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Background

Dementia is a syndrome that leads to a deterioration in cognitive function beyond what might be expected from the usual consequences of biological aging (World Health Organization (WHO), 2023).

Dementia has physical, psychological, and social impacts for individuals who live with it, as well as for their carers and families (WHO, 2023). Therefore, healthcare and community collaboration is required for people living with dementia to successfully age in place.

The Grant

In 2020 Alberta Health Services' (AHS) Strategic Clinical Networks and Provincial Seniors Health & Continuing Care were awarded a \$1.4 million grant from the Health Canada Health Care Policy Contribution Program.

The Connecting People and Community for Living Well (CPCLW) grant aimed to support a wellbeing driven, collaborative approach to improving care and support for people living with dementia and carers.

A provincial CPCLW grant team supported five rural communities (Drumheller, Innisfail, Kneehill area, Stony Plain, and Westlock) to develop context adapted, community driven services led by multi-sector collaboratives to enhance the wellbeing of people living with dementia, their carers, and the community collaboratives themselves.

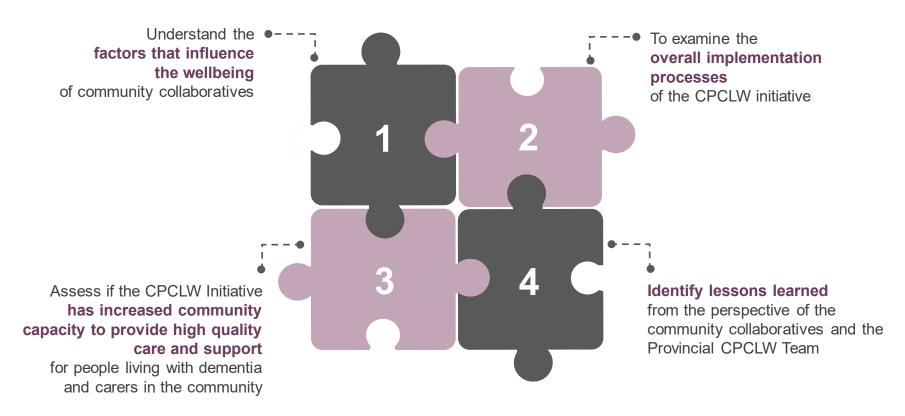
This short report provides an overview of the full CPCLW Evaluation
Report prepared by Health Systems Knowledge and Evaluation (Stasiewicz,
M., Bourassa, L., Mallinson, S., & Graham, L., 2023). For additional details on
the evaluation process and findings, please click here to access the full evaluation report.



Evaluation: Objectives & Scope

Objectives

Health Systems Knowledge and Evaluation (HSKE) were engaged by the CPCLW leadership team at the beginning of the grant and worked closely with them to identify four evaluation objectives:



Scope

The HSKE evaluation focused on CPCLW implementation processes and impacts for the provincial CPCLW team and the five participating community collaboratives.

- Impacts for people living with dementia and their care partners were not considered directly in this evaluation.
- The CPCLW team supported collaboratives by completing applied research activity to gather insights from people living with dementia and their carers.
- Both the grant team and the evaluation team provided evaluation consultation to community collaboratives upon request.

Evaluation: Approach & Methods



Approach

This evaluation was guided by a **principle-focused evaluation** methodology. This approach is suited to innovative programs and complex settings, particularly if the model and activities are still in the development stage and there is potential for ongoing change (Patton, 2018).

To meet the four evaluation objectives, and consider the impact of the overarching CPCLW principles (click here for details and definitions) the following principle-focused evaluation questions were addressed:

- Is there evidence of alignment between principles and program activities?
- Are they leading to the desired results?



Methods

Primary evaluation data were collected using two main methods:

Focus Group Discussions:

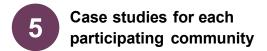
HSKE conducted focus group discussions with the five community collaboratives in the spring and autumn of 2022 and a final focus group with the provincial team in the winter of 2022. Qualitative focus group data were analyzed with NVivo 12.

Survey:

An online survey was distributed to members of the five collaboratives in October 2022. The survey comprised a mix of closed response option and free text questions about the experience of being part of CPCLW. Quantitative data were analyzed using Microsoft Excel, and qualitative responses were coded and themed in NVivo



Key Deliverables



These documents were based on focus groups with the collaboratives and highlighted each team's unique characteristics and accomplishments within three-year grant period. The case studies were finalized and distributed in April 2023.

1 Final evaluation report

The final report synthesizes data from focus groups with the provincial team, the case study reports, and the survey in order to provide a picture of the overarching initiative.



Factors Influencing Collaborative Wellbeing

The CPCLW model is wellbeing focused and acknowledges that material, relational, and subjective factors contribute to a person or a collective's ability to live well (CPCLW, 2022, McGregor & Pouw, 2017).



"When [a group's] wellbeing is looked after, they are

able to work together and support the people living in their community."

- CPCLW Wellbeing Guide



Using this definition, **evaluation objective 1** explored factors facilitating community collaboratives' ability to work together to support people affected by dementia in their community, and factors that made it more challenging.

Factors Contributing to Collaborative Wellbeing

The following factors contributed to, or facilitated, community collaborative wellbeing by promoting their ability to work together and/or support the people affected by dementia in their communities:

A Collaborative Approach



Every collaborative highlighted teamwork as foundational for supporting their communities effectively. By leveraging their various skillsets, expertise, and ideas, most groups were able to accomplish more for their communities together than they could individually.

Shared Vision and Passion



Across all five collaboratives, a passion for supporting people living with dementia and their care partners was evident. All the collaboratives highlighted that this shared passion helped create team synergy, an energy for the work, and a tenacious commitment despite challenges.

Factors Influencing Collaborative Wellbeing

Municipal Support & Involvement



Municipal Town or Village involvement in the community collaboratives generally helped advance objectives. Town Council support enhanced their credibility and visibility. Municipal representation in the collaboratives (e.g., staff from Family & Community Support Services, Community Social Development) also improved access to data, funding, and/or spaces to run local programs/activities.

Access to Funding



Access to funding was an important material contributor to collaborative ability to support people impacted by dementia and therefore their wellbeing as a collective. Funding was critical for implementing initiatives, accessing training, and/or allocating dedicated staff support for projects.

Leadership Support



In most cases, support from local leaders and municipal representatives was felt to be influential. Leaders can facilitate access to communication channels where collaboratives can bolster the visibility of their work and, sometimes, access resources.

Dedicated Staff Capacity



Collaboratives who had members who could dedicate their work hours to providing or coordinating wellbeing supports described this as an important contributor to their successes.

Community Engagement



Most collaboratives mentioned that their tight knit, generous communities were a strength. Community members and businesses often rallied together to support fellow residents. For example, local volunteers provided hands-on support with program delivery, and donations by residents and businesses provided materials for people impacted by dementia.

Access to Data & Evaluation



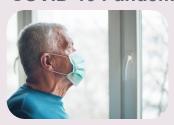
Where collaboratives had existing data and evaluation resources this was noted as a strength. It kept them informed of unmet needs of their communities and/or the outcomes of their collaborative initiatives.

Factors Influencing Collaborative Wellbeing

Factors Detracting from Collaborative Wellbeing

Some factors had a negative effect on collaborative wellbeing because they hindered collaboratives' ability to effectively work together and support the people affected by dementia in their communities. Although these challenges were beyond the control of the CPCLW initiative, they affected implementation of some CPCLW initiative components:

COVID-19 Pandemic



The COVID-19 pandemic created major challenges for all five community collaboratives, including reduced service access, staff feeling overwhelmed, periods of uncertainty, and stalled momentum.

Organizational Barriers



Navigating organizational policies and procedures ("red-tape") could be time consuming for collaboratives. It sometimes hindered their ability to creatively and nimbly support their communities.

Funding Uncertainty & Overlapping Grants



Most community collaboratives did not have sufficient internal funding or staff to optimally support their communities. To access funds, they often needed to apply for grants or lobby for funding. Not only could these efforts be complex (e.g., navigating multiple grants at once) and burdensome, but the uncertainty of these funding sources made it difficult to plan or sustain projects for their communities.

Partner Recruitment & Retention



A few collaboratives had difficulty recruiting partners to participate in their groups and run activities. Collaborative members thought this was because of; limited awareness of dementia care and resources; low staff capacity to take part in collaborative work; and difficulties in finding like-minded partners who valued a flexible and community-oriented approach.

Staff & Organizational Capacity



All five community collaboratives faced various capacity issues. In most cases, collaborative activities were not the members' primary job responsibility. Therefore, it was often difficult for them to find time to advance their efforts to support community wellbeing.

Other Challenges



Other challenges mentioned included systemic capacity limitations (e.g., staffing/bed shortages in healthcare facilities), poor awareness of dementia, and stigma around dementia, which could reduce care seeking.

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Overall Implementation Processes of the CPCLW Initiative



Implementation Approach

The CPCLW provincial team used learnings from the pilot phase to inform key components and deliverables of the current grant. At the same time, they embraced a **developmental approach**, characterizing their strategy for developing and implementing the initiative as 'building the plane as we fly it'.

In other words, they started with general goals and ideas that could be built and adjusted over time, rather than a static, pre-built program model for implementation. With this ethos, they aimed to create appropriate, acceptable strategies, processes, and resources to meet community needs



Key Support Activities

The key support activities and documents CPCLW provided to collaboratives throughout the grant term included:

- ✓ CPCLW Information Sessions
- ✓ CPCLW Principles
- ✓ CPCLW Community Reports
- ✓ Covid-19 Pandemic Case Studies
- ✓ The Wellbeing Guide
- ✓ Competency Framework for Multi-Sector Teams
- √ Partner's Meetings
- ✓ Working Group Sessions, Touch Base Meetings, & Ad-hoc Contact



Building Trust

The CPCLW team identified building trust with community collaboratives as important. They therefore avoided the following:

Identifying AHS as a 'backbone' organization: There were efforts to ensure all organizations/ collaborative members thought of their roles as equal but different.

Identifying themselves as 'the experts': Each collaborative was seen as experts in

identifying supports needed in their areas; the CPCLW team adopted a facilitative role.

Completing the collaboratives' work:

To enable collaborative sustainability and capacity, the CPCLW team avoided making decisions for members or completing tasks.

Other important implementation processes identified for evaluation objective 2 include:

Recruiting CPCLW communities

In the early stage of the grant, the CPCLW team took various routes to find community partners who were willing to be part of the CPCLW development and implementation journey.

Creating CPCLW Resources

The CPCLW team created a suite of resources and processes to support partner engagement and implementation of the CPCLW model. These included the Wellbeing Guide and Competency Framework.

Lessons learned from engaging with collaboratives

By engaging with collaboratives, the CPCLW team gained insights on effective partner engagement, communication, and representation.

Identifying collaborative goals and support needs

Because community needs and goals are not static, the CPCLW team had regular conversations with members to ensure goals and objectives continued to be met.

Helping collaboratives understand and use the CPCLW model

The CPCLW initiative aimed to align frontline community work with a high-level conceptual model. Therefore, the CPCLW team worked to help collaboratives see connections between their work and model components.



Successes, Challenges, and Facilitating Factors

Successes



- 1. The applied research activity and recruiting people living with dementia and carers to participate in interviews at the beginning of the pandemic.
- 2. By leveraging their capacity and experience, the CPCLW team created opportunities for communities to share knowledge and support (e.g., Partners' Meetings).
- 3. With their connections to leadership in AHS and beyond. CPCLW helped raise awareness of actions at the community level, which are often unseen by leaders in large organizations.

Challenges



- 1. The COVID-19 pandemic created various challenges, such as:
 - Reduced chances to engage with vulnerable people living with dementia and carers.
 - · An inability to meet with collaboratives face to face.
 - · Reduced priority among leaders and collaboratives. who needed to respond to the pandemic.

- 2. Some collaborative members have had negative experiences with AHS.
 - This damaged rapport required that the CPCLW team invest significant efforts into building/ repairing relationships with collaborative members.
- 3. As a grant funded initiative, the CPCLW team had to undertake extensive process for grant approvals and extensions. They also had to implement all key support activities within pre-defined grant timelines.
- 4. Some collaboratives experienced turnover during the grant period. This required the CPCLW team to build relationships with new contacts who did not have full background knowledge of CPCLW.

Facilitating Factors



- 1. Despite its challenges, COVID-19 also created new opportunities. For instance, the pandemic exposed existing gaps in care for people living with dementia and carers.
- 2. Being guided by the terms of the grant, the CPCLW team had flexibility to make decisions on deliverables and changes without some of the usual constraints of a hierarchical, bureaucratic structure.



Increased Community Capacity to Provide High Quality Care

Evaluation objective three explored whether the CPCLW Initiative increased community capacity to support people living with dementia and carers in the community. Findings for this objective are framed from a principles-focused lens, to illustrate how capacity-building efforts aligned with the ten overarching principles of the initiative.

Community Collaboratives

In focus group discussions, there was evidence of the collaborative aligning with all the CPCLW principles. Many members indicated that these values are intrinsic to their daily work and were therefore routine practice. Some found it valuable to have these concepts articulated and documented.

Strengths-Based

Community
Driven

Multi-Sector
Collaboration

Wellbeing
Focused

While there is early evidence of adherence, the following two principles may need additional development in future CPCLW work:



The first is the **Change Monitoring** principle. This principle is defined as "*Utilizing the Connecting People & Community Wellbeing Guide to track progress toward expected outcomes of change actions."* At the time of the evaluation, some communities were still implementing their change actions. Therefore, there is limited data on what the Change Monitoring principle looks like in practice.



The second area of opportunity is the **Ongoing Learning** principle, defined as "Supporting networking across communities and with champions of the approach to share learnings and identify potential areas of collaboration. Incorporate new knowledge into ongoing local planning and implementation."

Evaluation results indicate that while all the collaboratives were open to networking and learning, the time and capacity needed to adhere to this principle could be difficult to find amid other responsibilities. For instance, while the CPCLW Partners' Meetings were a forum for learning, collaborative members could only attend when they had time to.

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Increased Community Capacity to Provide High Quality Care

Provincial CPCLW team

When considering the provincial CPCLW team's principle adherence, the evaluation results showcase that by providing provincial support, the CPCLW team assisted community collaboratives in adhering to the principles. For instance, the CPCLW team gathered applied research data on community needs. This data supported the collaboratives in remaining needs driven. The CPCLW team also created various

Additionally, there is evidence of the CPCLW team adhering to these values themselves, in provincial-level work.

Strengths-Based

Change Monitoring

Multi-Sector Collaboration

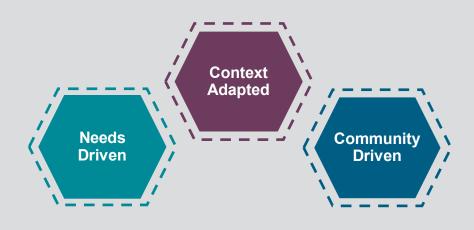
Wellbeing Focused

Wellbeing Focused

While there is early evidence of adherence to all the principles, some community collaboratives felt there was room for additional tailoring of CPCLW documents and processes to fit their needs.

For instance, some of the collaboratives had already done some of the foundational work in identifying community needs and priorities for implementing local activities. In these areas, some CPCLW activities such as completing the Wellbeing Guide were seen as a duplication of work. Some of the language of CPCLW documents were also viewed as too high level or abstract for all collaborative members to understand.

There is therefore room for the CPCLW team to invest more time in understanding the unique context and needs of each collaborative so that they may better tailor their approach and supports to each area and allow the collaborative work to be as **needs driven**, **context adapted**, **and community driven** as possible.





Increased Community Capacity to Provide High Quality Care

What Worked Well for Collaboratives

- An **evidence-based approach** to collaborative work.
- A provincial-level perspective to inform local decisions.
- High level guidance and a structured framework to focus on priority objectives.
- Articulation of community-level work in new ways.
- Shareable documents to aid communication with partners and leaders.
- Evidence-gathering and evaluation support when time and knowledge/skill in the community were limited.
- **Empowerment & Advocacy** to help access resources
- Networking support to build connections beyond communities.
- **Ad hoc support** for things like grant applications.
- Positive interpersonal rapport making it easy to ask for help.

"[...] The [CPCLW team] was very helpful when we needed something...

they always tried to guide us along."

- Focus Group Participant

What was Challenging for Collaboratives

Feeling confused:

People sometimes struggled to understand the initiative and the purpose of some activities, especially in the first year.



Understanding improved with time and experience, as the CPCLW initiative evolved.

 The number of meetings, documents, activities: CPCLW activities required a time commitment that people found difficult to manage. It could be hard to know which CPCLW meetings to prioritize when time was limited, particularly early on.



Some collaboratives formed a subgroup for CPCLW activities and the CPCLW information was distributed as appropriate to the rest of the collaborative.

• Insufficient tailoring/alignment of CPCLW activities: Some communities did not feel that adequate context adaptation had been done by the CPCLW team prior to the model's implementation in their area.



The CPCLW team's knowledge of the communities' unique qualities increased with time and experience.

"It's essential that [CPCLW] know and have a better understanding of who is at the table and [that] every community is going to be different."





Lessons Learned

Learnings from the CPCLW development and implementation process and considerations for the next phase of work are grouped by the four evaluation objectives.



Factors that contribute to and detract from a collaborative's wellbeing operate at both the local and system level; some are easier to nudge than others. For instance, building collaborative teams guided by a shared vision is easier to influence than resource and funding constraints that limit collaboratives' capacity.

Future implementation efforts should consider:

- Opportunities for quick wins to build collaborative momentum, alongside efforts to achieve longer-term wellbeing goals.
- Identifying resources to invest in dedicated coordinator support, given that collaboratives with dedicated coordinator time appear to be more successful.



Evaluation Objective 2: Implementation Processes

The real-time evolution of the CPCLW model and resources was unfamiliar to many project participants and the complexity of a theory-driven model was sometimes challenging to work with.

Going forward, the CPCLW team should consider:

- Ways to ensure project communication remains clear, succinct, and purposeful.
- That CPCLW supporting documents are acceptable to intended users and audiences.
- Increased focus on CPCLWs potential to align and tailor implementation to local context and needs.



Overall, support provided by the CPCLW team was viewed as being beneficial for both collaborative wellbeing and capacity building.

Future implementation efforts should consider:

- Continuing to build the flexibility and variety of support options for various stages of collaborative establishment.
- Further review of the purpose and use of CPCLW Guiding Principles. While they are potentially a useful strategic tool, some evidence suggests they were not an explicit part of internal communication or planning.



All collaboratives said they wanted to continue their engagement with CPCLW in some capacity in the future. Upon completion of the project and this evaluation, the CPCLW team secured additional funding from Health Canada to continue implementation efforts with interested communities.

Key considerations for sustainability are:

- Building multi-sector representation on the core CPCWL team.
- Continued efforts to secure permanent operational funding instead of term-limited grant funding.
- Ongoing advocacy for a holistic approach to wellbeing rather than a healthcare driven definition that focuses on acute and tertiary care.
- Exploring opportunities for new partnerships, within Alberta and beyond.

Conclusion

Over the past three years, the CPCLW team has built supportive relationships with the members of five community collaboratives across Alberta and fulfilled numerous key support activities.

Each participating community collaborative experienced the benefits of some or all of these supports, but most also faced challenges in navigating the developmental nature of the initiative, the complexity and time intensity of CPCLW activities, and the effects of system-level constraints on their capacity. Ultimately, the provincial team's support was seen as beneficial for many aspects of collaborative wellbeing and capacity building.

Looking to the future, the CPCLW team has successfully secured additional funding from Health Canada to continue and expand their implementation efforts. As this work progresses, the CPCLW team should consider:

- Balancing opportunities to facilitate "quick wins" within community collaboratives, alongside providing support to address longer-term wellbeing needs (e.g., dedicated coordination resources).
- Finding ways to ensure that provincial support (in its various forms) is clear, purposeful, tailored to local needs, and acceptable to intended users.
- Continuing efforts to optimize and sustain the core CPCWL team's operations within AHS, the province, and beyond.

For more information, please refer to the <u>full evaluation report</u>:

Stasiewicz, M., Bourassa, L., Mallinson, S., & Graham, L. (2023). Connecting People & Community forLiving: Final Evaluation Report. Location, AB: Health Systems Knowledge & Evaluation, Alberta Health Services.