Building Operational Excellence

Home-Based Palliative Care

PROJECT OUTCOMES & IMPACT REPORT

APRIL 2020

Canadian Home Care Association
canadienne de soins et services à domicile

CONTENTS

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Our heartfelt thanks to the patients, caregivers, health care providers and experts who shared their stories, experiences and insights.

ABOUT THE CANADIAN HOME CARE ASSOCIATION

Established in 1990, the Canadian Home Care Association (CHCA) is a national non-profit membership association dedicated to advancing excellence in home and community care. Through our diverse membership base, the CHCA represents public and private organizations that fund, manage and provide services and products in the home and community. In partnership with our members, the CHCA advances initiatives that address national priorities in home and community care. As a recognized authority, the CHCA facilitates knowledge sharing, creates connections, informs policy and practices, and advocates for integrated home and community care for all Canadians.

www.cdnhomecare.ca

EXECUTIVE SUMMARY

Supported through a Health Canada funding contribution, the Canadian Home Care Association led a 19-month project (2018–2020), Operational Excellence in Home-Based Palliative Care. This project built on *The Way Forward: An Integrated Palliative Approach to Care* by identifying innovative operational practices to address service gaps in the following four priority areas:

1. Inclusion of advance care plans into the delivery of care in home
2. Assessment and care planning
3. Effective communication strategies and tactics
4. Supplies, equipment and medication management

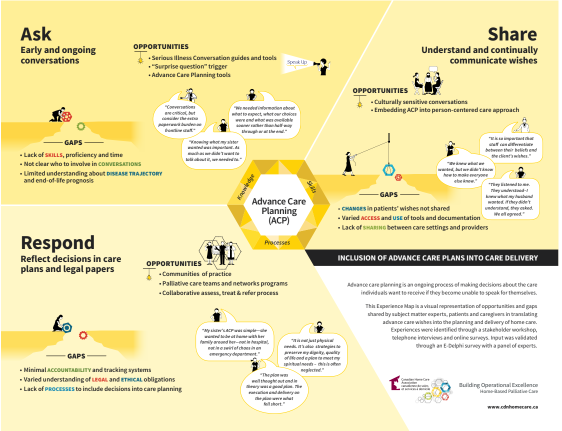
This project is a catalyst to improving operational infrastructure in home-based palliative care and enhancing access to better home care as outlined in the Common Statement of Principles on Shared Health Priorities, endorsed by federal, provincial and territorial governments. The project consisted of three main phases.

Phase 1: Mapping the palliative care experiences of providers, patients and their caregivers

The goal was to identify gaps and opportunities in home-based palliative care that would be addressed throughout the project. The mapping was done through a multi-phased stakeholder engagement process that included regional stakeholder workshops in Edmonton, Vancouver, Charlottetown and Ottawa; key informant interviews with cultural groups; key informant interviews and an online survey with patients and caregivers; and an e-Delphi to validate the input and prioritize areas for improvement. The experience maps identified gaps and opportunities in skills, knowledge application and processes.

Specifically, for the four priority areas, experiences reinforced the following priority actions:

1. Advanced care planning
   - Ask: Hold early and ongoing conversations
   - Share: Understand and continually communicate wishes
   - Respond: Reflect decisions in care plans and legal papers
2. Assessment and care planning
   - Identify: Conduct early assessments
   - Include: Consider all providers
   - Implement: Use appropriate tools
3. Communication
   - Expand: Engage all care partners
   - Update: Consistently communicate
   - Empower: Involve patients and their caregivers
4. Medication, equipment and supplies
   - Access: Ensure no duplication or delay
   - Manage: Organize and maintain inventory
   - Disposal: Implement systems for easy return



"Conversations are critical, but consider the extra paperwork burden on frontline staff."

"We needed information about what to expect, what our choices were and what was available sooner rather than half-way through or at the end."

"Knowing what my sister wanted was important. As much as we didn't want to talk about it, we needed to."

"It is so important that staff can differentiate between their beliefs and the client's wishes."

"We knew what we wanted, but we didn't know how to make everyone else know."

"They listened to me. They understood–I knew what my husband wanted. If they didn't understand, they asked. We all agreed."

"My sister's ACP was simple—she wanted to be at home with her family around her—not in hospital, not in a swirl of chaos in an emergency department."

"It is not just physical needs. It's also strategies to preserve my dignity, quality of life and a plan to meet my spiritual needs – this is often neglected."

"The plan was well thought out and in theory was a good plan. The execution and delivery on the plan were what fell short."

Advance care planning is an ongoing process of making decisions about the care individuals want to receive if they become unable to speak for themselves.

This Experience Map is a visual representation of opportunities and gaps shared by subject matter experts, patients and caregivers in translating advance care wishes into the planning and delivery of home care. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys. Input was validated through an E-Delphi survey with a panel of experts.

Download the Palliative Care Experience Maps

Phase 2: Identifying and disseminating leading practices in home-based palliative care

Access here

A national call for operational innovations was made to address gaps identified through the experience mapping work. A total of 24 innovations were selected, with 22 practices profiled during the 2018 Home Care Summits in Charlottetown, PEI (October 1 and 2) and Vancouver, BC (October 22 and 23). Presentations were live-streamed and made available via on-demand to maximize dissemination. Of these, a panel of experts selected five practices to be profiled in the CHCA High Impact Practice series and widely promoted across the country:

Whole Community Palliative Rounds from Interior Health in British Columbia – A strategy to support multi-disciplinary communication and shared decision-making

Rural Palliative Care In-Home Funding Program from Calgary Zone, Alberta Health Services – A flexible approach to enhancing care for rural patients nearing end of life

The INSPIRED COPD outreach program from Nova Scotia – A program to provide enhanced social supports and advance care planning throughout an individual's illness trajectory

Virtual Palliative Care Intervention from William Osler Centre in the Greater Toronto Area – A model that combines an app for early identification of symptoms with videoconferencing to help support palliative care patients in the community

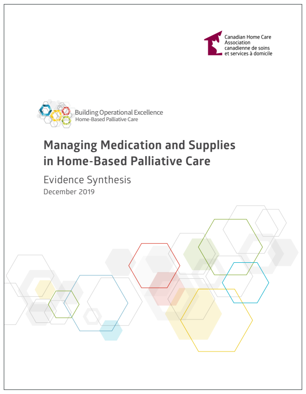
Implementing a Palliative Approach to Care by Having Conversations Early (IPACE) from Vancouver Coastal Health in British Columbia – A process to empower front-line staff to incorporate early conversations with patients about their goals for care


Building Operational Excellence
Home-Based Palliative Care
HIGH IMPACT PRACTICES
Whole Community Palliative Rounds
An innovative approach to inter-professional care planning and delivery in Interior Health

Download the High Impact Practices

A particularly challenging area identified through the experience mapping process was the management of medication, equipment and supplies. Three leading practices were identified through the call for innovation, mainly focusing on access to appropriate medications in the home setting. To gain a better understanding of potential opportunities and leading practices in this priority area, the CHCA conducted a review of research evidence and grey literature specifically on access, management and disposal of medications and supplies in home-based palliative care. This final synthesis highlights a number of options and approaches based on the degree and availability of high-quality evidence, including the following:

- organizational policies and procedures to manage and monitor controlled drugs for organizations that have access to these drugs;
- structured educational programs to assist patients with medication management;
- use of symptom management kits; and
- strategies for safe storage of medications and safe disposal of medications.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Managing Medication and Supplies in Home-Based Palliative Care
Evidence Synthesis
December 2019

Download Evidence Synthesis: Access, Management and Disposal of Medications and Supplies in Home-Based Palliative Care.

Phase 3: Facilitating implementation of a leading practice in home-based palliative care using a CHCA SPRINT Implementation Collaborative™

With the help of the project's advisory committee, the High Impact Practice "Whole Community Palliative Rounds (WCPR) was identified for deployment with 11 teams across Canada. Over a seven-month period, teams were involved in virtual learning webinars and customized coaching sessions, supported by clinical leaders and subject matter experts in quality improvement and implementation science. The participating teams tested and adapted key practice changes designed to support WCPR in various geographical and operational contexts. The emphasis on collaboration among teams promoted rapid dissemination of successful practices, and at the conclusion of the collaborative all teams were able to successfully implement WCPR.

Implementing WCPR through the SPRINT-WCPR Collaborative improved operational excellence in home and community-based palliative care. Although the collaborative timeframe did not allow for the evaluation of quantitative data, members of the practice teams shared their early successes. For example:

- Increased health care provider satisfaction and teamwork through improved relationships among people from all disciplines
- Timely feedback to physicians, so they are able to stay up to date on clients' conditions
- More holistic client care: "I was a 'whole' and not just a set of individual symptoms or diseases that we often get reduced to..."
- Acknowledgment by health ministries (BC, AB, SK, MB) of the value of WCPR in moving their provincial agendas forward and helping attain the goals stated in their federal/provincial bilateral agreements to advance shared health priorities
- Acquired knowledge from other teams [jurisdictions] from across the country and exposure to other home care leaders and innovations that can be adapted and spread in their own practice

SPRINT
Implementation Collaboratives™
Whole Community Palliative Rounds

Learn about the SPRINT-WCPR Implementation Collaborative.™

Lessons Learned

The project made a significant contribution to operational excellence in home and community-based palliative care. Gaining a clear understanding of gaps and opportunities from the provider and patient/caregiver perspective enabled the team to target specific areas and identify leading practices that would have an immediate impact on quality care. Sharing the knowledge gained throughout the initiative was an important component of the work.

The creation of an implementation framework and user guide to support organizations in implementing innovative practices in home and community care was an important outcome of this project. Facilitating broad engagement, listening to experts (providers and clients/caregivers), relating theory to practical application and fostering collaborative energy were all key lessons learned during our journey. Working with the 11 practice teams across the country, we realized that small tests of change implemented in a creative way can have big impact in a short timeframe.

A key consideration that we have included in our next steps for building operational excellence in home-based palliative care is creating more expertise and knowledge in developing a sustainability plan. The early results from this project show incredible promise for providers of home-based palliative care and especially for individuals with palliative care needs and their families. It is our hope that we will have an opportunity to continue this important work to ensure the sustainability of WCPR in 11 locations across the country and promote more leading practices to a wider audience.

Building Operational Excellence
Home-Based Palliative Care

FRAMEWORK
& USER GUIDE
FOR IMPLEMENTING
INNOVATIVE PRACTICES

Download the Implementation Framework and User Guide

Implementation Activities + Sustainability Planning = Long-Term Success

Once the practice teams were familiar with WCPR and began testing change ideas and achieving success, the project team used the results to support teams in creating sustainability plans, defining outcomes measures and articulating plans to achieve them. A review of the SPRINT approach confirms that the short timeline and high-intensity focus enable teams to test and adapt a leading practice, however a designated time period (5–7 months) should then focus on outcomes and sustainability. The CHCA supplied resources for teams to begin this process, although the value of collaboration and expert guidance and coaches could not be provided. A dedicated SPRINT sustainability collaborative would be beneficial for teams to ensure long-term adoption and impact.

"In hindsight, I would have loved to see more of a focus on the outcomes of this project. We need to be able to justify the work we do with measurements that support the project. This will not deter us, but we felt that we did take a few steps back and will need to re-evaluate what we are doing, how it aligns with our strategic priorities and how we can collect measurements to support our work."

PROJECT OVERVIEW

There has been growing interest in home-based palliative care as an approach to care management that is patient-centred and focused on quality of life. However, the availability of high-quality end-of-life care varies widely across Canada. A recent report released by the Canadian Partnership against Cancer identified an "overuse of, or over-reliance on acute-care hospital services near the end of life" due to inadequate availability of, or access to, home-based palliative care."[1]

The federally funded, national, multi-sector initiative, *The Way Forward: An Integrated Palliative Approach to Care* (2012–2015), created a framework for implementing an integrated palliative approach to care. It provided clear action steps for sectors, health care settings and providers. It also strongly emphasized home-based palliative care and resulted in a good understanding of the gaps and challenges providers face when providing care in the home setting. Building on this work, the Canadian Home Care Association (CHCA) implemented the B*uilding Operational Excellence: Home-Based Palliative Care* project (2018–2020). The goal was to identify leading operational practices in home-based palliative care that address the gaps identified in the Way Forward initiative and improve the quality and efficiency of end-of-life care. This project is a catalyst to improving operational infrastructure in home-based palliative care and enhancing access to better home care as outlined in the *Common Statement of Principles on Shared Health Priorities*, endorsed by federal, provincial and territorial governments.

This report provides an overview of the actions, outcomes and experiences of the Operational Excellence in Home-Based Palliative Care project. The information captured in the report provides an opportunity to appreciate the detailed activities and resulting achievements accomplished over the 19-month project. Detailed reports and proceedings documents are available for many of the initiatives for a more in-depth understanding. These detailed reports are noted throughout the report.

Supporting the actions and outcomes is a robust knowledge translation plan that was designed to raise awareness of the project activities, identify opportunities to become involved and share project outcomes and learnings. Through the fundamentals of knowledge translation, the project team used various formats to promote knowledge dissemination and implementation. Each phase of the project built upon the next to inform a wide audience of key stakeholders and inform home and community care policy and practice across the country.

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[1] Canadian Partnership Against Cancer. (2017). *Palliative and End-Of-Life Care: A Cancer System Performance Report*. Retrieved from https://www.partnershipagainstcancer.ca/topics/palliative-and-end-of-life-care/

PROJECT APPROACH

Building Operational Excellence: Home-Based Palliative Care focuses on meeting patient and caregiver expectations through continuous improvement of the operational processes and the culture of home care service provider organizations. The project focused on the following priority areas:

1. Translating advance care plans and health care wishes into the planning and delivery of services in the home
2. Early and ongoing identification of the needs and strengths of patients and caregivers and ways to incorporate assessment results into shared care plans
3. Strategies and methods to ensure effective and efficient communication, shared decision-making and care coordination
4. Timely access to, efficient management of and safe disposal of equipment, supplies and medications in the home

There were three main phases in the project:

Phase 1: Mapping the palliative care experience in Canada to identify opportunities and gaps in home-based palliative care
Phase 2: Identification and dissemination of operational innovations in home-based palliative care
Phase 3: Implementation of a leading practice through the SPRINT Implementation Collaborative™ model

The next section describes the key components and outcomes of each phase.

Phase 1: Mapping the Palliative Care Experience

The purpose of mapping the palliative care experience was to understand the patient, caregiver and provider experience when receiving or providing home-based palliative care. This interactive process encouraged participants to reflect on how they think, feel and behave at each stage of the integrated palliative care journey. The dialogue during mapping sessions provided an opportunity to engage participants in a structured and safe environment focused on identifying problems and exploring opportunities for improvement. The mapping exercise looked at the four priorities areas:

1. Inclusion of advance care plans into the delivery of care in the home
2 Assessment and care planning
3. Effective communication strategies and tactics
4. Management of supplies, equipment and medication

To create the palliative care experience maps, the CHCA project team conducted a multi-phased stakeholder engagement process from May–September 2018 that included the following activities:

a) regional stakeholder workshops
b) key informant interviews with cultural groups
c) interviews and an online survey with patients and caregivers
d) e-Delphi validation process (two rounds)

Regional Stakeholder Workshops

Four invitational stakeholder workshops were held across the country. Each workshop addressed one of the four areas of focus. The locations were selected to build on regional expertise and experience with the topic area.

Inclusion of advance care plans into the delivery of care in the home was the topic of the Edmonton workshop. Drawing upon the experience across Alberta with advance care planning, the participants explored the gaps and opportunities facing home care providers when translating advance care plans into the planning and delivery of care as part of the service menus under the provincial framework.

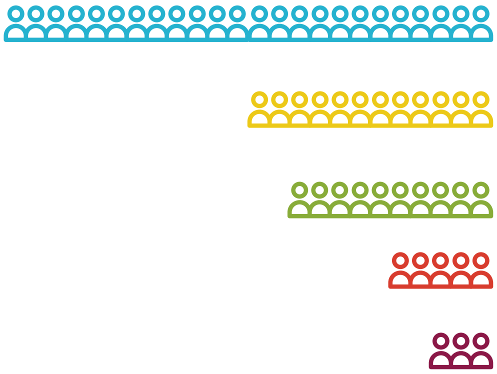
Assessment and care planning discussions were facilitated in the Vancouver workshop. Access to palliative care in the home and through primary health care is a key focus of British Columbia's health authorities through their End-of-Life Action Plans. Building on this foundation and the expertise in British Columbia, the workshop explored gaps in assessment and care planning, with an emphasis on the inclusion of patients, family caregivers and all health care team members.

Effective communication strategies and tactics were discussed by stakeholders in Charlottetown. This workshop focused on operational processes in support of effective communication within the PEI Palliative Care Program, specifically with an expanded palliative care team that includes paramedics, home care providers and specialists.

Supplies, equipment and medication management was the topic of the Ottawa workshop. The participants represented equipment providers, palliative care specialists, home care providers and representatives from the Ontario Palliative Care Network. This group explored the issues and opportunities in access, management and disposal.

A total of 51 experts participated in these sessions, including home care service providers with palliative care experience, palliative care physicians, directors and managers of palliative programs, policy-makers with direct responsibility for palliative care, paramedics and family caregivers.

Consultation Workshop Participants



24	Clinical Specialists, Front-line Staff
12	Senior Leaders (Directors of Clinical Practice, VP Home and Community Care)
7	Palliative Care Physicians
5	Ministry/Policy planners
3	Pharmacists

FINDINGS

The following summary tables highlight the touchpoints, gaps and potential interventions to enhance operational excellence.

Inclusion of Advance Care Plans in Care Delivery

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Thinking and talking about personal values and wishes	• Tools exist but are not always used in the home care admission process	• Pilot project underway in Central Zone to include tools • What Matters to You tool being implemented in Calgary
Individual care plans and goals of care	• Gaps between rural and urban regions • Insufficient time for conversations and development of care plans	• Rural In-Home Program in Calgary
Reviewing and updating plans	• More resources needed to support use and updating of Greensleeves tool	• Alberta is developing additional resources to support use of Greensleeves tool
Communications	• Gaps at transition points and between family members • All members of team need access to tools and documentation	• Simulation training on serious illness conversations in Calgary • Potential role for community liaison officer to improve communications
Integration	• Need for interdisciplinary teams to work collaboratively and provide continuity of care	• Paramedic Services – Assess, Treat and Refer Program (unique and best practice) • Programs and processes to reduce acute care admissions

Assessment and Care Planning

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Person and family needs identification	• Tools exist, but not used early • Need to shift to palliative care approach	• Fraser Health Advance Care Planning Framework • Centralized intake and registry
Assessment	• Rural and urban gaps in care • More effective assessment tools are required (quality of life, etc.)	• Interior Region Circle of Care Program • Research underway on Quality of Life Assessment
Developing a care plan	• Lack of awareness of why this is important	
Inclusion of patients and caregivers	• Lack of awareness of available options • Lack of services designed to meet unique needs of populations/groups	• Translation of Serious Illness Guide into 10 languages (including context interpretation for cultural groups) • Fraser Health Conceptual Model (under development)
Inclusion of all members of team	• Disconnect with primary care • Limited inclusion of paramedics • Lack of sharing of care plan	• Interior Weekly Rounds Program • Job aids for new nurses • Telephone consults with palliative care specialists • Palliative clinics
Review and updating	• Lack of guidelines for discharge and de-registering • Lack of good measurement and metrics	
Communications	• Lack of rural and remote access • More community awareness and public understanding required	• Virtual consults for remote patients

Effective Communication Strategies and Tactics

TOUCHPOINTS	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Overall strategy	• No overall strategy exists • Systems do not talk to each other	• More funding for systems upgrades
Team communications	• Lack of role clarity • Inefficient communications	
Communication across settings and transitions	• Poor communication leads to safety risks • No interoperability • Lack of information sharing	• Paramedic 24-hour care plans • Case conferences and collaborative care rounds
Communication tools for patients and caregivers	• Caregivers need to be at the centre of the system	• Medication tracker • Home care binders • 24/7 home care

Supplies, Equipment and Medication Management

TOUCHPOINT	IDENTIFIED GAPS	INNOVATIONS/INTERVENTIONS
Getting supplies and equipment	• Delays in receiving at home • Financial burden • Overprescribing	• Programs aimed at reducing waste – Champlain LHIN
Access to medications	• Just-in-time access to emergency medicines • Time delays due to ordering processes • Lack of consistent protocols and practices by pharmacies • Diversion of drugs	• Medication reconciliation programs in collaboration with pharmacies • Electronic ordering systems to reduce waste
Changing needs and maintenance	• Lack of continuity of care • Lack of education for caregivers • Need systems for organization in the home	• Telehealth Pilot – Champlain LHIN Hospice Ottawa Pilot
Storage and disposal	• No consistent protocols or processes for returns or recycling • Families often responsible for disposal—emotional burden	• Pharmacy programs for pick up
New technologies	• Duplication of information • Restrictions on using publicly available technologies such as texts, Skype, etc.	• Telehealth pilot – Champlain • 24/7 guidance available from pharmacy

Key Informant Interviews with Cultural Groups

An individual's culture, values and beliefs have a tremendous impact on the type of health care they wish to receive and how care is experienced. To better understand these unique needs from a sociocultural, biological and identity factors perspective, the CHCA interviewed both male and female patients and caregivers from a range of cultures and of different ethnicities, including individuals in same-sex relationships.

To identify groups representing patient diversity, the CHCA solicited recommendations from national and provincial palliative care organizations including: the Canadian Hospice Palliative Care Association; the Canadian Virtual Hospice; the Ontario Palliative Care Network; Hospice Palliative Care Ontario; Family Caregivers of British Columbia; and the Alberta Hospice Palliative Care Association. The following organizations were interviewed:

Rainbow Health Centre, Ontario – A province-wide program of Sherbourne Health designed to improve access to services and promote the health of Ontario's lesbian, gay, bisexual, trans and queer (LGBTQ) communities

S.U.C.C.E.S.S., British Columbia – A multicultural, multi-service agency that helps people at all stages of their Canadian journey

Jewish Family Services, Ottawa – A full-service, non-sectarian agency providing programs and services to children, youth, adults and seniors, be they individuals, couples, families or groups

REALIZE Canada – A leader and catalyst for improved rehabilitation services for people living with HIV through integrated research, education, policy and practice

FINDINGS

The results of the key informant interviews showed that palliative care experiences can be variable for patients and caregivers who identify with specific cultural groups. Factors that impact these experiences include geography, language and literacy barriers, assumptions about cultural needs and expectations or trauma experiences (e.g., refugee population). The following tables summarize the key findings.

Inclusion of Advance Care Plans into Care Delivery

CONSIDERATIONS	OPPORTUNITIES FOR IMPROVEMENT	EXPERIENCES
Person-centred approach to the development and use of advance care plans	• Ensure person-centred approach is applied, allowing individuals to self-identify wishes and needs	*"In order for a person's Advance Care Plan to be incorporated into their care, it is important to engage people in conversations about their wishes. And it is about the how again—not so much about the content piece."*
Non-judgmental attitude of the palliative team	• Flexibility in care delivery that accommodates/respects an individual's wishes	*"Don't presume that the family knows what the dying person wants. They may not have had the conversations either."*

Assessment and Care Planning

CONSIDERATIONS	OPPORTUNITIES FOR IMPROVEMENT	EXPERIENCES
Barriers caused by language and literacy	• Reduce language and literacy barriers through better access to translation services and availability of resources in multiple languages	*"Care is only truly person-centred when the effort is entirely looking to understand and meet the individual's needs, values and wants."*
System navigation	• Provide specialized system navigation, including navigators with awareness/experience working with diverse groups	
Belief in stereotypes and cultural preconceptions	• Approach care planning and assessments with a person-centred approach that focuses on the holistic needs of the person	*"It's important to maintain cultural humility. Don't presume to understand everything about that patient, everything they want and need. Go in being open to learn and without preconceived notions."*
Understanding/awareness of individual context	• Specific to patients from the transgender community, ensure assessments address gender surgical reassignment • Respect those receiving care and prepare those delivering care	*"I would suggest that before any actions or care planning takes place, there should be an emphasis on the systems of the individual—their belief system, their value system, their family system."*

Effective Communication Strategies and Tactics

CONSIDERATIONS	OPPORTUNITIES FOR IMPROVEMENT	EXPERIENCES
Establish trust with the patient	• Ensure there is a clear understanding of confidentiality and acceptance • Normalize conversations and recognize diversity—acceptance of everyone regardless of religion, culture, sexual identity, gender, sexual behaviour	*"Communication is never one-sided. Part of the key elements is to look at who you are communicating with. The 'who' and 'how' of communication is vitally important in maintaining culturally appropriate care."*
Non-judgmental approach in communication	• Allow patients to identify pronouns and terminology to be used in communication (he/she/they; partner/spouse/husband/wife) when engaging LGBTQ communities • Communication strategies and tactics should consider not just the message, but also the delivery	*"Communication is not just about how you do it. It is not necessarily what you communicate—the message—but how the message is delivered. Communication needs to be culturally safe."*

Supplies, Equipment and Medication Management

CONSIDERATIONS	OPPORTUNITIES FOR IMPROVEMENT	EXPERIENCES
Lack of awareness and understanding of impact of medications used for palliative care (e.g., pain medications) on hormone treatments used by transgender patients	• Involve pharmacists in reviewing a person's medications, effects of stopping, compatibility with the patient's current therapies	*"Never forget that this is someone's home. An incredible amount of respect needs to be given to the fact that you are entering into someone's home, into their lives at a very critical time. Most people choose to die in the home because they don't want to die in hospital. Keep it a home."*

Interviews and Survey with Patients and Caregivers

A flexible approach was used to capture the experiences of patients with palliative care needs and their caregivers. The CHCA engaged patients and caregivers through scheduled telephone interviews and an online survey. A total of 15 caregivers participated in 30-minute one-on-one telephone interviews using a structured interview process and guide. These participants were from Ontario, Alberta, British Columbia and Prince Edward Island. The online survey was completed by 61 respondents from seven provinces (BC, AB, MB, ON, PQ, NB, PEI). The key findings are summarized in the following tables.

FINDINGS

Inclusion of Advance Care Plans into Care Delivery

TOUCHPOINTS	IDENTIFIED GAPS	EXPERIENCES
Ways to support conversations about end-of-life wishes with front-line staff, patients and caregivers	• Early discussions about options and choices when diagnosed with a life-limiting disease • Who is involved in the conversations? Skills, understanding and comfort level vary	*"I think more information needs to be provided around what end of life can look like, what the options for care are, what supports are available. How can people make informed choices without a full picture?"*
Process for ensuring front-line staff understand and respond to an individual's wishes at end of life	• Case manager, palliative resource nurse, doctor, ER doctor and EMS all need to know when changes are made • Communication gaps at transitions of care and between family members	*"We knew what we wanted, but we didn't know how to make everyone else know."* *"I just didn't know what could be done. I'd never done anything at all like this before."*
Care planning approaches that incorporate advance care wishes	• Gaps between urban and rural—limited services in rural areas • Lack of time for home care providers to have conversations and develop care plans	*"The plan was well thought out and in theory was a good plan. The execution and delivery on the plan were what fell short."*

We asked caregivers if the care their loved one received reflected their wishes (n=35):
- 64% said the care provided reflected their loved one's end-of-life wishes
- 21% said the care provided DID NOT reflect their loved one's end-of-life wishes

Assessment and Care Planning

TOUCHPOINTS	IDENTIFIED GAPS	EXPERIENCES
Early identification and response to the needs of individuals with life-limiting illness	• Identification done too late—need to use palliative approach to care • Access to services is limited—not available early • Variation in access between rural and urban locations	*"My aunt turned down palliative care too long, thinking it was only for when you were near your death bed. This thinking was never questioned, discussed, revised by her medical team. Just shrugged off with an 'OK'. I was the one who took the bull by the horns and made it happen."*
Assessment tools that provide a comprehensive understanding of patients' needs	• No standardized assessment tool—different language and understanding between care providers • Lack of knowledge of front-line home care staff in assessing and understanding needs	*"Every time the nurse came, she asked questions, sometimes the same, sometimes different. The doctor would ask questions when we would go there, or she would call. Always lots of questions."*
Process to make sure the patient and caregiver are both included in the development and updating of the care plan	• Changes in health status and care plan not shared • Disconnect with family doctors	*"The nights were by far the worst. It was like being in a life raft at night in the middle of a black ocean and the sharks were circling. Waiting. You knew disaster was waiting to happen, but you didn't know when. And there was no help."*

- We asked caregivers if they were provided with an opportunity to give input into their loved one's care plan (n=39):
- 67% were asked to provide input into the development of care plan
- 15% were not asked to provide input into the development of a care plan

Effective Communication Strategies and Tactics

TOUCHPOINTS	IDENTIFIED GAPS	EXPERIENCES
Ways to share information and communicate changes in the patient's condition to the individual, caregiver and all members of the care team	• Systems don't talk to each other—requires work-arounds and lots of communication by care coordinators • Disconnect with primary care and EMS	*"I have an information binder they gave me. I have everyone's phone number there, all the people I need are there. If I need anything I can go back and check. It is important to have something to go back to afterwards. You forget. You worry."*
Process to rapidly and effectively share information between home care, acute care, primary care, palliative specialists and community paramedics (urban and rural considerations)	• Lack of role clarity • A wide variety of teams, so communication varies across teams • Challenge in keeping the family doctors in the loop—communication is very spotty here	*"There was no care team. We rarely had the same nurse in hospital nor in the community. We were always dealing with strangers. The doctors didn't talk to each other. We were always re-stating our loved one's health history. The difference in nursing every few days meant inconsistent care. It's exhausting."*
Communication tools and resources for patients, families and caregivers	• Caregivers do not fully understand that they are responsible for being the hub for communication • Information overload—materials not designed for patient and caregiver	*"I became the information hub."* *"There was a lack of accountability for sharing information (between members of the team)."* *"When you are told the news you're not thinking clearly; it's overwhelming and hard to take in. And then the whole care changes and the people change and the supports change and you don't understand any of it. It becomes a big mess and no one to help sort it out."*

- We asked caregivers and patients if the health care team was available to answer their questions in a prompt and timely manner (n=35):
- 40% said the care team was always available
- 29% said the care team was often available
- 28% said the care team was occasionally available
- 3% said the care team was never available

Equipment, Supplies and Medication Management

TOUCHPOINTS	IDENTIFIED GAPS	EXPERIENCES
Process to ensure necessary equipment, supplies and medication are on-site in the home (without duplication or delay)	• Delays, duplication and excess • Supplies and equipment not funded • Expensive products—no coordinating buying system to address high pricing • Access to supplies after-hours may depend on what the nurse has in their bag or car	*"Here in PEI we need to pay for the equipment we need. This is not the case in other places, which doesn't make sense."* *"There was an overabundance of supplies. The deliveries were constant. Every time the door was opened it was another delivery. It was so wasteful. And none of it went back."*
Systems to help organize supplies and medication in the home for quick and easy access and effective inventory management	• Kits arrived in the home BUT no organization—a lot of time was spent by the nurses searching through boxes of supplies • No medication storage—nurses panic if they can't find medications—often order duplicates • Up to family to recognize need for changes and reassessment for equipment and supplies • Lack of education for caregivers in complex equipment and meds	*"Watching the nurse go through the boxes and panic when they couldn't find the supplies and mediation made me and my dad question their competency."* *"The nurses were very frustrated and embarrassed when we asked them if we could help them find something."*
Protocols or processes for returning and/or recycling of supplies, equipment and medications that are cost-effective and user-friendly	• No consistent protocols or processes for return/recycling of supplies, equipment and meds • Family has to dispose of expensive equipment	*"After my husband's death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home. They were very concerned about what was here while he was alive and audited it regularly, but once he died, they did not seem at all interested that I still had large doses of morphine and midazolam and one other similar drug in my home... not to mention the many other dangerous drugs that he had been prescribed over several months."*

We asked patients and caregivers where they think improvements should be made (multiple selections) (n=34):
- Managing and organization the supplies and medications to ensure they are always available and accessible: 53%
- Getting the medicines or prescriptions: 38%
- Disposing of medications: 35%
- Administering the medications: 25%

Caregivers' experiences of palliative care in Canada

Learn more

e-Delphi Validation Process

Based on the input from the workshops, interviews and online survey, an e-Delphi process was undertaken with a group of experts to validate and prioritize the key areas of improvement. A wide range of experts were recruited for the panel, including all participants from the four regional workshops, representatives of leading home care provider organizations, relevant non-governmental organizations and government agencies. Interested caregivers from the consultation phase were also invited to participate. The goal was to have a panel of experts with a range of experiences with palliative care and home care.

The objectives of the e-Delphi process were to:

- share the initial considerations from the first phase of engagement and consultation;
- validate key areas for operational improvement;
- identify other significant issues and areas for improvement in operational processes;
- inform the palliative care experience mapping; and
- determine stakeholders' ranking of priority areas of improvement.

An electronic consultation was carried out through a web-based survey over a period of 44 days. The iterative process included two consultation rounds and questionnaires, building on the results of the previous one. Invitations to participate in the e-Delphi process were sent to 92 people. For round 1, a total of 36 responded to the survey; for round 2, 26 responded to the survey. Responses were kept anonymous and amalgamated to reveal the most important areas for improvement in operational processes for home-based palliative care. The findings are summarized in the following tables.

FINDINGS

Inclusion of Advance Care Plans into Care Delivery

PRIORITY	PRIORITY GAPS	SCORE (out of 5)
1	Ways to support early and ongoing conversations about end-of-life wishes with patients and caregivers	4.72
2	Ways to support early and ongoing conversations about end-of-life wishes that involve front-line staff	4.44
3	Processes that help front-line staff understand and respond to an individual's wishes at end of life	3.92
4	Structured care planning that incorporates advance care wishes	3.08
5	Processes that are sensitive to spiritual, cultural, gender and other considerations	2.65
6	Structured documentation of all wishes and identification of legal documents and sharing across sectors and jurisdictions	2.46

Assessment and Care Planning

PRIORITY	PRIORITY GAPS	SCORE (out of 5)
1	Processes for early identification and response to the needs of individuals with life-limiting illness	3.00
2	Processes to make sure the patient and caregiver are included in the development and updating of care plan	2.46
3	Constant review of care plans and assessment that includes family coping, distress and resiliency	2.42
4	Assessment tools that provide a comprehensive understanding of the patient's needs	2.12

Effective Communication Strategies and Tactics

PRIORITY	PRIORITY GAPS	SCORE (out of 5)
1	Processes to rapidly and effectively share information between home care, acute care, primary care, palliative specialists and community paramedics	3.92
2	Ways to share information and communicate changes in the patient's condition to the individual, the caregiver and all the members of the team	3.54
3	Information and resources designed for family caregivers that are user-friendly, practical and timely	2.69
4	Single point of access such as palliative care nurse navigator	2.65
5	Communications that are culturally sensitive and use respectful language about the individual's identity	2.28

Supplies, Equipment and Medications

PRIORITY	PRIORITY GAPS	SCORE (out of 5)
1	Processes to ensure that necessary medications are on-site in the home without duplication or delay	4.38
2	Processes to ensure that necessary equipment and supplies are on-site in the home without duplication or delay	3.92
3	Systems to organize supplies and medications in the home for quick and easy access and effective inventory management	2.72
4	Protocols for returning and/or recycling of supplies, equipment and medications that are cost-effective and user-friendly	2.04
5	Processes for safe disposal or diversion of narcotics such as opioids	2.04

Download the Multi-Phase Stakeholder Engagement Report

Creating the Experience Maps

Experience maps are an effective tool to identify expectations, opinions, needs and preferences of patients, caregivers and providers, and then use that information to assist with health care redesign initiatives.[2,3] In addition to highlighting opportunities for improvement, they help capture the emotional and social experiences of individuals and groups interacting with a complex system.[4] By uncovering these insights, there is a better understanding of how to connect with patients and their caregivers on an emotional level and address their challenges.

Although each mapping process explored a different aspect of home-based palliative care, the results of the consultations and dialogue identified three shared touchpoints that impacted all experiences in home-based palliative care:

1. Knowledge – A person's intellectual understanding of palliative care
2. Skills – An individual's abilities, experience and competency in palliative care
3. Processes – Procedures, structure and tools that enable home-based palliative care

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[2] Boyd, H., McKernon, S., & Old, A. (2010). *Health Service Co-design: Working with Patients to Improve Healthcare Services: Guide and Toolkit.* Aukland, NZ: Waitemata District Health Board.

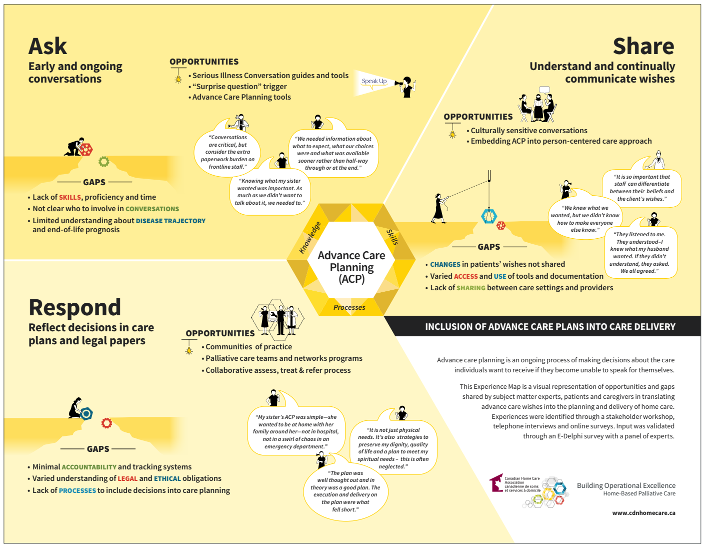
[3] Trebble, T. M., Hansi, N., Hydes, T., Smith, M. A., & Baker, M. (2010). Process mapping the patient journey: an introduction. *BMJ*, *341*, c4078.

[4] McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y. L., Kenny, L. C., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems*, *25*(sup1), 354-368.

Inclusion of Advance Care Plans into Care Delivery

Advance care planning is a lifelong process of thinking and talking about the kind of health and care an individual would want if they are unable to speak for themselves. Health care providers and family caregivers must clearly understand these wishes and ensure they are reflected in the type of services, treatments and care an individual receives. Although the process sounds simple and straightforward, the experiences in home and community-based palliative care are varied. Potential areas for improvement include ways to support early and ongoing conversations about end-of-life wishes with patients, caregivers and front-line staff, structured documentation of all wishes, identification of legal documents and sharing across sectors and jurisdictions. The experience map laid out three areas of focus as outlined in the following table.

AREA OF FOCUS	GAPS	OPPORTUNITIES
Hold early and ongoing conversations	• Lack of skills, proficiency and time for home care providers to engage in these important conversations • Limited understanding of disease trajectory and prognosis • Lack of knowledge about who to involve in initial and ongoing conversations	• Resources and tools to guide advance care planning conversations (e.g., Serious Illness Conversation guides and tools, "Surprise question" trigger, other advance care planning tools)
Understand and continually communicate wishes	• Changes in patient's wishes not shared • Varied access to and use of tools and documentation • Lack of sharing between care settings and providers	• Ensuring person-centred approach is applied, allowing individuals to self-identify wishes and needs • Flexibility in care delivery that accommodates and respects an individual's wishes
Reflect decisions in care plans and legal papers	• Minimal accountability and tracking systems • Varied understanding of legal and ethical obligations • Lack of processes to include decisions into care planning	• Communities of practice • Palliative care teams and networks programs • Collaborative assess, treat and refer process



Ask

Early and ongoing conversations

OPPORTUNITIES
- Serious Illness Conversation guides and tools
- "Surprise question" trigger
- Advance Care Planning tools

"Conversations are critical, but consider the extra paperwork burden on frontline staff."

"We needed information about what to expect, what our choices were and what was available sooner rather than half-way through or at the end."

"Knowing what my sister wanted was important. As much as we didn't want to talk about it, we needed to."

GAPS
- Lack of SKILLS, proficiency and time
- Not clear who to involve in CONVERSATIONS
- Limited understanding about DISEASE TRAJECTORY and end-of-life prognosis

Share

Understand and continually communicate wishes

OPPORTUNITIES
- Culturally sensitive conversations
- Embedding ACP into person-centered care approach

"It is so important that staff can differentiate between their beliefs and the client's wishes."

"We knew what we wanted, but we didn't know how to make everyone else know."

"They listened to me. They understood–I knew what my husband wanted. If they didn't understand, they asked. We all agreed."

GAPS
- CHANGES in patients' wishes not shared
- Varied ACCESS and USE of tools and documentation
- Lack of SHARING between care settings and providers

Respond

Reflect decisions in care plans and legal papers

OPPORTUNITIES
- Communities of practice
- Palliative care teams and networks programs
- Collaborative assess, treat & refer process

"My sister's ACP was simple—she wanted to be at home with her family around her—not in hospital, not in a swirl of chaos in an emergency department."

"It is not just physical needs. It's also strategies to preserve my dignity, quality of life and a plan to meet my spiritual needs – this is often neglected."

"The plan was well thought out and in theory was a good plan. The execution and delivery on the plan were what fell short."

GAPS
- Minimal ACCOUNTABILITY and tracking systems
- Varied understanding of LEGAL and ETHICAL obligations
- Lack of PROCESSES to include decisions into care planning

INCLUSION OF ADVANCE CARE PLANS INTO CARE DELIVERY

Advance care planning is an ongoing process of making decisions about the care individuals want to receive if they become unable to speak for themselves.

This Experience Map is a visual representation of opportunities and gaps shared by subject matter experts, patients and caregivers in translating advance care wishes into the planning and delivery of home care. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys. Input was validated through an E-Delphi survey with a panel of experts.

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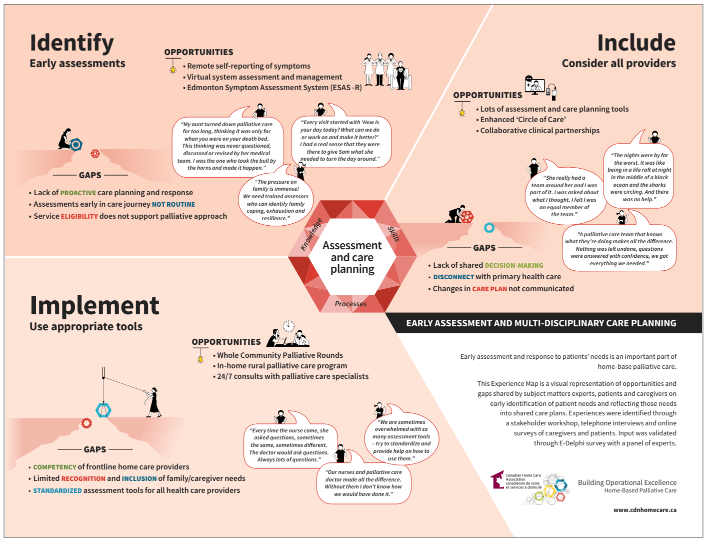
Assessment and Care Planning

An important part of home-based palliative care is assessing needs and planning care. This includes understanding the strengths, preferences and needs of individuals with palliative care needs and their caregivers. Experiences show that although many evidence-informed assessments tools are available, lack of knowledge, skills and time to complete them often limit the use of these valuable tools. Patients and caregivers also lack information about what assessments are taking place and how the information gained through these can be used to modify care/improve the client's quality of life.

Although early identification and assessment of palliative needs is critical to implementing a palliative approach to care, this vital step is often missing in current operational processes. Potential areas for improvement include processes for early identification and response to the needs of individuals with life-limiting illness, processes to make sure the patient and caregiver are included in developing and updating the care plan, constant review of care plans and assessment, and assessment tools that provide a comprehensive understanding of patients' needs. The experience map identified three areas of focus, as summarized in the following table.

AREA OF FOCUS	GAPS	OPPORTUNITIES
Provide early assessments	• Lack of proactive care planning and response • Assessments early in care journey are not routinely done due to limitations in eligibility criteria and intake processes • Service eligibility does not support palliative approach	• Remote self-reporting of symptoms • Virtual system assessment and management • Edmonton Symptom Assessment System (ESAS-R)
Consider all providers	• Lack of opportunities and mechanisms for shared decision-making • Disconnect with primary health care • Changes in care plan not communicated to all members	• Assessment and care planning tools • Enhanced circle of care • Collaborative clinical partnerships
Use appropriate tools	• Varying competency of front-line home care providers in using tools • Limited recognition and inclusion of family/caregiver needs—lack of understanding/awareness of individual context • Lack of standardized assessment tools for all health care providers	• Whole Community Palliative Rounds • In-home rural palliative care program • 24/7 consults with palliative care specialists



Identify
Early assessments

OPPORTUNITIES
- Remote self-reporting of symptoms
- Virtual system assessment and management
- Edmonton Symptom Assessment System (ESAS -R)

"My aunt turned down palliative care for too long, thinking it was only for when you were on your death bed. This thinking was never questioned, discussed or revised by her medical team. I was the one who took the bull by the horns and made it happen."

"Every visit started with 'How is your day today? What can we do or work on and make it better?' I had a real sense that they were there to give Sam what she needed to turn the day around."

"The pressure on family is immense! We need trained assessors who can identify family coping, exhaustion and resilience."

GAPS
- Lack of PROACTIVE care planning and response
- Assessments early in care journey NOT ROUTINE
- Service ELIGIBILITY does not support palliative approach

Include
Consider all providers

OPPORTUNITIES
- Lots of assessment and care planning tools
- Enhanced 'Circle of Care'
- Collaborative clinical partnerships

"The nights were by far the worst. It was like being in a life raft at night in the middle of a black ocean and the sharks were circling. And there was no help."

"She really had a team around her and I was part of it. I was asked about what I thought. I felt I was an equal member of the team."

"A palliative care team that knows what they're doing makes all the difference. Nothing was left undone, questions were answered with confidence, we got everything we needed."

GAPS
- Lack of shared DECISION-MAKING
- DISCONNECT with primary health care
- Changes in CARE PLAN not communicated

Implement
Use appropriate tools

OPPORTUNITIES
- Whole Community Palliative Rounds
- In-home rural palliative care program
- 24/7 consults with palliative care specialists

"Every time the nurse came, she asked questions, sometimes the same, sometimes different. The doctor would ask questions. Always lots of questions."

"We are sometimes overwhelmed with so many assessment tools – try to standardize and provide help on how to use them."

"Our nurses and palliative care doctor made all the difference. Without them I don't know how we would have done it."

GAPS
- COMPETENCY of frontline home care providers
- Limited RECOGNITION and INCLUSION of family/caregiver needs
- STANDARDIZED assessment tools for all health care providers

EARLY ASSESSMENT AND MULTI-DISCIPLINARY CARE PLANNING

Early assessment and response to patients' needs is an important part of home-base palliative care.

This Experience Map is a visual representation of opportunities and gaps shared by subject matters experts, patients and caregivers on early identification of patient needs and reflecting those needs into shared care plans. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys of caregivers and patients. Input was validated through E-Delphi survey with a panel of experts.

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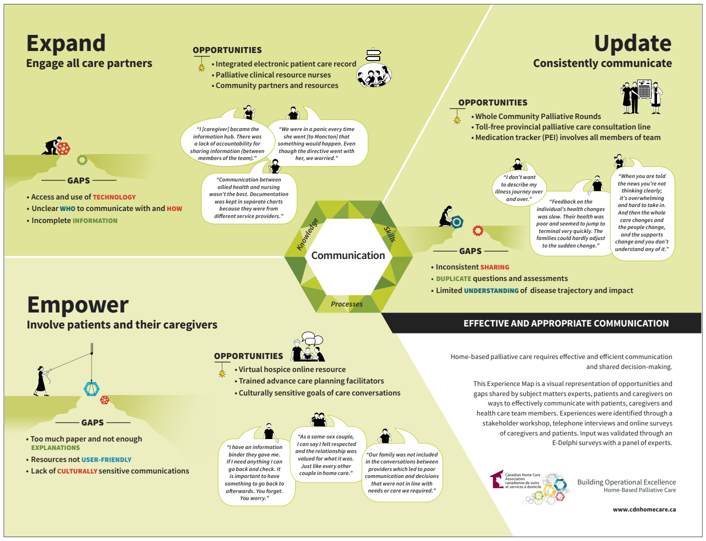
Effective Communication Strategies and Tactics

Home-based palliative care requires effective communication, shared decision-making and efficient care coordination among the health care provider team, the patient and their caregivers. Patients and caregivers often experience information overload, especially when transitioning from curative to palliative care.

It was suggested that closed-loop communication strategies can potentially help avoid misunderstandings and establish trust with patients and caregivers. Other areas for improvement included processes to rapidly and effectively share information between home care, acute care, primary care, palliative specialists and community paramedics; user-friendly, practical and timely resources for family caregivers; communications that are culturally sensitive and use respectful language about the individual's identity; and providing a single point of access such as a palliative care nurse navigator. The experience map identified three areas of focus, as outlined in the following table.

AREA OF FOCUS	GAPS	OPPORTUNITIES
Engage all care partners	• Lack of access to and use of technology • Unclear who to communicate with and how • Incomplete information	• Integrated electronic patient care record • Palliative clinical resource nurses • Community partners and resources
Consistently communicate	• Inconsistent sharing—communication across transitions is fragmented • Duplicate questions and assessments • Limited understanding of disease trajectory and impact	• Whole Community Palliative Rounds • Toll-free provincial palliative care consultation line • Medication tracker involving all members of team
Involve patients and their caregivers	• Too much paper and not enough explanations • Resources not user-friendly • Lack of culturally sensitive communications	• Virtual hospice online resource • Trained advance care planning facilitators • Culturally sensitive goals-of-care conversations



Expand
Engage all care partners

OPPORTUNITIES
- Integrated electronic patient care record
- Palliative clinical resource nurses
- Community partners and resources

"I [caregiver] became the information hub. There was a lack of accountability for sharing information (between members of the team)."

"We were in a panic every time she went [to Moncton] that something would happen. Even though the directive went with her, we worried."

"Communication between allied health and nursing wasn't the best. Documentation was kept in separate charts because they were from different service providers."

GAPS
- Access and use of TECHNOLOGY
- Unclear WHO to communicate with and HOW
- Incomplete INFORMATION

Update
Consistently communicate

OPPORTUNITIES
- Whole Community Palliative Rounds
- Toll-free provincial palliative care consultation line
- Medication tracker (PEI) involves all members of team

"I don't want to describe my illness journey over and over."

"Feedback on the individual's health changes was slow. Their health was poor and seemed to jump to terminal very quickly. The families could hardly adjust to the sudden change."

"When you are told the news you're not thinking clearly; it's overwhelming and hard to take in. And then the whole care changes and the people change, and the supports change and you don't understand any of it."

GAPS
- Inconsistent SHARING
- DUPLICATE questions and assessments
- Limited UNDERSTANDING of disease trajectory and impact

Empower
Involve patients and their caregivers

OPPORTUNITIES
- Virtual hospice online resource
- Trained advance care planning facilitators
- Culturally sensitive goals of care conversations

GAPS
- Too much paper and not enough EXPLANATIONS
- Resources not USER-FRIENDLY
- Lack of CULTURALLY sensitive communications

"I have an information binder they gave me. If I need anything I can go back and check. It is important to have something to go back to afterwards. You forget. You worry."

"As a same-sex couple, I can say I felt respected and the relationship was valued for what it was. Just like every other couple in home care."

"Our family was not included in the conversations between providers which led to poor communication and decisions that were not in line with needs or care we required."

EFFECTIVE AND APPROPRIATE COMMUNICATION

Home-based palliative care requires effective and efficient communication and shared decision-making.

This Experience Map is a visual representation of opportunities and gaps shared by subject matters experts, patients and caregivers on ways to effectively communicate with patients, caregivers and health care team members. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys of caregivers and patients. Input was validated through an E-Delphi surveys with a panel of experts.

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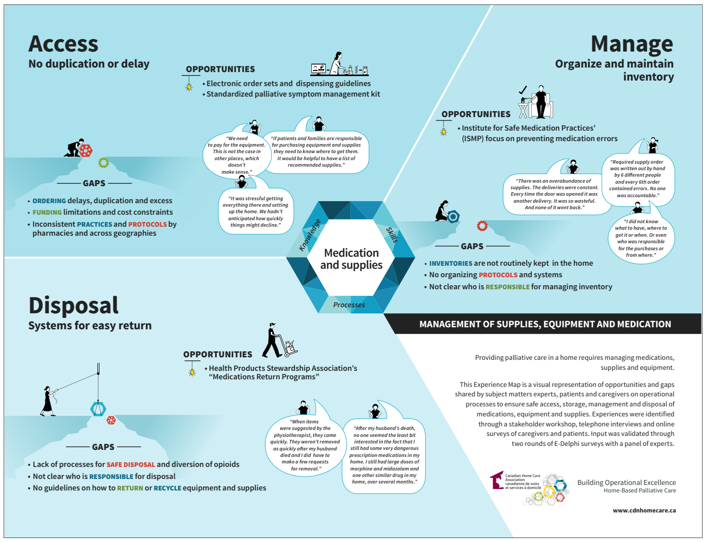
Supplies, Equipment and Medications

An important part of home-based palliative care is the safe and effective management and disposal of equipment, supplies and medication. Patients and caregivers experience the burden of not only purchasing equipment, but also ensuring its removal and safe disposal. Several strategies can ease the burden on caregivers and make the care process more efficient, such as implementing processes to ensure that necessary medications are on-site in the home without duplication or delay; ensuring cost-effective and user-friendly processes and protocols for returning and/or recycling of supplies, equipment and medications; and implementing systems to organize supplies and medications in the home for quick and easy access and effective inventory management. The experience map identified three areas of focus, as outlined in the following table.

AREA OF FOCUS	GAPS	OPPORTUNITIES
Ensure no duplication or delay	• Ordering delays, duplication and excess • Funding limitations and cost constraints • Inconsistent practices and protocols by pharmacies and across geographies	• Electronic order sets and dispensing guidelines • Standardized palliative symptom management kit
Organize and maintain inventory	• Inventories are not routinely kept in the home • No organizing protocols and systems • Not clear who is responsible for managing inventory	• Institute for Safe Medication Practices' focus on preventing medication errors
Implement systems for easy return	• Lack of processes for safe disposal and diversion of opioids • Not clear who is responsible for disposal • No guidelines on how to return or recycle equipment and supplies	• Health Products Stewardship Association's "Medications Return Programs"



"We need to pay for the equipment. This is not the case in other places, which doesn't make sense."

"If patients and families are responsible for purchasing equipment and supplies they need to know where to get them. It would be helpful to have a list of recommended supplies."

"It was stressful getting everything there and setting up the home. We hadn't anticipated how quickly things might decline."

"There was an overabundance of supplies. The deliveries were constant. Every time the door was opened it was another delivery. It was so wasteful. And none of it went back."

"Required supply order was written out by hand by 6 different people and every 6th order contained errors. No one was accountable."

"I did not know what to have, where to get it or when. Or even who was responsible for the purchases or from where."

"When items were suggested by the physiotherapist, they came quickly. They weren't removed as quickly after my husband died and I did have to make a few requests for removal."

"After my husband's death, no one seemed the least bit interested in the fact that I still had some very dangerous prescription medications in my home. I still had large doses of morphine and midazolam and one other similar drug in my home, over several months."

Providing palliative care in a home requires managing medications, supplies and equipment.

This Experience Map is a visual representation of opportunities and gaps shared by subject matters experts, patients and caregivers on operational processes to ensure safe access, storage, management and disposal of medications, equipment and supplies. Experiences were identified through a stakeholder workshop, telephone interviews and online surveys of caregivers and patients. Input was validated through two rounds of E-Delphi surveys with a panel of experts.

KNOWLEDGE TRANSLATION AND DISSEMINATION OF EXPERIENCE MAPS

The CHCA used a variety of methods and messages to ensure wide dissemination of the experience maps to a broad range of stakeholders.

Featuring Caregiver Experiences in National Carers Day Campaign 2019

- The theme of the National Carers Day 2019 campaign was Caregiver Experiences in Home-Based Palliative Care. This campaign featured 46 organizations from across the country and increased awareness of the experiences and roles of caregivers, as well as facilitating connections to resources to support end-of-life caregiving.
- The experience map showing experiences of caregivers in home-based palliative care was used to inform the communication toolkit for participating stakeholders, which included 1,628 individuals (CHCA members and stakeholders were involved in the consultation process for the Operational Excellence Project).
- The experience map was shared as a web page on the Carers Canada site and through web banners and Twitter badges..
- Two infographics were produced to highlight caregiver experiences in home-based palliative care:
  - The first infographic provided an overview of access to palliative care across different settings in Canada. To view the infographic, click here
  - The other infographic showed experiences of caregivers in home-based palliative care. To view the infographic, click here

Targeting Home Care Providers, Administrators and Policy Planning

CHCA Virtual Learning Series webinars

- Learnings from the project and feedback received from caregivers about their experience in receiving home-based palliative care was shared through the webinar, My Caring Experience Matters.
  - Jeanne Bank, Project Lead, shared findings from consultation with caregivers regarding gaps and opportunities in home-based palliative care.
  - 118 participants attended this webinar, representing service providers and regional health authorities from across the country, including Ontario, Alberta, Saskatchewan, British Columbia, Newfoundland and Labrador, and New Brunswick.
  - To view the webinar slides, click here To watch the presentation, click here

- Experience maps were included as part of introduction in the webinars featured through the CHCA Virtual Learning Series. Participants in these webinars included service providers; representatives of regional health authorities across the country; representatives of national organizations such as Alzheimer's Society of Canada, Canadian Foundation for Healthcare Improvement, Pallium Canada and Canadian Virtual Hospice; and researchers from leading Canadian universities, including McMaster University, University of Calgary and University of Toronto. There was a high rate of attendance at each of these five webinars:
  - 147 participants attended the Whole Community Palliative Rounds webinar on May 14, 2019.
  - 143 participants attended the Rural Palliative Care In-Home Funding Program webinar on June 4, 2019.
  - 146 participants attended the INSPIRED COPD Outreach Program webinar on July 9, 2019.
  - 118 participants attended the Virtual Palliative Care webinar presented on September 24, 2019.
  - 148 participants attended the Integrating a Palliative Approach to Care by having Conversations Early (IPACE) webinar presented on October 29, 2019.

Targeted e-blasts to CHCA membership network

Electronic versions of the experience maps were shared with a network of 2,200 stakeholders with a click-through rate of 33% (providing direct access to the online experience maps).

Building Awareness with National NGOs

Quality End-Of-Life Care Coalition of Canada (QELCCC) Annual Meeting
The project findings and experience maps were profiled at the QELCCC annual meeting. The QELCCC is a group of 35 national organizations dedicated to improving end-of-life care for all Canadians.

Presenting the Experience Maps to Palliative Care Stakeholders

Canadian Hospice Palliative Care Association (CHPCA) Annual Conference
The project findings, including the experience maps, were profiled at the CHPCA Annual Conference in September 2019. This national conference focused on hospice palliative care and was attended by 400 delegates with representatives from Canada and abroad. The attendees included doctors, nurses, social workers, other allied health care providers, researchers, educators and administrators.

- Conference delegates were encouraged to engage in a booth activity in which they were asked to find solutions to the gaps highlighted in the experience maps. This provided an opportunity for the CHCA to have targeted conversations about home-based palliative care.
  The CHCA CEO presented project findings during a concurrent session attended by 52 participants. Following the presentation, the exhibit booth experienced significant interest in the project. Approximately 195 stakeholders visited the booth during the two-day conference.
- Several stakeholders expressed interest in knowing more about the project and completed a form with their contact information to keep in touch regarding project updates. This included Yukon Department of Health, Southern Health (Manitoba), BC Centre for Palliative Care and McMaster University.

Phase 2: Identification and Dissemination of Operational Innovations

Call for Leading Practices

Building on the knowledge gained through the extensive consultations, the CHCA conducted a national call for operational innovations in home-based palliative care. The call focused on finding leading practices that address the gaps identified in the experience maps. These included:

Inclusion of advance care plans into the delivery of care in the home

- Ways to support conversations about end-of-life wishes with front-line staff, patients and caregivers
- Care planning approaches that incorporate advance care wishes
- Process for ensuring front-line staff understand and respond to an individual's wishes at end of life

Assessment and care planning

- Early identification and response to the needs of individuals with life-limiting illness
- Assessment tools that provide a comprehensive understanding of patients' needs
- Process to make sure the patient and caregiver are both included in the development and updating of the care plan

Effective communication strategies and tactics

- Ways to share information and communicate changes in the patient's condition to the individual, caregiver and all members of the care team
- Process to rapidly and effectively share information between home care, acute care, primary care, palliative specialists and community paramedics (urban and rural considerations)
- Information and resources designed for family caregivers that are user-friendly and practical

Supplies, equipment and medication management

- Process to ensure necessary equipment, supplies and medication are on-site in the home (without duplication or delay)
- Systems to help organize supplies and medication in the home for quick and easy access and effective inventory management
- Protocols or processes for returning and/or recycling of supplies, equipment and medications that are cost-effective and user-friendly

An online submission process through the CHCA website was set up to collect responses from stakeholders across the country. The call remained open from August 15, 2018 to September 14, 2018, and was promoted through the CHCA membership network and knowledge translation stakeholders. A targeted request of submissions was also made by directly reaching out to consultation participants who shared leading practices during the workshop sessions (described earlier). A total of 47 submissions were received, 26 through the open call and 21 through the targeted call.

The project team evaluated the innovations using the following criteria:

- Piloted or implemented in Canada
- Developed with stakeholder input
- Evaluated results and demonstrated outcomes
- Addresses one or more of the designated areas for improvement
- Supports the Harmonized Principles for Home Care in Canada (e.g., person- and family-centred care, accessible care, accountable care, evidence-informed care, integrated care and sustainable care)

Twenty-four leading practices were chosen, and successful organizations were notified and scheduled to present at the 2018 Home Care Summits in either Charlottetown, PEI (October 1–2) or Vancouver, BC (October 22–23). A total of 22 practices from across the country were profiled because presenters from two groups were unable to attend the event.

The following table lists the leading practices that address the four priority areas.

PRIORITY AREA	LEADING PRACTICES
Advance Care Planning	Access to Advice and Advance Care Planning – An Edmonton Perspective, *Alberta Health Services*
	Utilizing Interpreters to Support Culturally Sensitive Goals of Care/Advance Care Planning Discussions, *Vancouver Coastal Health*
	Responding to Policy Issues: How a Provincial Advance Care Planning/Goals of Care Designation Community of Practice Promotes Excellence, *Alberta Health Services*
	Rural in-Home Palliative Care Program, *Alberta Health Services*
	Integrating a Palliative Approach to Care by Having Conversations Early (IPACE), *Vancouver Coastal Health*
	Advance Care Planning Framework, *Fraser Health, British Columbia*
Assessment and Delivery	Telepalliative Care, *Champlain LHIN, Ontario*
	Integrated Palliative Care Approach in Home Care, *New Brunswick*
	Virtual Palliative Care: Right Patient, Right Time, Right Place, Right Care, *William Osler Health System, Ontario*
	Continuum of Care for Clients with Advanced Heart Failure, I*nstitut de Cardiologie de Montréal* and the *Société des Soins Palliatifs à domicile du Grand Montréal*
Equipment and Medication	End-of-Life Symptom Management Kit for use at Home in Rural Northwestern Ontario, *North West LHIN*
	Cost Benefit of Elastomeric Infusors in a Residential Palliative Care Setting, *The Hospice of Windsor and Essex County*
	Using Electronic Clinical Management Systems to Drive Best Practices in Palliative Care, *Bayshore Health Care, Ontario*
Communication	Whole Community Palliative Rounding: An Innovative, Collaborative Approach for Rural BC, *Interior Health*
	Reducing the Silo Mentality, *SPLC Geriatric Assessment & Intervention Network, Ontario*
	Integrated Palliative Care Approach in Home Care, *VHA Home HealthCare, Ontario*
	Spectrum Health Care's Operational Excellence in MAiD, *Spectrum Health Care, Ontario*
	The Integration of Palliative Home Care Services and Acute Care Teams in the Provision of Medical Assistance in Dying in the Community, *Champlain LHIN, Ontario*
	The INSPIRED COPD Outreach Program™: Role of the Advance Care Planning Facilitator, *Nova Scotia*
	Redefining the Circle of Care, *Interior Health, British Columbia*
	Provincial Palliative Care Consultation Phone Line, *Vancouver Coastal Health*
	The New Normal: The Palliative Clinical Resource Nurse Role in Community Home Health, *Vancouver Coastal Health*

High Impact Practices

Sharing of knowledge and best practices among home and community-care providers across the country is an effective strategy for strengthening and accelerating the development of operational excellence in palliative care. Through the identification, documentation and dissemination of leading practices, stakeholders can access expertise to address common challenges.

CHCA High Impact Practices (HIP) are evidence-informed practices that improve the effectiveness and efficiency of home care. By identifying and disseminating these practices, the CHCA advances excellence and facilitates the scaling and spreading of promising practices across the country. The CHCA uses a collaborative process to develop these knowledge translation tools, which requires expertise and experience of both the writer and key informant teams involved in the practice. HIPs are developed in a concise (2500–3000 words) and clear format over a period of 6–8 weeks that includes interviewing, researching, writing, verifying content, editing and final layout.

From the 22 leading practices, a panel of experts selected five practices to be profiled as HIPs. The project lead and content writer developed an evaluation matrix and template for the final selection of the HIPs. The project advisory committee evaluated these 10 initiatives using the following criteria to select the five leading practices to be profiled as HIPs:

1. APPLICATION AND RELEVANCE – The degree to which the practice addresses one of the common operational gaps in home-based palliative care:
    - Assessment and care planning
    - Inclusion of advance care plans into care delivery
    - Effective communication strategies and tactics
2. EVIDENCE-BASED – The degree to which the program is based on evidence (i.e., reflects research evidence, clinical expertise, patients' experience)
3. STAKEHOLDER ENGAGEMENT – The degree to which policy-makers, service providers, patients and caregivers are actively engaged in the program (e.g., co-design, active part of program)
4. IMPACT – The degree to which the operational practice is evaluated and has clearly documented outcomes (i.e., qualitative and quantitative measurements)
5. SUSTAINABILITY – The degree to which the operational practice demonstrates/has the potential to spread further beyond its current site, across sectors and/or care settings
6. CLARITY – The degree to which the submission clearly and comprehensively describes the operational practice
7. INTEREST – The degree to which the submission captures interest and desire to learn further about the operational practice

The following five leading practices were profiled as HIPs.

Whole Community Palliative Rounds

An innovative approach to interprofessional communication, shared decision-making and rapid clinical problem-solving for symptom burden in high-risk individuals who require palliative care services.

Goal: To enable rapid clinical problem-solving for symptom burden in high-risk individuals, purposeful and timely communication, shared decision-making and collaborative care planning among members of an interprofessional care team.

Target population: Individuals and their families who:

- present with transitioning or unstable physical symptoms (e.g., ESAS-r 4 or greater);
- are experiencing challenges with care management and planning;
- present with psychosocial, emotional, spiritual, financial or other care needs that are complicated and require an interprofessional solution-oriented approach; and
- are transitioning between sectors of care and require planning and communication from a whole community approach.

Key outcomes:

- The number of communities hosting a WCPR ("hubs") throughout British Columbia's Interior Health has grown from four to nine, with an additional eight communities exploring possible development and implementation.
- Internal and external health care team members are consistently attending the weekly WCPR.
- The number of weekly referrals has increased.

Building
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Home-Based Palliative Care

HIGH IMPACT PRACTICES
Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

Whole Community Palliative Rounds
An innovative approach to inter-professional care planning and delivery in Interior Health

Whole Community Palliative Rounds is a strategy to enable rapid clinical problem-solving for symptom burden in high-risk individuals, purposeful and timely communication, shared decision-making and collaborative care planning among members of an inter-professional care team. **This High Impact Practice showcases how Interior Health in British Columbia has successfully implemented this strategy.**

BACKGROUND

People with palliative needs and their families often experience periods of escalating and fluctuating symptom burden[i] as their illness advances. Responding to the complex needs of the individual's physical and psychological symptoms requires coordinated and active involvement between the person, their caregiver(s) and an inter-professional health and social care team. Lack of communication structure, inadequate sharing of clinical information, poor reconciliation of medicines and duplicate or missing assessments are among the operational gaps that leave many people with palliative needs and their caregivers experiencing fragmented and poorly integrated care.[ii]

Ensuring responsive, coordinated care for individuals receiving palliative care throughout the Interior Health (IH) region is a challenge given the large geography (215,000 sq. km) and low population density (3.5 people per sq. km) In 2017, the population of the region was 749,853 (15% of the BC population), with an average life expectancy of 81 years. With a 21% expected growth rate for individuals aged 75+ and a 17% expected growth for individuals aged 85+, the demand for quality palliative care services in the area will increase over the coming years.[iii] In anticipation of this challenge, IH has embraced a primary generalist palliative model with consultation services to serve the majority of people living in small communities.

The BC Ministry of Health's *2018/19-2020/21 Service Plan*[iv] emphasizes the importance of transformational health system redesign across metro, urban, rural and remote communities. Creating team-based care with linkages to specialized services was identified as a key priority. In response to this strategic directive, IH committed to an inter-professional integrated approach to care. Specific to palliative care, this emphasizes active symptom management for individuals and their families. Whole Community Palliative Rounds (WCPR) is one of the strategies IH has developed and implemented to meet this goal.

This inclusive approach reflects the reality that we all experience and define our lives within the context of our relationships. Professionals from various health sectors and programs, as well as community partners are all included. The goal is to encourage collaborative input into the discussion and management of an individual's symptom burden and ultimately their quality of life and well-being.

Under the guidance of the IH Regional Palliative and End -of-Life Care Team, the concepts of "whole community" and "palliative rounds" were adapted to meet the needs of the palliative population, particularly for rural and remote areas.

"Whole Community"
Recognizes the inter-relationship and connections between formal and informal care (volunteers, family, friends) across all care settings.

"Palliative Rounds"
An expanded inter-professional team (circle of care) across health sectors, programs and disciplines focused on providing the best supports for the palliative population.

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Building Operational Excellence: Home-Based Palliative Care builds on "The Way Forward: An Integrated Palliative Approach to Care" by identifying innovative operational practices to address specific service gaps and improve the quality, efficiency and accessibility of home-based palliative care. The project is supported through a health funding contribution agreement from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Available in English and French

Rural Palliative Care In-Home Funding Program–Calgary Zone

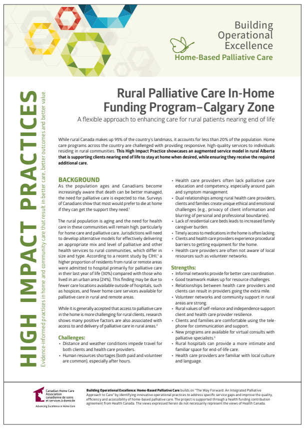
An augmented service model in rural Alberta that supports clients nearing end of life to stay at home when desired, while ensuring they receive the required additional care.

Goal: To augment rural home care services and resources for palliative clients in order to reduce rural–urban inequities.

Target Population: Any client with a progressive, life-limiting illness living at home in the rural Calgary Zone.

Key outcomes:

- Survey results showed that the ability to hire 24-hour care is an important feature for many clients and families. Even if clients and families did not take advantage of the extra funding and care, just knowing that it existed provided them with peace of mind and confidence to manage at home.
- From its launch in October 2017 until March 31, 2019, the program has served a total of 104 clients and families. Clients received extra care for an average of four days and survived a median of 21 days from the time the funding was first accessed. Out of a total of 94 deaths, 52% took place at home and 40% in a hospice. Only seven clients died in acute care.



Building
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HIGH IMPACT PRACTICES
Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

Rural Palliative Care In-Home Funding Program–Calgary Zone
A flexible approach to enhancing care for rural patients nearing end of life

While rural Canada makes up 95% of the country's landmass, it accounts for less than 20% of the population. Home care programs across the country are challenged with providing responsive, high-quality services to individuals residing in rural communities. **This High Impact Practice showcases an augmented service model in rural Alberta that is supporting clients nearing end of life to stay at home when desired, while ensuring they receive the required additional care.**

BACKGROUND

As the population ages and Canadians become increasingly aware that death can be better managed, the need for palliative care is expected to rise. Surveys of Canadians show that most would prefer to die at home if they can get the support they need.[1]

The rural population is aging and the need for health care in these communities will remain high, particularly for home care and palliative care. Jurisdictions will need to develop alternative models for effectively delivering an appropriate mix and level of palliative and other health services to rural communities, which differ in size and type. According to a recent study by CIHI,[1] a higher proportion of residents from rural or remote areas were admitted to hospital primarily for palliative care in their last year of life (30%) compared with those who lived in an urban area (24%). This finding may be due to fewer care locations available outside of hospitals, such as hospices, and fewer home care services available for palliative care in rural and remote areas.

While it is generally accepted that access to palliative care in the home is more challenging for rural clients, research shows many positive factors are also associated with access to and delivery of palliative care in rural areas.[2]

Challenges:

- Distance and weather conditions impede travel for both clients and health care providers.
- Human resources shortages (both paid and volunteer are common), especially after hours.
- Health care providers often lack palliative care education and competency, especially around pain and symptom management.
- Dual relationships among rural health care providers, clients and families create unique ethical and emotional challenges (e.g., privacy of client information and blurring of personal and professional boundaries).
- Lack of residential care beds leads to increased family caregiver burden.
- Timely access to medications in the home is often lacking.
- Clients and health care providers experience procedural barriers to getting equipment for the home.
- Health care providers are often not aware of local resources such as volunteer networks.

Strengths:

- Informal networks provide for better care coordination .
- Good teamwork makes up for resource challenges.
- Relationships between health care providers and clients can result in providers going the extra mile.
- Volunteer networks and community support in rural areas are strong.
- Rural values of self-reliance and independence support client and health care provider resilience.
- Clients and families are comfortable using the telephone for communication and support.
- New programs are available for virtual consults with palliative specialists.[3]
- Rural hospitals can provide a more intimate and familiar space for end-of-life care.
- Health care providers are familiar with local culture and language.

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Advancing Excellence in Home Care

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Available in English and French

The INSPIRED COPD Outreach Program ™

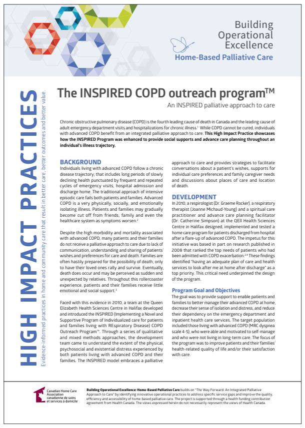
An enhanced program to provide social supports and advance care planning for individuals with advanced COPD who would benefit from an integrated palliative approach to care.

Goal: To provide support to enable patients and families to better manage their advanced COPD at home, decrease their sense of isolation and distress, and reduce their dependency on the emergency department and inpatient health care services. The focus was on improving patients' and their families' health-related quality of life and/or their satisfaction with care.

Target population: Individuals living with advanced COPD (MRC dyspnea scale 4-5) who are able and motivated to self-manage and who are not living in long-term care.

Key outcomes:

- There has been a 50–70% reduction in facility reliance and a total cost aversion over 6 months of $1.23 million. This amounts to 2–3 times the program costs.
- Patient and family feedback has been very positive, showing new confidence in self-management and sustained optimism.



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Home-Based Palliative Care

HIGH IMPACT PRACTICES

Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

The INSPIRED COPD outreach program™

An INSPIRED palliative approach to care

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in Canada and the leading cause of adult emergency department visits and hospitalizations for chronic illness.[1] While COPD cannot be cured, individuals with advanced COPD benefit from an integrated palliative approach to care. **This High Impact Practice showcases how the INSPIRED Program was enhanced to provide social supports and advance care planning throughout an individual's illness trajectory.**

BACKGROUND

Individuals living with advanced COPD follow a chronic disease trajectory; that includes long periods of slowly declining health punctuated by frequent and repeated cycles of emergency visits, hospital admission and discharge home. The traditional approach of intensive episodic care fails both patients and families. Advanced COPD is a very physically, socially, and emotionally isolating illness. Patients and families may gradually become cut off from friends, family and even the healthcare system as symptoms worsen.[2]

Despite the high morbidity and mortality associated with advanced COPD, many patients and their families do not receive a palliative approach to care due to lack of communication, understanding and sharing of patients' wishes and preferences for care and death. Families are often hastily prepared for the possibility of death, only to have their loved ones rally and survive. Eventually, death does occur and may be perceived as sudden and unexpected by relatives. Throughout this rollercoaster experience, patients and their families receive little emotional and social support.[2]

Faced with this evidence in 2010, a team at the Queen Elizabeth Health Sciences Centre in Halifax developed and introduced the INSPIRED (Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease) COPD Outreach Program™. Through a series of qualitative and mixed methods approaches, the development team came to understand the extent of the physical, psychosocial and existential distress experienced by both patients living with advanced COPD and their families. The INSPIRED model embraces a palliative approach to care and provides strategies to facilitate conversations about a patient's wishes, supports for individual care preferences and family caregiver needs and discussions about places of care and location of death.

DEVELOPMENT

In 2010, a respirologist (Dr. Graeme Rocker), a respiratory therapist (Joanne Michaud-Young) and a spiritual care practitioner and advance care planning facilitator (Dr. Catherine Simpson) at the QEII Health Sciences Centre in Halifax designed, implemented and tested a home care program for patients discharged from hospital after a flare-up of advanced COPD. The impetus for this initiative was based in part on research published in 2008 that ranked the top needs of patients who had been admitted with COPD exacerbation.[2,4] These findings identified "having an adequate plan of care and health services to look after me at home after discharge" as a top priority. This critical need underpinned the design of the program.

Program Goal and Objectives

The goal was to provide support to enable patients and families to better manage their advanced COPD at home, decrease their sense of isolation and distress, and reduce their dependency on the emergency department and inpatient health care services. The target population included those living with advanced COPD (MRC dyspnea scale 4-5), who were able and motivated to self-manage and who were not living in long-term care. The focus of the program was to improve patients and their families' health-related quality of life and/or their satisfaction with care.

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Available in English and French

Virtual Palliative Care Intervention

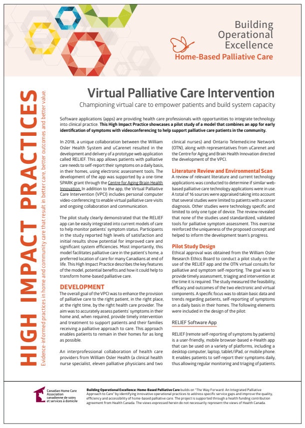
An innovative model that combines an app for early identification of symptoms with videoconferencing to help support palliative care patients in the community.

Goal: To accurately assess patients' symptoms in their home and, when required, provide timely intervention and treatment to support patients and their families receiving a palliative approach to care. This approach enables patients to remain in their homes for as long as possible.

Target population: Existing and newly referred patients to the Brampton Civic Hospital Supportive Palliative Clinic, patients with palliative care needs enrolled in an outpatient clinic/or community service and/or accessing home and community care services.

Key outcomes:

- Efficiency and access to care improved as daily reporting of symptoms led to early identification of symptoms, before symptoms escalated, which resulted in fewer ER visits (during the study there were 0 ER visits).
- Patients indicated increased satisfaction from ease of use of supports.
- 92% of clinicians reported improved confidence and 75% of clinicians felt the tool improved quality of care.



Building
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HIGH IMPACT PRACTICES

Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

Virtual Palliative Care Intervention

Championing virtual care to empower patients and build system capacity

Software applications (apps) are providing health care professionals with opportunities to integrate technology into clinical practice. **This High Impact Practice showcases a pilot study of a model that combines an app for early identification of symptoms with videoconferencing to help support palliative care patients in the community.**

In 2018, a unique collaboration between the William Osler Health System and uCarenet resulted in the development and delivery of a prototype web application called RELIEF. This app allows patients with palliative care needs to self-report their symptoms on a daily basis, in their homes, using electronic assessment tools. The development of the app was supported by a one-time SPARK grant through the Centre for Aging Brain Health Innovation. In addition to the app, the Virtual Palliative Care Intervention (VPCI) includes personal computer video-conferencing to enable virtual palliative care visits and ongoing collaboration and communication.

The pilot study clearly demonstrated that the RELIEF app can be easily integrated into current models of care to help monitor patients' symptom status. Participants in the study reported high levels of satisfaction and initial results show potential for improved care and significant system efficiencies. Most importantly, this model facilitates palliative care in the patient's home, a preferred location of care for many Canadians at end of life. This High Impact Practice describes the key features of the model, potential benefits and how it could help to transform home-based palliative care.

DEVELOPMENT

The overall goal of the VPCI was to enhance the provision of palliative care to the right patient, in the right place, at the right time, by the right health care provider. The aim was to accurately assess patients' symptoms in their home and, when required, provide timely intervention and treatment to support patients and their families receiving a palliative approach to care. This approach enables patients to remain in their homes for as long as possible.

An interprofessional collaboration of health care providers from William Osler Health (a clinical health nurse specialist, eleven palliative physicians and two clinical nurses) and Ontario Telemedicine Network (OTN), along with representatives from uCarenet and the Centre for Aging and Brain Health Innovation directed the development of the VPCI.

Literature Review and Environmental Scan

A review of relevant literature and current technology applications was conducted to determine if similar web-based palliative care technology applications were in use. A total of 16 sources were appraised taking into account that several studies were limited to patients with a cancer diagnosis. Other studies were technology specific and limited to only one type of device. The review revealed that none of the studies used standardized, validated tools for palliative symptom assessment. This exercise reinforced the uniqueness of the proposed concept and helped to inform the development team's progress.

Pilot Study Design

Ethical approval was obtained from the William Osler Research Ethics Board to conduct a pilot study on the use of the RELIEF app and the OTN virtual consults for palliative and symptom self-reporting. The goal was to provide timely assessment, triaging and intervention at the time it is required. The study measured the feasibility, efficacy and outcomes of the two electronic and virtual components. A specific focus was to obtain basic data and trends regarding patients, self-reporting of symptoms on a daily basis in their homes. The following elements were included in the design of the pilot:

RELIEF Software App

RELIEF (remote self-reporting of symptoms by patients) is a user-friendly, mobile browser-based e-Health app that can be used on a variety of platforms, including a desktop computer, laptop, tablet/iPad, or mobile phone. It enables patients to self-report their symptoms daily, thus allowing regular monitoring and triaging of patients.

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Implementing a Palliative Approach to Care by Having Conversations Early (IPACE)

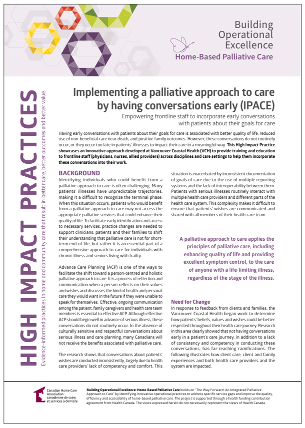
An innovative approach to providing training and education to front-line staff (physicians, nurses, allied providers) across disciplines and care settings to help them incorporate early conversations with patients about their goals for care into their work.

Goal: To increase clinical capacity and competency to facilitate patient conversations. The objectives for the pilot phase were as follows:

- Identify clients who could benefit from a palliative approach to care.
- Hold regular and consistent goals of care conversations with clients and families that were documented and respected.
- Provide timely, coordinated quality of care for patients receiving end-of-life care at home or in hospice.
- Facilitate appropriate referrals to community-based services.
- Decrease inappropriate emergency and hospital-based care for end-of-life patients.

Key outcomes

- Staff increased their confidence and competence in identifying patients who could benefit from a palliative care approach and in holding serious illness conversations.
- There was a 33% increase in documented Goals of Care plans.
- Records show that patients are more likely to die at home or in a hospice.



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HIGH IMPACT PRACTICES

Evidence-informed practices in home and community care that result in better care, better outcomes and better value.

Implementing a palliative approach to care by having conversations early (IPACE)

Empowering frontline staff to incorporate early conversations with patients about their goals for care

Having early conversations with patients about their goals for care is associated with better quality of life, reduced use of non-beneficial care near death, and positive family outcomes. However, these conversations do not routinely occur, or they occur too late in patients' illnesses to impact their care in a meaningful way. **This High Impact Practice showcases an innovative approach developed at Vancouver Coastal Health (VCH) to provide training and education to frontline staff (physicians, nurses, allied providers) across disciplines and care settings to help them incorporate these conversations into their work.**

BACKGROUND

Identifying individuals who could benefit from a palliative approach to care is often challenging. Many patients' illnesses have unpredictable trajectories, making it a difficult to recognize the terminal phase. When this situation occurs, patients who would benefit from a palliative approach to care may not access the appropriate palliative services that could enhance their quality of life. To facilitate early identification and access to necessary services, practice changes are needed to support clinicians, patients and their families to shift their understanding that palliative care is not for short-term end-of-life, but rather it is an essential part of a comprehensive approach to care for individuals with chronic illness and seniors living with frailty.

Advance Care Planning (ACP) is one of the ways to facilitate the shift toward a person-centred and holistic palliative approach to care. It is a process of reflection and communication when a person reflects on their values and wishes and discusses the kind of health and personal care they would want in the future if they were unable to speak for themselves. Effective, ongoing communication among the patient, family caregivers and health care team members is essential to effective ACP. Although effective ACP should begin well in advance of serious illness, these conversations do not routinely occur. In the absence of culturally sensitive and respectful conversations about serious illness and care planning, many Canadians will not receive the benefits associated with palliative care.

The research shows that conversations about patients' wishes are conducted inconsistently, largely due to health care providers' lack of competency and comfort. This situation is exacerbated by inconsistent documentation of goals of care due to the use of multiple reporting systems and the lack of interoperability between them. Patients with serious illnesses routinely interact with multiple health care providers and different parts of the health care system. This complexity makes it difficult to ensure that patients' wishes are communicated and shared with all members of their health care team.

A palliative approach to care applies the principles of palliative care, including enhancing quality of life and providing excellent symptom control, to the care of anyone with a life-limiting illness, regardless of the stage of the illness.

Need for Change

In response to feedback from clients and families, the Vancouver Coastal Health began work to determine how patients' beliefs, values and wishes could be better respected throughout their health care journey. Research in this area clearly showed that not having conversations early in a patient's care journey, in addition to a lack of consistency and competency in conducting these conversations, has far-reaching ramifications. The following illustrates how client care, client and family experiences and both health care providers and the system are impacted.

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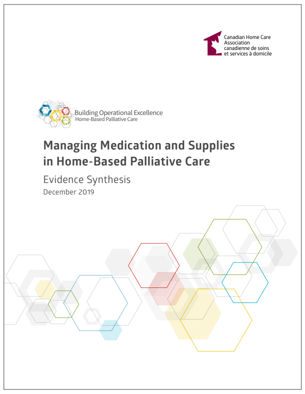
Medication and Supplies Management – Evidence Synthesis

The consultations and e-Delphi process identified numerous gaps and challenges with respect to medication and supplies in home-based palliative care. A limited number of promising practices were identified through the call for innovations process held from August 15–September 15, 2018. Given the importance of this area for operational excellence in home-based palliative care, the CHCA conducted an evidence synthesis on access, management and disposal of medication and supplies in the home setting. The purpose of the synthesis was to gain a better understanding of models, barriers and enablers to access, manage and dispose of medications and supplies through a review of the research evidence and grey literature.

Considering the broad scope of the challenge, it was necessary to narrow the search parameters for the evidence synthesis. The decision was made to exclude equipment from the evidence synthesis, not only to focus the search, but also because there is not as much risk for social harm from the diversion of equipment from the home (e.g., hospital beds, wheelchairs) as there is from used supplies (e.g., medication sharps and used IV bags) and unwanted medications, especially opioids and benzodiazepines.



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Building Operational Excellence
Home-Based Palliative Care

Managing Medication and Supplies in Home-Based Palliative Care

Evidence Synthesis

December 2019

Download Evidence Synthesis: Access, Management and Disposal of Medications and Supplies in Home-Based Palliative Care.

Building on a previous review conducted in May 2019 by the Canadian Agency for Drugs and Technologies in Health (CADTH), the CHCA used the same parameters with a bigger range of synthesized evidence. A total of 103 identified sources were then assessed for relevance. Following the primary relevance assessment, 30 sources remained, and their full-text review eliminated eight more sources. These 22 sources were then critically appraised, leaving 14 sources.

Based on the evidence review, the following key findings of the highest quality and the highest applicability were identified (in order to priority):

- Organizational policies and procedures to manage and monitor controlled drugs for organizations that have access to these drugs
- Structured educational programs to assist patients with medication management
- Use of symptom management kits
- Safe storage of medications and safe disposal of medications

KNOWLEDGE TRANSLATION

Building awareness and understanding of these evidence-informed practices was a key activity in the knowledge translation plan. Applicable to a broad audience (e.g., home care providers, administrators, policy planners, NGOs), the approach to knowledge translation provided opportunities for stakeholders to learn about the innovative models using printed High Impact Practices in addition to live webinars to enable interested stakeholders to ask questions and gain further insight into each practice.

Dissemination of Leading Practices

The 22 leading practices were lived-streamed at the 2018 CHCA Home Care Summits, attended by 386 delegates in addition to 75 virtual participants. The on-demand videos are available HERE (Downloads from the site averaged 120/month between October 1, 2018 and December 31, 2019).

Featuring HIPs in the CHCA Virtual Learning Series and On-Demand Videos WATCH HERE

- 147 participants attended the Whole Community Palliative Rounds webinar presented on May 14, 2019 (sold out capacity of 150), including representatives from regional health authorities across the country, service providers and national organizations such as Accreditation Canada, Institute for Safe Medication Practices Canada, Pallium Canada and Canadian Virtual Hospice.
- 143 participants attended the Rural Palliative Care In-Home Funding Program webinar presented on June 4, 2019 (sold out capacity of 150), including representatives from regional health authorities, service providers, national organizations such as Life and Death Matters, and researchers from leading Canadian universities such as the University of Toronto.
- 146 participants attended The INSPIRED COPD Outreach Program webinar presented on July 9, 2019 (sold out capacity of 150), including representatives from regional health authorities, service providers and national organizations such as Canadian Foundation for Healthcare Improvement.
- 118 participants attended the Virtual Palliative Care webinar presented on September 24, 2019 (sold out capacity of 150), including representatives from regional health authorities, service providers, national organizations such as Canadian Foundation for Healthcare Improvement and researchers from leading Canadian universities such as Queen's University.
- 148 participants attended the Integrating a Palliative Approach to Care by having Conversations Early (IPACE) webinar presented on October 29, 2019 (sold out capacity of 175), including representatives from regional health authorities across the country, service providers and national organizations such as Accreditation Canada and Canadian Hospice Palliative Care Association.

Presenting HIPs at the Canadian Hospice Palliative Care (CHPCA) Annual Conference

The HIPs were profiled at the CHPCA Annual Conference in September 2019. This national conference focused on hospice palliative care and was attended by 400 delegates with representatives from Canada and abroad. The exhibit booth featured a backdrop of all the experience maps and hard copies of the High Impact Practices were available to all interested delegates. During the two-day event, approximately 195 participants stopped by the exhibit booth to learn about the HIPs and take a hard copy.

Sharing User-Friend Infographic on Medication and Supplies Management

The knowledge translation plan identified reaching stakeholders and breaking through the high volume of communication as a continuous challenge. Individuals do not have the time to read lengthy reports and therefore scan documents to gather relevant information. Given the significant yet lengthy content of the evidence synthesis on medication and supplies management, the CHCA created and disseminated a high-level information graphic. This user-friendly infographic presents the core learnings from the synthesis and encourages organizations that provide home care to consider ways to manage medication and supplies in the home setting. The infographic will help stakeholders to understand and identify the most important information from the synthesis. The information is posted on the CHCA website , was promoted through Twitter conversations to CHCA followers, and was featured in an e-blast to the 2,200 contacts within the CHCA network.

Phase 3: Implementation of a Leading Practice through a CHCA SPRINT Collaborative™

CHCA SPRINT Implementation Collaboratives™ (SPRINT Collaboratives™) use a structured process to help organizations and local practice teams test new models of care, better understand and use quality improvement methodologies, and create sustainable change that results in positive client/patient outcomes. SPRINT Collaboratives are uniquely designed for home and community-based care providers. This customized process focuses on rapid, effective change that requires minimal investment and time to achieve significant results.

Adapted from the Institute for Healthcare Improvement Collaborative Model for Achieving Breakthrough Improvement[5] and the evidence-based system for innovation support (EBSIS), [6] SPRINT Collaboratives provide tools, training, coaching and technical assistance in:

- testing for knowledge using rapid plan-do-study-act (PDSA) cycles;
- applying practical learning and experience from leading practices experts;
- using proven interventions to motivate individuals and change behaviour through COM-B[7];
- working as a collaborative and maximizing learning opportunities; and
- developing sustainability plans to achieve long-term outcomes.

Whole Community Palliative Rounds (WCPR) Collaborative—Practice Teams

The project advisory committee chose Whole Community Palliative Rounds (WCPR) for deployment through the SPRINT Collaborative. A call for participation in the SPRINT-WCPR Implementation Collaborative was made in May 2019 with the goal of recruiting four to six teams. Following the informational webinar highlighting the importance and impact of WCPR and the SPRINT Collaborative approach, the CHCA received numerous expressions of interest and selected 11 qualified teams from across the country.

Teams were comprised of an executive sponsor, team lead, measurement lead and additional members from a variety of disciplines. A total of 67 individuals participated, including palliative program directors/managers, clinical specialists (e.g., nurses, social workers, palliative care physicians), operational leads, care coordinators and quality assurance experts.

The following organizations participated in the SPRINT-WCPR Implementation Collaborative:

Alberta Health Services – Edmonton Zone (6 team members)
Alberta Health Services offers programs and services at over 400 facilities throughout the province, including hospitals, clinics, continuing care facilities, mental health facilities and community health centres. Edmonton Zone serves the city of Edmonton and the capital region.

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[5] Institute for Healthcare Improvement. (2003). The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Boston, MA: Institute for Healthcare Improvement. Retrieved from www.IHI.org

[6] Wandersman, A., Chien, V. H., & Katz, J. (2012). Toward an evidence-based system for innovation support for implementing innovations with quality: tools, training, technical assistance, and quality assurance/quality improvement. American Journal of Community Psychology, 50(3-4), 445-450. doi: 10.1007/s10464-012-9509-7.

[7] Michie, S., Atkins, L., & West, R. (2014) The Behaviour Change Wheel: A Guide to Designing Interventions. Bream, UK: Silverback Publishing.

Bayshore HealthCare (5 team members)
Bayshore HealthCare is one of the country's leading providers of home and community health care services and is a Canadian-owned company. With over 100 locations across the country, including home care offices, pharmacies and infusion clinics, Bayshore has more than 13,500 staff members and provides care to over 350,000 clients.

CarePartners (6 team members from two locations in Ontario)
CarePartners provides personal support workers, rehabilitation services and nursing care for patients in homes, schools, retirement homes, clinics and workplaces. CareParners' services are available across Ontario in both urban and rural communities.

Eastern Health (7 team members)
Eastern Health is the largest integrated health organization in Newfoundland and Labrador. The organization provides the full continuum of health services to a regional population of more than 300,000 and is responsible for a number of unique provincial programs.

Health PEI (6 team members)
Health PEI is responsible for the delivery of publicly funded health services in Prince Edward Island. The organization operates hospitals, health centres, public long-term care nursing facilities and community-based programs and services.

New Brunswick Extra-Mural Program (7 team members)
The New Brunswick Extra-Mural Program (EMP), known as the "hospital without walls," is the provincial program that provides health care services to New Brunswickers' of all ages in their homes (i.e., personal residence, special care home, nursing home).

Saskatchewan Health Authority: (Prince Albert – 7 team members; North West Battleford – 3 team members; Regina Qu'Appelle – 7 team members)
The Saskatchewan Health Authority is the largest organization in Saskatchewan, employing over 40,000 employees and physicians who are responsible for delivering high-quality and timely health care for the entire province.

SE Health (7 team members)
SE Health is a social enterprise that applies knowledge, vision and drive to impact how people live and age at home. They deliver quality, trusted home care to people where and when they need it in Ontario. SE Health is a social enterprise that applies knowledge, vision and drive to impact how people live and age at home.

Southern Health-Santé Sud (6 team members)
Southern Health-Santé Sud is a designated bilingual regional health authority located in southern Manitoba. With over 6,000 employees, they partner with communities to deliver a spectrum of quality health care services.

SPRINT Implementation Collaborative Approach to Implementation of WCPR

Onboarding Teams

A team-based face-to-face onboarding workshop was held on June 24–25, 2019, to create an environment for teams to share their expertise and experiences and build a foundation of collaborative information sharing. The goal of the two-day session was to provide an overview of the structure and approach of a SPRINT Collaborative and prepare teams to test and adapt WCPR. Designated working sessions addressed the following core topics:

- **Operational practice changes required for WCPR** – Vicki Kennedy, Regional Clinical Nurse Specialist, IH Palliative and End-of-Life Care from Interior Health, reviewed key considerations and discussed fundamental elements of WCPR and from the Interior Health Authority's experiences.
- **Clinical considerations for WCPR** – Elisabeth Antifeau, Regional Clinical Nurse Specialist, IH Palliative and End-of-Life Care from Interior Health, introduced the clinical elements for WCPR including clinical decision-making tools and guidelines and interprofessional team approaches for rapid clinical problem solving and care planning.
- **Quality improvement methodology** – QI subject matter expert Mike Hindmarsh from Quality Expert, The Centre for Collaboration, Motivation & Innovation, introduced the Model for Improvement used in the SPRINT Collaborative and guided teams through the creation of a project charter, aim statement and action plan to implement and test WCPR in their local contexts.
- **Implementation science strategies** – Dr. Julia Moore, Senior Director, The Centre for Implementation, guided team members through a discussion on the concepts of behaviour change theory and practical tactics specific to WCPR practice changes.
- **Interprofessional collaboration and communication** – Dean Lising, Team-Based Practice and Education Lead, Centre for Interprofessional Education from the University of Toronto, reinforced the importance and effectiveness of the interprofessional team and how effective communication and role clarity supports team competence and collaboration.

A total of 33 individuals attended the onboarding workshop, including representatives from all 11 practice teams. Day 1 started with an overview of the project, followed by presentations to improve the understanding of WCPR and implementation strategies. Day 2 provided participants with hands-on experience through comprehensive working sessions.

Virtual Learning Sessions and Action Periods

The SPRINT-WCPR virtual learning sessions provided an opportunity for all practice teams to learn new approaches and strategies to advance and support their unique goals. The content of these sessions was determined through individual coaching sessions and tailored to meet the needs of practice teams. Accessed through a user-friend platform (Adobe Connect) and supported through a phone conferencing system, core concepts were shared and discussed. Each session concluded with a set of actions for teams to consider and undertake locally.

Virtual Learning Session 1 (July 19, 2019): Identifying Approaches and Action for Rapid Testing (PDSA cycles)

This webinar enabled practice teams to present their aim statements and change ideas and receive feedback from the QI subject matter expert. A live question-and-answer chat feature enabled participants to pose their questions to the QI expert and other team members. This session was attended by 42 participants representing all practice teams. An on-demand video of the session was made available through the online resource HUB for individuals who were not able to attend.

> Action Period (July–August): Key tasks for teams included completing and submitting their project charter, conducting a local PDSA cycle and defining community partners to be included in the enhanced circle of care.

Virtual Learning Session 2 (September 9, 2019): Tactical Tools and Resources to Promote Behaviour Change Specifically for WCPR Practice Changes

This webinar introduced behaviour change theory and motivational tools and tactics that practice teams could use to engage stakeholders. The session also featured the lived experience of Interior Health, with a guest presentation by a home care nurse who shared her experience of being part of WCPR. Practice team members were encouraged to share their experiences through the online chat feature. The session was attended by 37 participants representing all practice teams. An on-demand video was made available through the online resource HUB for individuals who were not able to attend.

> Action Period (September–October): Teams were encouraged to continue their PSDA cycles and log their results using a PDSA tracing worksheet. CHCA SPRINT coaches addressed specific requests from the session (e.g., key messages and value statements to support stakeholder engagement) and tools were created and provided to the teams through the online resource HUB.

Virtual Learning Session 3 (October 9, 2019): Lesson Learned and Success Factors for Hosting a WCPR

This webinar provided a forum to share practical advice and answer team members' questions on the logistics of hosting WCPR. Clinical specialists for Interior Health role played an actual round and answered questions posed through the chat dialogue during the session. Attended by 30 participants, this session was designed to target WCPR facilitators and clinicians from the practice teams. Unfortunately, due to a technical error, an on-demand video was not available for teams. Instead, the CHCA provided a written transcript of the role-playing session.

> Action Period (October–November): Application of PDSA cycles and different approaches such as testing changes to existing processes or testing new processes were encouraged. Measurement and data collection were reinforced using the PDSA tracking worksheet. The CHCA team modified the facilitator guide they developed (outlining core competencies and role of the WCPR facilitator) to reflect new concepts of behaviour change theory.

Virtual Learning Session 4 (November 4, 2019): Successful PDSA – Process and Outcome Measures

This webinar provided practical advice for teams on the quality improvement approach, how to make small tests of change and considerations for measuring outcomes. It was attended by 36 participants, which included at least one representative from each team. An on-demand video was made available through the online resource HUB for individuals who were not able to attend.

> Action Period (November–December): Teams were encouraged to continue their PSDA cycles in addition to preparing for their process presentations at the capstone event. To facilitate collaboration, teams were asked to take a group picture and share their experience of being involved in the SPRINT Collaborative. These testimonials were featured at the capstone event.

The slides and recordings from all sessions were uploaded to a secure online repository for future reference. To view the presentations, visit

Coaching Support

A key success factor for the SPRINT-WCPR Collaborative was the tailored coaching calls to understand and address local needs. Through regular calls, a relationship was fostered between practice team members and their coaches to enable rapid resolution to challenges. Greater understanding of the unique requirements and challenges of practice teams supported coaches in customizing and more effectively accessing resources and subject matter expertise knowledge. The SPRINT-WCPR coaches worked collaboratively to share common challenges and identify solutions that were featured in the scheduled virtual learning sessions.

Each practice team was assigned one SPRINT coach who scheduled monthly check-in calls with team members to discuss progress, identify barriers, brainstorm ways to address challenges and determine supports needed from the CHCA. Coaches accessed subject matter experts in quality improvement, implementation science and clinical specialties as required. Coaches were tasked with sharing ideas, encouraging teams to connect with each other, researching and creating new tools and resources, and generally serving as a prompt resource for their practice teams. The coaching sessions enabled the sharing of strategies being tested and tried by other teams. This cross-pollination of ideas encouraged teams to think outside of the box and try different approaches. It also provided them with opportunities to build on each other's successes.

Resources for SPRINT-WCPR Teams

The SPRINT coaches sourced resources needed by the teams and ensured that tools developed by individual teams were shared among all practice teams. Although some of the tools were context-specific (e.g., referral forms), they could be adapted easily for use in different locations. The CHCA developed a number of resources to support teams in their work, including:

Communication/Value Statements

- **National key messages** – These messages target communication for health care leaders on how the SPRINT-WCPR Implementation Collaborative advances a national priority and aligns with the Framework on Palliative Care in Canada.
- **Value statements for front-line clinicians** – This information addresses key concerns and reinforces how WCPR leads to better outcomes for patients and saves time for clinicians.
- **Value statements for physicians/palliative care specialists** – Customized to this audience (building on the Patient's Medical Home concept for the College of Family Physicians of Canada), this piece profiles ways that physicians should participate (or have their practice participate) in WCPR; how WCPR can help achieve better clinical outcomes for patients with palliative care needs; and why attending is an effective use of their time.

FACILITATING COLLABORATION: A PROFILE

The SPRINT-WCPR coach assigned to the three practice teams from Saskatchewan encouraged them to share resources and work together to implement WCPR. This action forged a foundation for province-wide adoption. It started with coordinating activities such as involving privacy officers from the other regions to ensure consistency in work standards, but soon the teams realized the benefit of working collaboratively to standardize the implementation of WCPR. Through their efforts, they built momentum in the province of Saskatchewan to implement WCPR.

ENABLING COMMUNICATION

In addition to the tools created by the CHCA, resources from the practice teams (e.g., referral forms, communication templates) were shared with practice teams through direct email, discussed during coaching calls and provided to practice team members at the capstone event. To simplify and expand access to resources, a password-protected online HUB was created and updated throughout the Collaborative. The internal site averaged 45 visits/month.

Research/Scoping Documents

- **Summary of provincial privacy laws** – This table summarizes provincial privacy legislations across Canada, including extracts regarding the use and disclosure of personal information.
- **Testing for knowledge –** This quick reference guide outlines the differences between testing for improvement (PSDA), program evaluation (QI) and research (experimentation) to help teams understand how to collect and analyse data.

Practical Tools

- **Facilitator guide** – This user-friendly handbook outlines the WCPR facilitator's role, responsibilities and tactical suggestions to support a facilitator in running effective rounds.
- **Outcome and process measures** – This piece provides example of measurements that teams can use to demonstrate current performance (or baseline), set goals for future performance and monitor the effects of changes as they are made.
- **Sustainability workbook** – This manual describes several evidence-informed factors that can impact long-term success. The factors were adapted to reflect the SPRINT-WCPR Collaborative approach: success factors for behaviour change (COM-B) and success factors for evaluation and evidence.

Download the Framework and User Guide for Implementing Innovative Practices.

Capstone Event

The SPRINT-WCPR capstone event was held on December 2–3, 2019, in Banff, Alberta, to celebrate the learnings and experiences of the 11 teams involved in the collaborative. Over 50 health care leaders from across the country attended the event. The sessions stimulated dialogue on practical ways to sustain innovations in home and community palliative care. Practice teams presented their experiences in the collaborative and how testing for knowledge and using behavioural change theories resulted in sustainable change.

Plenary, small group and facilitated sessions engaged participants in conversations about the necessary steps to implement WCPR, including:

- strategies to engage senior leadership throughout the initiative with targeted and strategic communication;
- recognizing the importance of building trusting relationships and engaging teams;
- facilitating rapid implementation by clarifying what is being sustained, by whom and how;
- making measurement relevant and easy to communicate through PDSA cycles; and
- harnessing the power of people by understanding what motivates them using behaviour science models.

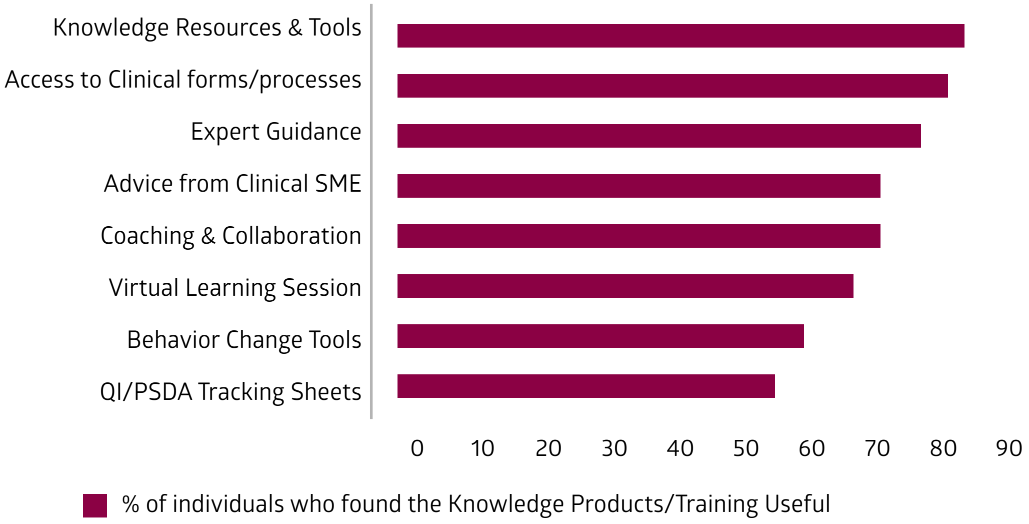
To learn about the practice teams achievement visit

OUTCOMES FROM THE SPRINT-WCPR IMPLEMENTATION COLLABORATIVE™

Advancing a Knowledge-based Health Care System

The SPRINT-WCPR introduced practice teams to a variety of new learning products and training strategies. These included new resources and knowledge tools, along with advice from subject matter experts and coaching and collaboration. The following chart summarizes the evaluation of the usefulness of these different learning opportunities for the practice teams.

Effectiveness of Learning Products and Training Strategies in SPRINT-WCPR Collaborative



Modernizing Health Care Systems Delivery

All practice teams successfully implemented a whole community palliative round by the end of the Collaborative. The number of health care professionals who participated in the WCPR circle of care and the number of clients discussed at each round varied among practice teams.

ALBERTA HEALTH SERVICES – EDMONTON ZONE encouraged patients to be involved in their WCPR and tested the concept through several mock rounds where the spiritual advisor and others reviewed cases in a holistic manner. Integrated into their provincial palliative care strategy, the team used the Alberta Health Services Insite pages to share WCPR guidelines, contact information, an FAQ document on privacy and confidentiality, and the SBAR referral.

> *"There is a saying: 'Nothing about us without us'. My involvement in the WCPR was proof in fact of this philosophy. I am glad my voice was welcomed."*
>
> **—PARTICIPANT IN AHS WCPR**

The goal for **EASTERN HEALTH TEAM FROM NEWFOUNDLAND** was to establish a weekly WCPR in the Clarenville area that included interdisciplinary representation from acute care, community care, primary care and long-term care/personal care homes. The team worked to identify a medical leader to participate in the round and provide additional palliative care training if needed. Through several PDSA cycles (plan-do-study-act), the team evolved their recruitment approach to account for compensation and time and ensure appropriate skills and clarity of roles and accountabilities. Successful recruitment of the medical leader involved providing clarity on their role, addressing concerns regarding liabilities, and creating a supportive relationship with the palliative care specialist. Their goal to include long-term care/personal care homes in WCPR has not yet been achieved.

LESSONS LEARNED

The **Eastern Health** practice team reflected on the lack of participation of long-term care/personal care homes in WCPR to understand what barriers and enablers impacted the difference in engagement.

Medical leaders:

- Understood the barriers and designed strategies appropriately (i.e., compensation, time, skills and knowledge, beliefs about capabilities, beliefs about consequences)
- Had a good understanding of the value of WCPR through early and effective communication with leadership at the acute care facility and manager attendance at LEAP
- Created a safe and supportive environment

Long-term care leaders:

- Didn't have a good understanding of the potential barriers
- Had a poor understanding of the value of WCPR; did not engage the right senior leadership early in the process; managers did not attend LEAP
- Perceived WCPR as a potential threat

The team will continue to test and evaluate ways to engage long-term care in WCPR in addition to evaluating if communication has become more effective because of WCPR.

The **NEW BRUNSWICK EXTRA-MURAL PROGRAM** practice team focused on redefining and enhancing the circle of care. Their goal was to facilitate an interprofessional palliative care rounds team through the WCPR approach in Miramichi. The circle of care included (but was not limited to):

- Nursing leadership (manager)
- Presenting clinician (person who sent the referral)
- EMP palliative resource nurse
- EMP rounds facilitator
- Palliative care coordinator (hospital)
- Medical palliative leader (palliative physician/general practitioner/nurse practitioner)
- Family doctor/nurse practitioner
- Community paramedics
- Hospice nurse manager
- Pharmacist
- Front-line staff: RN/LPN/PT/OT/RT/SLP/RD/SW
- Other participants per referral as needed, such as health care providers working in Indigenous communities, spiritual health professionals, oncology coordinators, clinical ethics professionals

LESSONS LEARNED

The **New Brunswick Extra-Mural Program** practice team used a variety of communication techniques and tools to promote understanding of and the value of the circle of care and generate interest in attending a WCPR. These included discussions with stakeholders, information flyers/posters, a PowerPoint presentation, a guidebook, emails and newsletters. They learned that face-to-face meetings worked best.

The **BAYSHORE HEALTH CARE** practice team focused their work on creating effective WCPR for patients living in the Stormont, Dundas, Glengarry region who have a life-limiting disease/condition. They wanted to encourage clinicians to use WCPR as an additional resource to assist in patient and family care management. Their tests of change looked at a variety of ways to engage and motivate partners, such as:

- providing an introductory presentation and package;
- conducting "roadshows" (i.e., physician offices, community centres, long-term care homes);
- using reminders such as magnetic business cards;
- facilitating large communication sessions through a mock WCPR session (included 90 clinicians); and
- providing networking presentations at clinical events.

As of early December 2019, the practice team has successfully completed three WCPR with multiple professionals in attendance. Their goal is to increase attendance by community practitioners by 50%, reduce early admission to hospice and reduce transfer to hospital rates—all within six months of the first round.

The **SOUTHERN HEALTH** Team's goal was to complete five WCPR by November 28, 2019 with a focus on improving communication and shared decision-making between providers, as well as ensuring the continuity and quality of care for individuals receiving a palliative approach to care. Their tests of change focused on a multiple of factors, including:

- defining "community enhanced circle of care";
- identifying and engaging with a medical lead;
- identifying a site and catchment areas;
- identifying and supporting a WCPR facilitator;
- identifying, engaging with and educating front-line partners and referral sources to participate in rounds;
- developing an appropriate referral process; and
- developing documentation for follow-up for referrals through WCPR.

With a defined population and catchment area, the practice team worked to build clinicians' understanding of who to refer to WCPR. Various approaches were used, including a roadshow in the defined catchment area to educate potential referrers with case study examples for acute patients, long-term care residents and community clients, and encouraging people to send referrals even if they are not sure they meet the criteria. A detailed referral process and forms were created and tested.

> *"Our team consists of members from home care and palliative care, two programs that currently work independently of each other while caring for shared clients. Participating in the SPRINT collaborative has provided an opportunity for the two programs to come together, brainstorm and work toward improving end-of-life care to our clients/patients."*
>
> —**SOUTHERN HEALTH**

LESSONS LEARNED

The **Southern Health** team identified a number of issues to consider when motivating partners to make referrals:

- Make connections with individual service providers and use face-to-face promotion strategies.
- Ensure leadership buy-in.
- Use education roadshows for WCPR.
- Use team members to do local promotion (e.g., medical lead emailed other physicians about service and palliative care team encouraged service providers to refer certain cases).

The Southern Health practice team is steadily building their reference numbers. They are committed to continuing to promote WCPR to professionals for referrals and maintain team momentum. A priority is to receive more referrals from home care to build interprofessional communication. Reviewing referrals and determining who should attend WCPR is an ongoing process. Given the early successes, the practice team anticipated that WCPR will spread through the Southern Health region as all palliative care team members are playing more of a role in promoting and educating on WCPR.

The **CARE PARTNERS** practice team wanted to implement WCPR in the northern region of Ontario (North Bay). The team focused on awareness and engagement; however, they experienced a major barrier with the health restructuring in Ontario that impacted stakeholders' desire to commit to new programs.

Testing a number of engagement strategies (e.g., face-to-face meetings, key messages, meeting with local planning tables, educating CarePartners employees on WCPR, and one-on-one calls to key palliative physicians), they were able to hold a mini-round on November 22, 2019. The round was tailored to meet the needs of the supporting palliative physician. A first step has been taken, but the local administrator of home and community care is still showing a high level of resistance given the uncertain environment in Ontario.

LESSON LEARNED

The **Care Partners** team recognizes that timing plays a key factor in implementing new initiatives, and will continue to work with local champions and introduce WCPR again when the new health care structure is more firmly in place or other service areas within Ontario are ready for WCPR.

The **HEALTH PEI** practice team's goals were to optimize and expand the existing palliative rounds in Prince County, include the mobile integrated health coordinator (linkage to community paramedics) and gain greater involvement at rounds by acute care. They began by testing a targeted engagement strategy and recognized that promotion and understanding of WCPR was critical.

Using a person-centred approach to WCPR is important, and reinforcing client experiences and improvement was effective. Targeted communications to leadership were also important. Given that palliative rounds currently exist, the practice team emphasized how WCPR would improve them and help integrate services through a palliative approach to care. Being a part of a national implementation collaborative and passionately believing in the importance of WCPR were a bonus to the engagement process.

The **PEI HEALTH** practice team is using an innovative and flexible approach to implementing WCPR. Recognizing the time constraints on clinicians from acute care, they have offered to have clinicians present referrals at the beginning of the meeting and have created Palliative Rounds Client Presentation Guidelines to assist acute care clinicians in their presentation at rounds. They are awaiting a response to these recommendations. The director of nursing (acute) attended a WCPR, met with the home care manager and showed an interest in further partnerships. The goal is to now expand the WCPR to include the mobile integrated health coordinator, a dietitian and a pharmacist.

The **SE HEALTH** practice focused their implementation of WCPR on broad population bases that included individuals receiving a palliative approach to care for frailty, advanced dementia, end-stage CHF and COPD. Through their PDSA cycles, the team focused on the facilitation role for their WCPR practice change. Change ideas included:

- application of the WCPR Guideline and Rounds Record;
- selection of an experienced facilitator (known to staff/partners, confident in facilitation and available);
- providing the facilitator with coaching and feedback;
- using the LEAP facilitator course; and
- gaining senior leadership support to help with time allocation for the facilitator.

Using communication strategies such as face-to-face meetings, multiple communications and follow-up, and ensuring detailed client lists are sent to providers weekly have improved the effectiveness of WCPR. The SE Health team sees great potential in WCPR, notwithstanding the health restructuring challenges in Ontario.

> *"The collaborative allowed us to acquire knowledge from other teams from across the country. We were given the ability to participate in evidence-based and best practice initiatives with the invaluable support of the Canadian Home Care Association. Networking at a national level provides exposure to other home care leaders and innovations that we can then adapt and spread to our own practice."* —**HEALTH PEI**

The **SASKATCHEWAN HEALTH AUTHORITY** team leveraged their current rounds and set out to improve support and symptom management for palliative patients and their families/caregivers within the Prince Albert Area. Their goal was to have the process set up by December 2019 and to review 75% of referrals at the next scheduled WCPR. The team had a clear focus on improving operational processes, specifically the quality of discussion at the WCPR, the referral mechanism and timely information flow to most responsible practitioner.

> *"I think there is inherent value in WCPR in that it builds palliative capacity in community and among practitioners. It has potential to improve quality of life for people who may not have had the opportunity to be seen by experts in palliation. It helps build better teams by improving relationships among people from all disciplines."*
>
> — **SASKATCHEWAN HEALTH AUTHORITY – REGINA**

The team was successful in improving the quality of discussions as the WCPR facilitator helped keep team members focused on the current goals. Communications and follow-up to MRP were facilitated by having Dr. Alanna Surkan attend the WCPR and completing the communication sheet back to the MRP/referring provider. The facilitator faxes these communication sheets the same day as rounds and will follow up with the MRP via phone if something is more urgent. As WCPR build, several potential barriers have been identified that must be addressed, including:

- changing the old way of rounding to this new WCPR format;
- motivating acute care team members to support change; and
- addressing the “more forms” concerns.

The Power of Collaboration

All three Saskatchewan Health Authority practice teams collaborated on a WCPR practice change, Enhancing the Circle of Care. To address privacy concerns, the northern team reached out to their local privacy officer regarding WCPR to get clarification about confidentiality. They informed their local officer that Regina was also implementing WCPR so both privacy officers could communicate, and the same message was sent across the Health Authority. Both privacy officers attended the WCPR (either in person or through conference call) and have developed recommendations based on each site’s rounds. Communication between all three teams and both privacy officers continues to ensure everyone is on the same page and that developed standards work for all parties.

KNOWLEDGE TRANSLATION

Actively engaging with 11 practice teams throughout the seven-month collaborative provided numerous opportunities to share the project findings and the experiences of home and community-care providers in building operational excellence in home-based palliative care.

Recognition from Provincial Governments

To support the SPRINT-WCPR practice teams, the CHCA provided customized updates to respective ministers of health in each jurisdiction. An overview of project goals and objectives were provided in order to increase awareness of the project and understand how the provincial governments where enhancing home-based palliative care in their respective provinces and territories. The ministers of health also received an update regarding the involvement of SPRINT-WCPR practice teams in their provinces and their achievements in the implementation of WCPR. The office of the Minister of Health in British Columbia, Alberta, Saskatchewan and Manitoba acknowledged the value of WCPR in moving their provincial agendas forward to enhance community and home-based palliative care in achieving shared health priorities.

Influencing Key Stakeholders

The SPRINT-WCPR capstone event held in December 2019 provided an opportunity to share the outcomes of the entire project in addition to profiling the learnings for the SPRINT-WCPR practice teams. In addition to the practice team representatives, 25 key stakeholders attended the event, representing government ministries, health authorities, palliative care networks and home care providers from across the country. Special guests included the following:

- Senior leaders from Alberta Health Services, Interior Health (BC), Saskatchewan Health Authority, Shared Health Services (MB), Health PEI, NB Department of Health, CIUSSS West Central Montreal, Nunavut Department of Health and Yukon Health and Social Services
- CEO from national and regional home care organizations and Medavie Health Services (NB)
- Representatives from Health Canada
- Palliative care experts from Alberta, British Columbia and Ontario

Sharing our Know-How

Recognizing the vast amount of knowledge and learning acquired through the SPRINT-WCPR Collaborative, the CHCA team created a knowledge tool to enhance the awareness and understanding of the approach and support stakeholders in implementing leading practices in operational excellence in home-based palliative care. The Framework and User Guide includes recommendations and resources drawn from the SPRINT-WCPR Collaborative practice teams. Providing a step-by-step overview of how to move from “what we know” to “what we do,” the document is designed to make available to a wider audience the valuable lessons learned from the SPRINT-WCPR Collaborative participants and implementation coaches.

CONCLUSION

With an aging population and increased prevalence of chronic diseases, a palliative approach to care supports quality living and dying. The project made a significant contribution to this vision by building operational excellence in home and community-based palliative care.

Gaining a clear understanding of gaps and opportunities from the provider and patient/caregiver perspective enabled the teams to target specific area and identify leading practices that would have an immediate impact on quality care. The palliative care experience maps provide a guide for future initiatives to focus on identified gaps and challenges in four areas:

- Including advance care plans in the delivery of care in the home
- Assessment and care planning
- Effective communication strategies and tactics
- Supplies, equipment and medication management

Identification of 22 leading practices addressing these four priority areas and featuring them in a universally accessible website will go a long way toward promoting excellence and spread across the country. The High Impact Practices featured in written and digital formats provide users with an overview of the context, implementation and outcomes for five innovative approaches to home-based palliative care.

Using the CHCA's SPRINT Implementation Collaborative™ approach to facilitate the testing and adoption of Whole Community Palliative Rounds (a High Impact Practice) with 11 practice teams across the country resulted in more effective multi-disciplinary collaboration, communication and shared decision-making for high-risk individuals with palliative care needs.

The knowledge products and learning strategies, including the experience maps, implementation framework and user guide, virtual learning sessions and capstone event, will support knowledge transfer and application and will help home care providers move from "what they know" to "what they do." The knowledge, tools and resources created through this project will also inform the CHCA's future work and assist us in strengthening integrated home and community-based care.

Home care is a priority for all Canadians—for patients and their carers, for health care providers and for governments. As an essential part of an integrated health system, home care provides seamless patient- and family-centred care and supports for older adults living with frailty; those with complex, chronic disabling conditions; and individuals at the end of life. By building operational excellence in home and community-based care, the following outcomes can be achieved:

- Patients access the health care and support services they need, when they need them, outside of the hospital.
- Patient and health care team members work together and easily access and share relevant health information and care plans.
- Individuals' health care wishes at the end of life are shared, understood, respected and acted upon.