine, whereby video-conferencing technologies allow health professionals to offer health services when separated from patients by great distances. The first of Telehealth Saskatchewan's network was launched in 1999 as a pilot project and has now expanded to over 60 facilities across the province (Morgan *et al.* 2011). An advisory committee in 2004 identified several problems in terms of MND care strategy, including stigma, lack of understanding of required resources, lack of a timely diagnosis, and a lack of support for caregivers (SCACOP 2004). The committee identified a need for a streamlined assessment process in order to shorten the time to diagnosis and a need for better continuity of care, especially in remote, underserviced areas. Funding was soon after committed to expanding the telehealth network (Government of Saskatchewan 2005). To further address the issues surrounding coordinated care, wait times, and rural service delivery, a group at the University of Saskatchewan launched a new RRMC in 2005 (Morgan *et al.* 2005).

3 GOALS OF THE PROGRAMS

Both Saskatchewan and Ontario sought to create a collaborative memory clinic integrating primary care and specialty care to address challenges of diagnosing and maintaining a continuum of care for older adults with MND, with the RRMC specifically devoted to improving accessibility in rural and remote areas (Morgan *et al.* 2009; Lee *et al.* 2010). Although accessibility in rural areas was not an initially stated goal of the PCCMC in Ontario, the subsequent expansion of the program to underserviced areas underscores the province's implicit priorities (ARTIC 2017). In addition, the PCCMC implicitly sought to reduce the need for specialist referrals and to maintain the family physician as a central role in the patient's continuum of care. The RRMC, being an academic research team funded by the Canadian Institutes of Health Research (CIHR), had secondary stated goals germane to their research: the team was to evaluate the performance of telehealth as a substitute to regular follow-up, specifically in northern communities where patients may face barriers in terms of cost and distance of travel (Morgan *et al.* 2009). The team additionally sought to develop culturally-safe cognitive autonomy assessments for Indigenous older adults.

In Québec, the stated goal of the program was to expedite detection and diagnosis of the loss of cognitive autonomy for older adults (aged 70 and above) and maintain a comprehensive continuity of care for patients by fostering communication between health care professionals and encouraging multidisciplinary care, with the goal of keeping the patient in the community as long as possible (Gervais *et al.* 2010).

In sum, all three programs sought to build capacity for assessment and management of cases involving MND that lead to a loss of cognitive autonomy by shortening the time to diagnosis, reducing the need for unnecessary specialist referral, and improving accessibility and continuum of care for patients.

4 FACTORS THAT INFLUENCED HOW AND WHY THE PROGRAMS WERE DESIGNED

All three provinces are home to influential chapters of the Alzheimer Society, a national not-for-profit organization with a highly federated model wherein each regional chapter enjoys a great deal of autonomy. The mission of the Alzheimer Society is to develop and promote national priorities to alleviate the consequences of Alzheimer's disease and other related diseases (Alzheimer Society Canada 2018). Other large national bodies, such as the Canadian Association for Retired Persons, also had a role in shaping Canadian policy and have advocated on behalf of older adults' and their needs.

Given the growing concern and demand for improved care for older adults with MND, collaborative approaches were being recognized as a valuable and transformative means to diagnosing and treating complex cases (Callahan *et al.* 2006, Wolfs *et al.* 2006). Memory clinics, in particular, were found to be effective in identifying MND earlier than traditional older age psychiatry services (Luce *et al.* 2001; Passmore and Craigs 2004). Memory clinics implemented several decades ago in other countries (e.g., the United Kingdom, the United States) provided clear frameworks for the Ontario and Saskatchewan programs. Similarly, Québec's RSI-PAPAC, though not explicitly a memory clinic, employed many of the practices of memory clinics, including multidisciplinary assessments and personalized care (Gervais *et al.* 2010).

With respect to funding, existing government structures allowed CSSS in Québec and the CFFM in Ontario to apply for government funding to pilot their projects: in Québec, the physicians of the three CSSS who first identified the need for a novel approach in care submitted a grant proposal to the MSSS (Gervais *et al.* 2010). Given the provincial government's established priorities at the time, the application was accepted and the program was allocated $396,000 in 2006 (MSSS 2005; Gervais *et al.* 2010). It received an additional $50,000 in 2008 from the Health and Social Services Agency of Montérégie (Gervais *et al.* 2010). These funds went toward the consultation process, the development of clinical tools, and the training of stakeholders and partners.

Meanwhile in Ontario, the scale-up of the PCCMC was facilitated by the Adopting Research to Improve Care (ARTIC) program, co-led by the Council of Academic Hospitals of Ontario and Health Quality Ontario and is currently funded by the MOHLTC (ARTIC 2017). The ARTIC program seeks to accelerate the spread of evidence-based health care interventions in Ontario. Government funding through the project was also directed through the province's Behavioural Supports Ontario project, an evidence-based framework to develop integrated supports and services for persons living with responsive behaviours, including memory clinics (Gutmanis *et al.* 2015). MOHLTC also provided alternative funding schemes for specialists working with the PCCMC as the program was rolled out across the province (Lee *et al.* 2010).

In Saskatchewan, the first five years of the RRMC were funded through a $750,000 CIHR New Emerging Team (NET) grant with specific focus on innovative and multidisciplinary research devoted to healthy aging (Morgan *et al.* 2005; CIHR 2010; CIHR 2012). Although Saskatchewan identified existing needs with respect to older adults with MND earlier, the province did not fund the RRMC until after this first CIHR grant ended (Ministry of Health 2015).

5 HOW THE PROGRAMS WERE IMPLEMENTED

The RSI-PAPAC in Québec was highly regional in terms of reach, with a large scope of services and high degree of coordination with local GMFs/CSSS, the Alzheimer Society of Suroît, community pharmacies, and long-term care homes (Gervais *et al.* 2010). The program design was implemented within GMFs with a workforce that was highly interprofessional. It received a 2-year funding grant from the MSSS. Rolling out from 2006 to 2010, the RSI-PAPAC included psychogeriatric training and new assessment tools for testing for the loss of cognitive autonomy in patients. Detection was supported by consulting with a neuropsychologist.

After diagnosis in an GMF or CSSS, the client was enrolled in a PAPAC phone register and follow-up appointments were managed by a clinic coordinator, who also supervised the patient's contact with other social services offered by the CSSS and the community. For example, the CSSS would be responsible for evaluating the prognosis and needs of the client, while the Alzheimer Society would offer training programs on dealing and living well with cognitive troubles to the patient and their family. The coordinator would also meet with the patient regularly for evaluation using the standardized assessment tool that considered vulnerability factors during follow-up. Individual intervention plans were developed for complex cases by doctors, nurses, social workers, neurologists, physiotherapists, and other health professionals working in concert with the patient and their family. The development of this project occurred alongside that of similar projects around the province which fit within the province's mandate at the time (MSSS 2005).

In Ontario, the CFFM FHT in Kitchener first established its PCCMC in 2006. The PCCMC model is now provincial, having been implemented in several rural and remote sites (ARTIC 2017). The model begins with a 5-day accredited training program targeted at health professionals with the goal of improving capacity of care for patients with MND (Lee, Kaperski, Weston 2011). After a family physician has identified a memory concern, the client is referred to the memory clinic which operates one to two days per month

(Lee *et al.* 2010). Before coming to the clinic, patients are mailed several questionnaires on their functional activities that they are to complete prior to their appointment date. Diagnosis and management are coordinated through team assessments: a nurse begins by gathering the client's medical history and administering cognitive tests; a social worker tests the patient for depression and executive dysfunction as well as home safety; and a pharmacist reviews appropriate medications and provides strategies to improve the patient's medication adherence. As with the RSI-PAPAC, individual intervention plans are developed after the team reviews the results and meets with the patient and their family for further assessment. Finally, the lead physician sends the team's findings back to the family physician through a comprehensive report that is maintained in the patient's electronic record. Post assessments and referrals to specialists are made as appropriate depending on the complexity of the case.

Saskatchewan's RRMC is more restricted in its scope of services than the programs in Ontario or Québec. Moreover, the program implementation is kept entirely within the RRMC location in Saskatoon, the province's largest city. As previously mentioned, the RRMC was originally supported by a CIHR NET grant in 2003 specifically devoted to research in the domain of older adults (Rural Dementia Action Research Team n.d.). Following this, joint funding from the University of Saskatchewan, the Saskatchewan Health Research Foundation, the Alzheimer Society of Saskatchewan, the Saskatchewan Ministry of Health, and the Saskatoon Health Region allowed the program to continue. The clinical structure of the RRMC was undergirded by the same basic principles as those of the PCCMC. However, referrals to the clinic can be initiated by any member of a health team (Morgan *et al.* 2009). Once referred, the patient is contacted via telehealth and a pre-clinical screening is administered to ensure that the referral is appropriate.

Once it is determined that the client fits the clinic's target population, the patient attends a streamlined and integrated one-day clinic session. Upon arrival, a nurse reviews consent forms and prepares the patient and their family for the following joint assessment and interview by a neurologist, a neuropsychologist, a geriatrician, and a physical therapist evaluating medical history, memory, stress, depression, fatigue, functional status, home environment, fall history, and other clinical measures. Family members complete written measures of the client's health and functional status in addition to their burden of care. Following a meeting by all specialists, in which the referring family physician may be included, the patient and family members are consulted and recommendations for management and care are provided. Follow-up assessments via telehealth are conducted at regular intervals. Table 1 below provides an overview of each program's implementation under the framework provided by Hutchison *et al.* (2011).

Table 1: Overview of program implementations

	Program (Province)		
Program Implementation Feature	RSI-PAPAC (Quebec)	PCCMC (Ontario)	RRMC (Saskatchewan)
Geographic reach is provincial		x	x
Workforce highly interprofessional	x	x	x
Inclusion of community organizations	x		
Individual intervention plans	x	x	x
Patient *and* family-oriented care		x	x
Use of electronic medical records		x	
Patient enrolment model (rostering)	x		x
Use of telehealth for follow-up			x
Training and support offered to practitioners		x	
Family physician maintains a central role		x	
Implementation within existing clinics (FHTs, GMFs, etc.)	x	x	

6 OUTCOMES OF THE PROGRAMS

6.1 Québec

The principal outcome was a significant drop in the mean wait time for evaluation of loss of cognitive autonomy, which dropped from two years to two months as a result of screening support and the development of a more convenient assessment tool (Gervais *et al.* 2010). Beyond this, the program underwent little evaluation, such that other performance metrics or patient or practitioner satisfaction are unknown. An interest was initially expressed in creating a centralized, data access portal that would facilitate greater communication between stakeholders and offer online training for those using the vulnerability assessment protocol. However, these goals were not attained while the program was in operation, and the clinic coordinator remained the only user of the tool.

Meanwhile, the MSSS had embarked on a comprehensive expert consultation on standards of care for older adults with MND, which ran from 2007 to 2009, followed by the launch of 13 pilot projects in 2013, and which finally resulted in the adoption and roll-out of an action plan in 2016, to be completed by 2019 (MSSS 2017). RSI-PAPAC was mentioned in the expert report as being one of five innovative local health authority initiatives across the province (MSSS 2009). Thus, it is quite surprising, given this favourable institutional context, that the RSI-PAPAC ceased operating by 2010. The cessation of this particular local program was attributed to a lack of continuing financial support from the regional health agency and to the departure of some of the program's "champions" (Gervais *et al.* 2010).

6.2 Ontario

The PCCMC model has proven to be a successful intervention for addressing the needs of older adults with MND. As previously mentioned, the original PCCMC model was quickly replicated in other FHTs across Ontario, including rural, remote, and underserviced areas through the support and funding of ARTIC (ARTIC 2017). Funding and support were provided by the Ontario College of Family Physicians, which helped develop the accredited 5-day training course for professionals (Lee 2013). Evaluation measures were collected continuously by the clinic(s) (Lee *et al.* 2010). The model has generally enjoyed high levels of support among patients and family physicians alike: the former expressed satisfaction with their clinic interactions and the support they received from team members, while the latter found that the PCCMC recommendations made it easier to manage the complexities of MND care (Lee *et al.* 2010, Lee and Hillier 2016, Lee *et al.* 2018). In addition, chart audits performed by geriatricians showed 97% agreement with diagnosis and intervention plan (Lee *et al.* 2010). The average wait time for assessment at a PCCMC was 1.5 months, with fewer than 20% of patients waiting more than 3 months for evaluation (Lee and Hillier 2016). Moreover, the need for specialist referral was reduced from 80% to less than 10% (Lee and Hillier 2016; ARTIC 2017).

The FHTs were instrumental in precipitating collaboration between health professionals. As such, the PCCMC model was easily incorporated into the health care system of Ontario. The success of the PCCMC model can also be attributed to the standardized training that team members received, the emphasis on face-to-face communication by professionals, and the integration of specialists and community members in the clinic (Lee 2016). However, resources are needed to ensure the continuation of the PCCMC model. The lack of a clear and current provincial MND strategy means funding dependent activities are sustained inconsistently, since current funding is based primarily on service volumes. Furthermore, inequitable funding and distribution of professions across sites threatens specialist involvement and fails to leverage what could be accomplished with a fully interdisciplinary team. Since patient selection is determined solely by referral from a family physician, there is a risk of inequitable patient access as those without a family physician may be the most vulnerable.

6.3 Saskatchewan

The RRMC in Saskatchewan proved to be a successful proof of concept. After 2009, several provincial and federal partnerships as well as private foundations mobilized to fund the continuation of the Rural Dementia Action Research (RaDAR) Team and the RRMC (Rural

Dementia Action Research Team, n.d.). In 2016, a $2.3 million CIHR grant was awarded for a 7-year term, supported by funding from the Saskatchewan Centre for Patient-Oriented Research and the University of Saskatchewan (CIHR 2016). Meanwhile, evaluations were conducted continuously. Immediately following telehealth sessions, patients and coordinators filled out evaluation questionnaires (Morgan *et al.* 2009). Some challenges were observed in the first five years of the clinic, including the large workload and time demands experienced by the team (Morgan *et al.* 2009). Moreover, the reach of the clinic was not as far as desired, specifically in remote northern communities. Some patient referrals in these communities expressed difficulty travelling to Saskatoon for the 1-day clinic stop due to time, work, or the cost of transportation. Nevertheless, most patients and families reported a high satisfaction with their experiences with RRMC. The use of telehealth was viewed as much more convenient than in-person visits to the clinic, and it was estimated that over 450 km of round-trip travel was saved (Morgan *et al.* 2009; CIHR 2015). The RRMC also brought benefits for clinicians, as team members and medical students were able to learn about the methods used in other disciplines in an interprofessional setting (Morgan *et al.* 2009).

7 ANALYTIC COMPARISONS

7.1 Integrating primary care and specialty care for older adults with MND and establishing a community-based support system

The three programs presented here purported to improve the integration of services for older adults with MND, and all implicitly sought the maintenance of these individuals in the community. However, we noted that the stated emphasis of the programs revolved more around the issues of diagnosis and continuity of primary care and specialty services than about home care services for instance. It is of course possible that the omission of social services from these programs' stated emphasis was, at least in Québec and perhaps in Ontario, due to the institutional embeddedness of these programs in existing primary care infrastructures. Indeed, in the Québec case, for instance, the CSSS du Suroît was at the centre of the delivery model, and with it, the assumption that the early diagnosis was critical to trigger the support of the associated interprofessional team, which would have included social workers.

Furthermore, all three programs included the family/immediate caregivers in their process for consulting, evaluation of the home environment, and dissemination of information. However, only the RRMC and PCCMC formally assessed the burden placed on the patient's family and their ability to care for the patient. Caregivers of people with MND are known to experience burnout, stress, and financial risk (Carpentier *et al.* 2010; Fast 2015). It is therefore imperative that programs consider the caregivers as part of a unit alongside the patient. By considering the role of those closest to the patient in terms of their capacity to care, these programs effectively provide support to one of the most significant resources they have for remaining in the community. Caregiver support was offered in the RSI-PAPAC through the Alzheimer Society of Suroît, but it was not dependent on any assessments made by members of the CSSS that received the patient. If the RSI-PAPAC had continued, such an evaluation would have been important, considering that the program sought to keep patients at home while reducing the risk of malnutrition and medication non-adherence. Though not an explicit goal, this approach could similarly be implemented in the PCCMC context via the mailed pre-appointment questionnaires. However, the needs of care for partners are addressed at each clinic visit and caregivers reported being satisfied with the services they received from the clinic (Lee 2016b). Moreover, neither PCCMC nor RRMC worked directly with organizations in the community like RSI-PAPAC did (with local Alzheimer Societies, etc.) to keep individuals in their communities. The inclusion of such organizations could be easily integrated into the other contexts.

7.2 Facilitators and barriers to implementation and scale-up

A first important observation is that both Ontario and Québec capitalized on their respective family medicine group infrastructure to implement these programs. As such, the PCCMC and RSI-PAPAC both presented frameworks that were easily embedded within their existing respective health care systems given the existence of FHTs and GMFs, which already featured integrated interprofessional primary care practices (though to varying degrees, see Hutchison *et al.* 2011). The PCCMC model, in particular, rolled out thanks to this existing care infrastructure, with many clinic members drawn from the patient's existing circle of care (Lee *et al.* 2018). By leveraging primary care infrastructure, the PCCMC shows potential to not only adapt the program to meet the needs of local populations, but to also expand to other complex, chronic geriatric health conditions. However, while these primary care teams certainly played a key leadership and facilitating role for Québec and Ontario, respectively, they were neither sufficient (as the Québec experience showed), nor necessary, as Saskatchewan established a successful program without the benefit of such infrastructure. Looking to the future, the lack of such infrastructure may be an impediment to the scale-up of this model, as the management challenges of a hub-and-spoke model may prove unwieldy for this program.

Telemedicine has proven to be a powerful tool in the arena of rural health, showing promise of high return by saving patients time, travel, and its associated expenses. In the case of Saskatchewan, provincial investment in telemedicine technology undergirded the success of the RRMC reach. It permitted easy, remote consults with specialists whom the patients might otherwise have difficulty accessing. Nevertheless, the original RRMC pilot study to increase referral rates for clients in remote northern communities (Morgan *et al.* 2009) was not met. Even one visit to the RRMC in Saskatoon is a remarkable challenge for patients, especially those with limited mobility and financial constraints (*Ibid.*). In contrast, the PCCMC model delivers timely, person-centred care in a location close to the patient's community (ARTIC 2017). As such, distance is less of a barrier for individuals.

Learning from Saskatchewan demonstrates that "champions" can be critically important to the implementation and persistence of a model. Much of the continued success of the Saskatchewan model can be attributed to the persistence of its principal investigator. Without her to secure funding, the program may not have lasted as long as it did. Although the RRMC has not yet sought to scale-up, proper mechanisms for funding and governance models will be critical factors ensuring in the sustainability of the program. In Ontario, the PCCMC's early success was due in part to the acumen of one physician (ARTIC 2017). Although the initial project lead still maintains an active role over the continued development of the PCCMC model, the project's expansion to multiple other FHTs reduces its dependence on her leadership, as each FHT operates with their own governance. This could pose potential problems in terms of evaluation if standards are not adequately maintained across such diffuse regional centres of care. Yet to date, ARTIC's efforts to mobilize and institutionalize the PCCMC model of care across the province has been extremely successful. However, a new provincial government, elected in 2018, has expressed plans to consolidate Ontario's separate health agencies. As a result, the program's expansion may be stifled. In sum, without institutional support (both financial and in terms of policy orientations), these programs may eventually falter.

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