



PROVINCIAL HOSPICE
WORKING GROUP



Hospice Care in British Columbia: The Path Forward

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About This Report

The Provincial Hospice Working Group (PHWG) is a collective of non-profit organizations who took the initiative to coordinate the development of a path forward to improve access to high quality, fully integrated, and sustained hospice care for all British Columbians.

The recommendations were developed in consultation with the PHWG, hospice organizations across British Columbia (BC), roundtable stakeholders, and industry experts.

The founding members of the PHWG are representatives of the British Columbia Centre for Palliative Care (BCCPC), British Columbia Hospice Palliative Care Association (BCHCPA), Sovereign Order of St. John of Jerusalem, Knights Hospitaller (SOSJ), Victoria Hospice, and Vancouver Island Federation of Hospices (VIFoH).

This report describes the current state of the non-profit hospice care sector in BC, highlighting the major gaps, challenges, and opportunities to leverage and sustain the sector.

It also outlines the importance of strengthening, sustaining, and integrating the volunteer-driven, person-centered hospice services within the health care system to help in the provision of the necessary practical and psychosocial supports for British Columbians affected by a serious illness.

METHODOLOGY

The information in this report was gathered from the following sources:

1. Relevant academic articles and grey literature that address the needs of persons living with a serious or life-limiting illness and their family or friend caregivers.
2. Administrators of hospice organizations who completed a survey on the current state of the sector in September 2019 (BCCPC).
3. Stakeholders in the health care system and community, specifically palliative care clinicians, physicians, and researchers, at the roundtable hosted by the PHWG in November 2019.

As such, the proposed path forward in this report is reflective of the insights and contributions made by hospice organizations, stakeholders, experts, and researchers.

ACKNOWLEDGEMENTS

The Provincial Hospice Working Group offers a heartfelt thanks to the time and efforts of the administrators of the 53 hospice organizations who participated in the current state assessment.

We would also like to express our deep gratitude and appreciation for the contributions made by the stakeholders as well as the experts and researchers who participated in the roundtable that was held in Vancouver in November 2019.

Finally, we would like to acknowledge the support of the AGE-WELL National Innovation Hub Advancing Policies and Practices in Technology and Aging (APPTA) for their facilitation of the stakeholder roundtable and contributions to the development of this report.

Disclaimer: Information contained in this report was obtained in 2019. It does not reflect the possible impact of any changes in care which have been implemented as a direct or indirect consequence of COVID-19.

Executive Summary

This first of its kind report describes the current state of hospice care in BC. It outlines the path recommended by stakeholders to leverage, sustain, and integrate the volunteer-driven services provided by hospice organizations to address the psychosocial, practical, and spiritual needs of persons living with a serious illness.

The recommended path is designed to support British Columbians affected by a serious illness to live the best quality of life possible. It is anticipated that implementation of the recommended path will alleviate some of the pressures on the formal health care system, such as those exerted by the aging population and the COVID-19 pandemic.

GROWING NEEDS FOR HOSPICE CARE

British Columbia is facing an important demographic shift in the coming years that will lead to growing demands for hospice care. By 2036, one-quarter of the province's residents will be over the age of 65. These older adults want to experience aging and end-of-life at home and in their communities. They also want to maintain their autonomy, especially in relation to the type of care and supports they receive.

The increased demands, caused by the demographic shift and the current gaps in meeting the practical and psychosocial needs of individuals living with serious illnesses, necessitate immediate action to improve access to high quality, sustainable, and integrated hospice care in BC.

Improved integration of hospice care services into the formal health care system will accelerate the ability of the province to leverage these strengths and improve quality of life for British Columbians.

STRENGTHS OF HOSPICE CARE

Hospice care is a whole-person approach that aims to improve the quality of life of individuals living with a progressive, life-limiting illness, as well as ensure the well-being of caregivers, family members, and friends impacted by the person's illness or death.

Hospice organizations are uniquely positioned to play

a leading role in a revitalized hospice care sector in BC. The 71 not-for-profit community hospice organizations are geographically spread out across rural, remote, and urban areas of British Columbia and already operate with a deeply ingrained person-centered philosophy. In addition, the highly qualified professionals on staff operate with the support of a vast network of well-trained volunteers. These volunteers include retired health-care professionals, educators, and family members of persons who receive or have received hospice care.

For the purposes of this report, hospice care refers to services provided by staff and volunteers of community-based, not-for-profit organizations with mandates for supporting individuals with life-limiting illnesses and their caregivers and bereaved.

Through their highly qualified staff and well-trained volunteers, BC community hospice organizations provide psychosocial, practical, and spiritual supports to over 10,000 British Columbians living with a serious illness and their caregivers every month, at minimal or no cost to the service recipient.

CURRENT GAPS

Although hospice organizations in BC have many strengths to offer, they are currently facing a number of challenges that prevent them from taking on a more meaningful partnership role in the hospice care sector.

First, there is little coordination across organizations, regions, and the formal health care system, resulting in a lack of standards for services and means to enable exchange of knowledge and resources.

Relationships with the government and regional health authorities are inconsistent and lack clear policy directives for formal collaboration and integration.

Furthermore, funding sources are limited and unstable, leading hospice organizations to compete against one another rather than work together.

WORKING TOGETHER FOR IMPROVED, INTEGRATED, AND SUSTAINABLE HOSPICE CARE

Empowering hospice organizations to take on a more integral role in addressing the increasing demand for person-centered care in these challenging times will require coordinated leadership and efforts among key stakeholders in the province.

The November 13 roundtable concluded with a unanimous call for the establishment of an Alliance, with representatives from hospice organizations, government, health authorities, professional organizations, researchers, health care facilities, charities and patient and family groups, to accelerate improvement of hospice care in BC.

Based on the stakeholders' recommendations, the Alliance and its membership will be responsible for taking a leadership role in leveraging hospices' strengths and addressing the gaps, challenges and barriers identified in this report.

THE PATH FORWARD

As recommended by stakeholders, the following 10-step path will build a better, fully integrated, and sustainable hospice care sector over the next few years:

1. Design a strong, integrated, governance structure for the Alliance.
2. Secure reliable funding for hospice organizations.
3. Advocate for a provincial policy and strategy for hospice care in BC.
4. Establish a common definition for hospice care in BC.
5. Establish provincial standards and an accreditation program for hospice care.
6. Raise public awareness of the importance of person-centered care and advance care planning education provided by hospice organizations in BC.

7. Establish core competencies and a provincial training program for hospice staff and volunteers.
8. Ensure an effective volunteer engagement strategy.
9. Leverage technology to facilitate networking, training, and knowledge exchange among the Alliance and its members.
10. Explore and facilitate opportunities for meaningful partnerships between hospice organizations with underserved communities in the province.

A CALL TO ACTION

Now more than ever is the time to move toward a future where hospice organizations are meaningful and recognized partners in the provision of accessible, credible, integrated, and sustainable hospice care in BC.

This report calls for coordinated implementation of the recommended path for improved hospice care by the Alliance in partnership with key stakeholders across sectors. Government support and a secured funding source are essential to the successful implementation of the recommended path.

With adequate resources and support, hospice organizations are capable of alleviating some of the current pressures on our health care system, while supporting British Columbians living with a serious illness and their caregivers to have the best possible quality of life.

Background

GROWING DEMAND

British Columbia is facing an important demographic shift in the coming years that is leading to growing demands for hospice care. By 2036, one-quarter of the province's residents will be over the age of 65ⁱ. As the aging population increases in both size and proportion, BC is expecting a growth in numbers of older adults living with chronic illnesses accompanied by significant demands for hospice care that the health care system alone is not adequately equipped to meet.

As recent reports have indicated, most older Canadians, including those living with serious chronic illnesses, would prefer to age and die in their own homes^{ii iii}. Furthermore, international evidence and local experience indicate that community-based care programs help patients and their caregivers maintain their comfort and independence at home while minimizing the unnecessary use of costly acute care^{iv}.

Despite this knowledge, 50-60% of deaths in Canada occur in acute care^v.

Ultimately, this demographic shift and the increased demand for person-centered care will necessitate significant policy and societal change toward a better resourced and more inclusive hospice care landscape.

UNMET NEEDS

For individuals living with serious illnesses, research indicates that support with spiritual well-being, coping, isolation and loneliness are notably lacking.^{vi vii} There are also significant service gaps in symptom and crisis management at home, commonly resulting in unnecessary acute care admissions^{viii ix x xi xii}.

Moreover, the practical needs of individuals living with serious illnesses such as housework, physical care, system navigation, informational needs, equipment retrieval and setup, as well as financial and legal support^{xiii xiv xv} typically become the responsibility of their caregivers, who often have limited access to resources and must balance these needs against their own professional and personal lives.



Improving availability of quality respite services, providing support with domestic responsibilities, and offering emotional and anticipatory grief supports^{xvi}
^{xvii xviii} all present important opportunities to assist caregivers and prevent burnout.

Addressing the psychosocial dimensions of living with serious illness, frailty, dying, and grief are central to the well-being of patients and their caregivers.

Finally, appropriate communication between patients and caregivers and their health care providers has been identified as a gap in the current health care system that is negatively impacting the psychosocial well-being of individuals living with serious illnesses^{xix xx}.

Enhanced cultural and religious sensitivity as well as increased involvement in decision-making are required^{xxi xxii xxiii} to ensure everyone receives the quality of care they want and need.

OVERBURDENED HEALTH CARE SYSTEM

The health care system lacks adequate capacity and resources required to fully support the practical and psychosocial needs of patients and their caregivers.

Exploring opportunities to leverage and sustain the unique strengths of hospice organizations will be critical to helping British Columbians living with a serious or life-threatening illness access person-centered care that will support them to live and die well in the place of their choosing.

A JOINT RESPONSE

It is in this context that BCCPC, BCHCPA, SOSJ, Victoria Hospice, and VIFoH came together to establish the PHWG.

The mission of PHWG was to assess the current state of hospice care in the province and act as a catalyst for the development of a path forward that empowers hospice organizations to play a leading role in person-centered care for all individuals living with serious illnesses in BC.

A CALL TO ACTION

This report provides an overview of the current state of not-for-profit hospice care in the province, highlighting the role and value of hospice organizations in the delivery of person-centered care. The challenges that are faced by hospice organizations will be explored in-depth to better understand the barriers and gaps that are currently preventing hospice organizations from achieving their fullest potential and playing an integral role in the health care system.

Following the assessment of the current state, this report provides a common vision for hospice care in BC and illustrates the existing opportunities that can be leveraged to achieve the future vision.

Finally, the report highlights a series of recommendations to pursue the path forward, through an integrated, collective approach to providing quality person-centered care for all individuals living with serious illnesses and their caregivers in the province.

Hospice Care In British Columbia

WHAT IS HOSPICE CARE?

Hospice care is an approach to care that provides comfort and support to individuals, their families, and loved ones during a serious illness, in the last stages of life, or while coping with grief and loss. Hospices help these individuals achieve the best quality of life possible by addressing their emotional, social, spiritual, and practical needs.

Persons with diseases such as cancer, congestive heart failure, chronic obstructive pulmonary disease, HIV/AIDS, and kidney failure experience difficulties managing pain, shortness of breath, fatigue, nausea, and other symptoms.

The role of hospice care is to ensure individuals are comfortable, pain-free, and able to cope with the difficult medical and personal decisions they may be required to make. The relief of pain and other symptoms is an important part of hospice care; however, hospice organizations also focus on prevention and relief of psychological and spiritual suffering.

Hospice care is more than end-of-life care; it improves the quality of life for people of any age and at any stage of the serious illness journey.

"I had a very positive experience with hospice when my sister, age 50, passed from cancer. They were wonderful. They gave her wonderful pain relief, giving us a chance to say goodbye with her not in pain. They took wonderful care of her, allowing me to take a breath and be there for her. And, everyone was on the same page. My sister didn't want any treatment, and her wishes were carried out. She passed pain-free and with dignity."

THE VALUE OF BRITISH COLUMBIA'S HOSPICE ORGANIZATIONS

Community-based, non-profit hospice care services are provided by more than seventy-one (71) hospice organizations located in urban, rural, and remote communities across BC.

Hospice organizations have been supporting BC's communities for decades. They have a long history of success in helping people living with life-limiting

illnesses and their families to have the best quality of life possible.

Hospice care complements the medical services already provided by the health care system by focusing services and resources on the unmet psychosocial, practical and spiritual needs of persons and their families.

More specifically, hospice organizations contribute numerous unique strengths to health and social care as detailed in the following:

- 1. Geographic Spread:** Hospice organizations are distributed throughout rural, urban, and remote communities in British Columbia. Uniquely placed to understand and support local needs, many of these organizations are deeply entrenched in the fabric of their communities.
- 2. Philosophy:** Hospice clinical staff and volunteers are trained to work closely with individuals and their care partners. Staff ensure each person receives the supports that matter most to them, with a focus on providing these services in the setting chosen by the individual.
- 3. Donor-Based Funding Models:** Hospice organizations are primarily funded by individual and corporate donors who support the hospice mission and related programs and services. Health authorities provide supplemental funding to support hospice organizations.
- 4. Qualified Professional Staff:** Hospice staff are highly qualified professionals who have specific training to address the needs of persons living with serious illness and their caregivers. Hospice staff have expertise in all forms of counselling, including grief and bereavement, and provide leadership in patient navigation and volunteer training and coordination. Staff are also experienced in working collaboratively with local partners, clients, and their caregivers to ensure all psychosocial and practical needs can be met in the community.

“The hospice team has been so wonderful, very caring, very informative. I can contact them at any time. It’s so reassuring.”

Hospice personnel deliver programs in their communities on a daily basis. They possess the necessary skills to implement and support expanded community programs that are specific to end-of-life at home. This expert resource in hospice organizations provides the structure needed to execute initiatives on both a regional and provincial basis.

5. **Volunteer Workforce:** In addition to highly qualified professional staff, hospice organizations are supported by a vast number of dedicated and passionate volunteers. The 2019 survey conducted by BCCPC found that over 3,500 volunteers were engaged with BC’s hospice organizations annually, in comparison to approximately 350 full-time employees. Furthermore, with an increasingly aging demographic, the number of volunteers is expected to increase significantly in the years to come.
6. **Supports for Caregivers:** Hospice organizations provide services not only to individuals with serious illnesses, but also to their caregivers and loved ones. Respite care, emotional counselling, navigation, and anticipatory grief support are some of the numerous programs and services that BC hospice organizations are currently providing to relieve caregiver burden and prepare individuals for the eventual loss of their loved ones.

With these distinctive features, hospice organizations are primed to play a pivotal role in the essential care of BC’s aging population.

Given the geographic spread, highly qualified personnel, strong volunteer workforce, and their person-centered philosophy, hospice organizations are able to support people impacted with a serious illness to live well in their communities.

As such, better integration of hospice organizations into the formal continuum of care presents opportunities for a new model of service delivery, one that should reduce the burden on the health care system while simultaneously supporting individuals with serious illnesses to live and die in the place of their choosing.

CURRENT STATE OF HOSPICE CARE

While acknowledging the unique strengths that hospice organizations can offer to the health care system, the PHWG set out to better understand the landscape of hospice care in British Columbia.

In autumn 2019, BCCPC conducted a survey of 71 not-for-profit hospice organizations in the province with the objectives of:

- Generating a deeper understanding of the variety of hospice programs and services in BC.
- Identifying the sources of funding received.
- Determining the structure and allocation of resources.

The current state assessment survey was completed by 53 hospice organizations, resulting in a **75% response rate**. The survey includes responses from rural, remote, urban, and suburban communities. [The full survey report is available on the BCCPC’s website.](#)

KEY HIGHLIGHTS FROM THE CURRENT STATE ASSESSMENT SURVEY

Hospice Services

The hospice organizations who participated in the survey reported that **they support:**

- **over 10,000 people monthly** through either their hospice palliative programs or their education programming
- **more than 300 hospice beds** across various care settings and facilities in the province

Hospice clients include individuals with life-limiting illnesses, older adults with chronic conditions and comorbidities, caregivers, and grieving family members and friends, among others.

Hospice services encompass diverse psychosocial dimensions that include the following: palliative support, vigil support, spiritual support, complementary

therapies, assistance with activities of daily living, symptom management, day programming, grief support, caregiver support, and respite programming.

These services are provided in a variety of settings including in the person’s home, long-term care homes, hospitals, and assisted living residences, **see Chart 1.**



The majority of hospice organizations also deliver a variety of education sessions for the general public to enhance their self-care skills and support engagement in advance care planning (ACP), a key enabler of person-centered care. Many hospice organizations have also established education programs to raise public awareness and knowledge of the benefits of hospice care and how to access these services when needed.

Funding

Revenue sources for hospice organizations include federal, provincial, and regional health authority funding, gaming grants, grants from not-for-profits, private donations, and fundraising initiatives. Contributions vary significantly across regions.

The few organizations that operate hospice beds reported that over 50% of their funding is provided by the government and/or the relevant regional health authority.

Conversely, almost all of the survey participants who do not operate hospice beds report that an overwhelming percentage of their funding (approximately 75%) is derived from community sources including fundraising, gaming grants, and donations.

“We work closely with the health authority but have yearly challenges with financial sustainability.”
—Hospice survey respondent #13

Human Resources

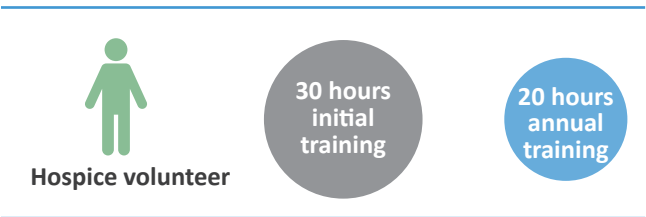
Hospice organizations that responded to the survey indicated that most of their services are provided by well-trained volunteers.

In fact, hospice staff are supported by volunteers at a nearly 1:10 ratio with 71% of hospice organizations reporting that at least 50% of volunteer hours are allocated to providing direct care and support to patients and families. For a more detailed breakdown of volunteer activities, **see Chart 2.**

“I don’t know what we would have done if we hadn’t had the support and guidance of the hospice volunteers. They made it possible for me to run errands and most importantly keep connected with my coffee group.”

Hospice volunteers receive 30 hours of basic training before commencing their hospice work through curriculum developed by the Canadian Hospice Care Association and the BCHPCA.

In addition, volunteers receive 20 hours of training annually on topics related to their work such as self-care training and facilitation of ACP sessions for the public. These training opportunities are critical, allowing volunteers to develop the skills necessary for providing quality hospice care services to the vast number of clients served by hospice organizations.



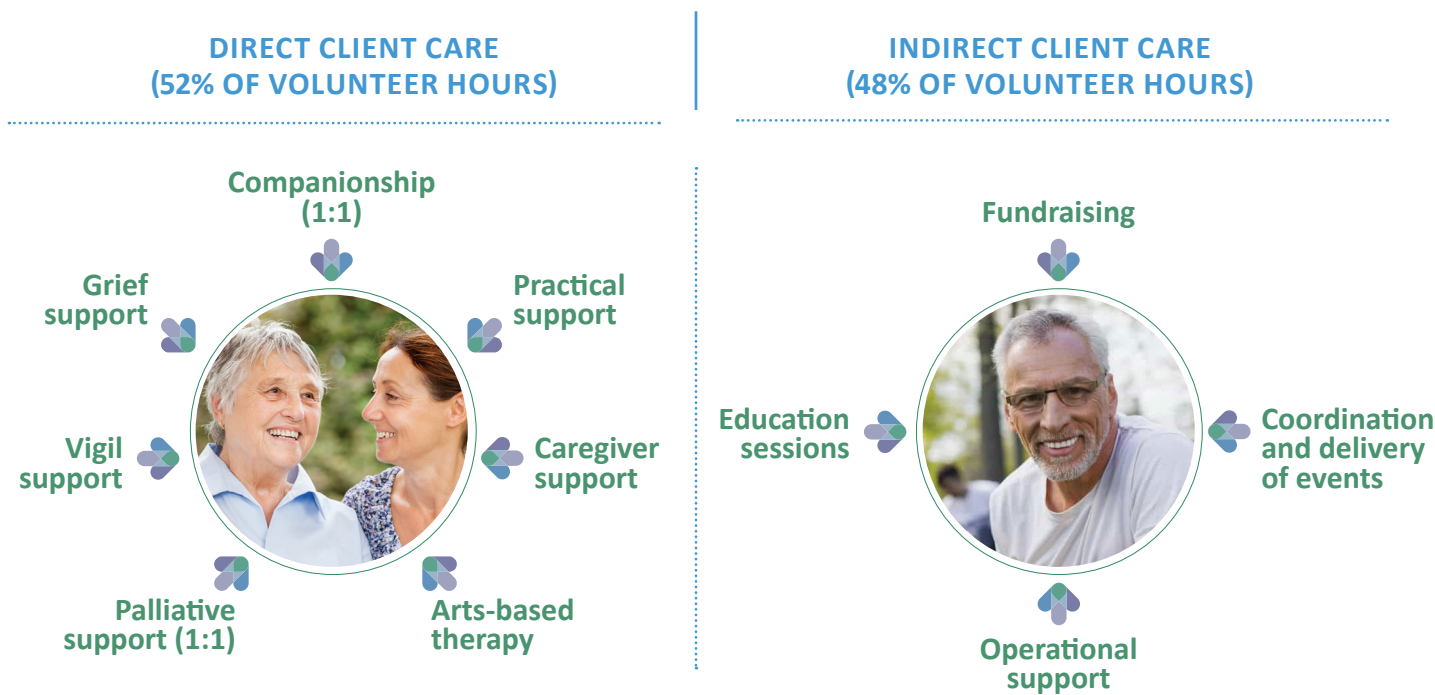
The results of the survey indicate the importance of committed volunteers as a valuable resource and highlights the unique strengths of this specialized and essential workforce. Through their volunteer networks, hospice organizations have been able to provide a wide range of direct and indirect care options to a larger segment of the BC population, supporting more individuals and their caregivers to live well in the place of their choosing.

“I trust the compilation of all the responses (to the survey) will give worthwhile information to support the future of all hospices in BC.”
—Hospice survey respondent #5

Chart 1. Percentage of hospice organizations that provide services in various care settings

CARE SETTINGS SUPPORTED BY HOSPICE SERVICES	BY STAFF	BY VOLUNTEERS
Private Homes	59%	84%
Long Term Care Facilities	50%	76%
Hospital & Acute Care Units	46%	64%
Hospital & dedicated palliative care units/beds	48%	60%
Hospice facilities with beds	46%	47%
Independent Living Facilities	35%	58%
Assisted Living Facilities	35%	67%
Other	35%	16%
Outpatient hospice facilities	7%	11%
Physician Offices	7%	4%
Homeless Shelter/Service Providers	7%	4%
Adult Day Programs	4%	11%

Chart 2. Hospice Services and Allocation of Volunteer Hours



Challenges to Hospice Care

Community-based, not-for-profit hospice organizations have many unique strengths to offer the health care system. However, they also face a number of challenges that limit their capacity to deliver quality hospice care to their fullest potential. The lack of coordination among hospice organizations and inconsistent relationships with the health care system result in variable funding and limited networking and collaboration.

Equally challenging is that the tools, resources, education, and training necessary for elevating hospice care to the highest attainable standards are often inaccessible for not-for-profit organizations. As a result, many hospice organizations continue to encounter significant barriers when integrating within the health care system. These challenges are detailed more fully in the paragraphs that follow.

PROVINCIAL COORDINATION

As independent not-for-profit organizations, hospices have traditionally operated on their own to meet the needs of their communities. Currently, no coordinated leadership is responsible for setting standards across the sector; little connection exists between organizations; and there is no province-wide strategy for the delivery of quality hospice care to individuals living with serious illnesses and their caregivers.

Yet, the provision of quality hospice care services has become a policy priority across Canada. With the release of the National Action Plan on Palliative Care^{xxv}, there is now a coordinated strategy and framework for moving forward with hospice care services at a national level. The Action Plan highlights the important role of community-based organizations in hospice care and emphasizes the need for innovative solutions to providing quality care for individuals living with serious illnesses. As such, it can serve as a roadmap for our provincial approach in BC.

A provincial hospice care policy and strategy would present opportunities for enhanced coordination and full integration of hospice care into the health care system. It would allow communication to occur more freely and frequently between organizations. Furthermore, the strategy would establish performance measures and benchmarks across the province to ensure consistency in delivering high quality hospice care.

Accordingly, a provincial strategy, in addition to a designated and funded leadership body, is needed to support hospice organizations working collaboratively toward a fully integrated seamless continuum of care.

RELATIONSHIPS WITH REGIONAL HEALTH AUTHORITIES AND THE GOVERNMENT OF BRITISH COLUMBIA

To provide quality supports for individuals living with serious illnesses and their caregivers, hospice organizations must be integrated and connected with all aspects of the health care system. However, current relationships among hospice organizations, regional health authorities, and the provincial government are not optimal for a number of reasons. First, there is no coordinating body or centralized authority within the Government of British Columbia for the overall care of persons with serious illness. As a result, there is a lack of clear policy directives for application across health regions, funding gaps for essential services provided by hospice organizations, and inconsistent communication between the provincial government and hospice organizations. Additionally, hospice organizations are not represented on provincial boards charged with overseeing palliative and end-of-life care, thereby limiting their ability to collaborate across sectors and coordinate the best possible care for their clients.

Nonetheless, hospice organizations are eager to form meaningful care partnerships with health authorities and other key stakeholders such as primary care networks, as well as home support and community palliative care teams. With their existing strengths in the provision of practical and psychosocial supports, hospice organizations are prepared to take on partnerships that will allow them to support more individuals living with serious illnesses and their caregivers across the province.

SUSTAINABLE FUNDING

Although integration of hospice care services has the potential to reduce hospitalizations and decrease overall costs in the health care system, community-based hospice organizations are often unequal partners in the planning and delivery of programs and services. Lack of recognition of the critical role of hospice

organizations has resulted in disparate funding models that negatively impact the ways in which hospice organizations work and reduce their opportunities for collaboration. Unstable funding also prevents individual hospice organizations from developing both innovative strategies and meaningful long-term plans. This creates an atmosphere of competition between organizations for the limited funding available, thereby building silos and limiting opportunities for networking and collaboration.

NETWORKING AND COLLABORATION

As hospice organizations compete for funding opportunities, organizations often operate independently rather than in collaboration with one another. As noted previously, the lack of sustainable funding results in a daily struggle to maintain services, thereby deterring hospice organizations from exploring long-term partnerships with others.

The limited opportunities for networking and collaboration also impact the accessibility and transfer of information regarding leading practices. Since few provincial conferences, events, and webinars that focus on hospice care occur, there are only a small number of opportunities to exchange knowledge and lessons learned. In addition, innovative practices are not shared widely among other hospice organizations, further exacerbating this challenge.

While current collaborations within the hospice sector are limited in scope and vary by region, the drive for building a strong network exists.

According to the results of the hospice survey, the majority of respondents expressed the need for opportunities and channels to support networking and partnerships with other hospice organizations, health care system partners, and community organizations. The roundtable participants echoed the feedback of survey respondents and called for the creation of a strong provincial body with membership from key stakeholders across the province.

“It’s encouraging that there is an attempt to understand what is going on province-wide in terms of hospice…”

A comprehensive, province-wide approach must be taken to ensure equity of access and support.”

—Hospice survey respondent #9

PUBLIC AWARENESS

The 2016 IPSOS survey showed that less than half of Canadians (49%) are aware of hospice care and only 55% are aware of palliative care^{xxiv}. Limited public awareness of hospice care is in part due to the lack of a common definition for the term. Current definitions of hospice care range from including only specialized medical care to incorporating psychosocial aspects such as emotional support, bereavement counseling, and spiritual resources. This lack of clarity, coupled with the stigma associated with conversations about death and dying, has resulted in common misperceptions about the role of hospice care as a service provided only at the end-of-life stages.

Despite the pervasiveness of this challenge, the national narrative around hospice care is now seeing promising changes. The primary goal in the National Action Plan on Palliative Care is to raise awareness and understanding of how palliative care can improve quality of life for individuals with life-limiting illnesses, specifically through public education activities on ACP and end-of-life care. Additional “re-branding” activities such as awareness campaigns and targeted education for clinicians, administrators, and politicians can also lead to further positive changes in hospice care.^{xxvi}

A VOLUNTEER WORKFORCE

Volunteers are an important resource and one of the unique strengths that support hospice organizations and their programs. The hospice volunteer workforce represents one of the more passionate, well-trained groups in the not-for-profit sector. However, heavy reliance on volunteers can pose significant risks for any organization. First, potential reductions in volunteer hours or numbers would present hospice organizations with serious barriers to the delivery of quality person-centered care, particularly in a time where the population is aging at an exponential rate. Moreover, reliance on a volunteer workforce renders hospice organizations vulnerable to potential legal risks and liability. A lack of standardized training, limited financial capacity for oversight, and diverging organizational policies on volunteer expectations can create gaps and pose risks for hospice administrators.

Nonetheless, the volunteers engaged in supporting hospice organizations are invaluable to the hospice care sector. Hospice programs with higher levels of direct care volunteer involvement consistently report



higher levels of care satisfaction from the bereaved families of hospice clients^{xxvii}. As such, developing a volunteer engagement strategy will be critical to supporting hospice organizations to attract, train, and retain a qualified volunteer workforce.

ACCESS TO EDUCATION, TRAINING, TOOLS, AND RESOURCES

In previous consultations conducted by BCCPC and BCHPCA, hospice staff and volunteers have indicated that access to education and training resources is fragmented and inequitable throughout the hospice sector for a number of reasons. First, the volunteer training curriculum and standards that are provided by BCHPCA have not been updated in several years, and as such, do not take into account recent innovations in hospice care practice.

Second, training curriculum that is developed within hospice organizations is not necessarily informed by the latest evidence-based tools and resources in hospice care, given that there is no coordinated mechanism in place for sharing these resources. This challenge is further exacerbated for hospice organizations in rural and remote communities, where fast internet connection is unreliable, limiting access to online training.

The final challenge is the limited financial support for training and education of staff and volunteers, which ultimately prevents hospice organizations from supporting their workforce to develop to its full potential.

The creation of a centralized e-hub containing a resource directory on ready-to-use tools, coupled with enhanced bandwidth in rural and remote communities, can

provide hospice staff and volunteers with the tools and training needed to provide better care to individuals living with serious illnesses and their caregivers.

CULTURAL COMPETENCY TO MEET THE NEEDS OF UNDERSERVED POPULATION GROUPS

British Columbia has become the most ethnically diverse province in Canada. Approximately 25% of residents of BC are a visible minority and another 5% of the population are Indigenous ([Government of BC website](#))^{xxviii}. Providing hospice care to newcomers, Indigenous peoples, and racial minorities, requires understanding of the norms, views, and beliefs in each culture in relation to health, illness, decision-making and death.

Current training and educational programs for hospice staff and volunteers do not adequately cover cultural competency requirements. Additionally, staff and volunteers often do not have access to further training to develop these skills.

Hospice organizations are committed to creating a welcoming environment that embraces diverse perspectives, cultures, and experiences. They also have long standing roots in their respective communities, sharing in the identity surrounding them. Although current training and education does not support the development of cultural competency, hospice organizations can learn from the broader institutional equity, diversity, and inclusion (EDI) movement. Combining their community ties with learnings from other organizations who are leaders in EDI, hospice organizations in BC are well-situated to become a model for culturally competent care.

ENVISIONING THE FUTURE OF HOSPICE CARE

On November 13, 2019 the PHWG sponsored a roundtable of 45 participants who were selected to represent the variety of professionals involved in hospice palliative care, inclusive of representatives from the provincial government, hospice organizations, regional health authorities, not-for-profits, and research institutes. For a full list of roundtable participants, see Appendix B.

The roundtable stakeholders completed a series of exercises which focused on confirming the unique

strengths of hospice services that can be leveraged to better support individuals with serious illness to live and die well in the setting of their choice.

A COMMON VISION

This collaborative exercise aimed to leverage the collective wisdom of participating stakeholders and leaders to develop a common vision for the future of hospice care in BC.

There was overwhelming agreement among the roundtable participants on the vision statement for hospice care in BC.

Through small group discussions and a strengths, weaknesses, opportunities, and threats (SWOT) analysis, the roundtable defined a set of guiding principles to inform the development and implementation of solutions for improved hospice care that will best support individuals living with serious illnesses and their caregivers in BC.

Guiding Principles

Hospice care services must be accessible to all British Columbians impacted by a serious or life-limiting illness

Hospice care services must adopt upstream or preventative interventions that enable person-centered care and improve quality of life

Hospice care services must be culturally competent and culturally safe

Hospice organizations must demonstrate accountability for the quality of their hospice care services

Hospice care services must be sustainable

Hospice care services must be fully integrated into the health care system



Vision

A future where hospice organizations are meaningful and recognized partners in the provision of accessible, adaptable, accountable, and sustainable hospice care that improves the quality of living and dying for individuals with serious illnesses across British Columbia.

Key Recommendations

Form an Alliance *to lead collective efforts towards improved, integrated, and sustainable hospice care.*

The roundtable stakeholders unanimously agreed to establish an Alliance with representatives from hospice organizations, government, health authorities, professional organizations, researchers, health care facilities, charities and patient and family groups, to accelerate improvements in hospice care in BC.

Based on the stakeholders' recommendations, the Alliance will assume a leadership role across sectors to actualize the vision and to leverage the hospices' strengths in order to address the gaps, challenges and barriers identified in this report.

The Alliance's mission will be to empower hospice organizations to assume a more integral role in addressing the increasing demand for person-centered hospice care in these challenging times.

THE 10-STEP PATH

Each step forward in the path is critical for driving stakeholders' efforts forward to fulfil the common vision as defined at the Roundtable.



1. DESIGN A STRONG, INTEGRATED STRUCTURE FOR THE ALLIANCE.

In order to support the development of a common vision for hospice care in BC and dissolve the silos that are hindering collaboration, the Alliance will require a strong and integrated governance structure. Members of the roundtable agreed to co-design the Alliance's membership and governance structure as well as terms of references. The roundtable emphasized that the Alliance must secure funding to cover the costs associated with the implementation of the path forward.

The roundtable also emphasized that improved, meaningful engagement with the Ministry of Health and regional health authorities is needed to support change. Enhanced collaboration among hospice organizations is also recommended as it accelerates advocacy and supports more streamlined relationships with government and non-government organizations.



2. SECURE RELIABLE FUNDING FOR HOSPICE ORGANIZATIONS.

Community hospice organizations currently receive funding through a variety of sources such as grants, fundraising activities, donations, and agreements with regional health authorities or provincial/federal governments. Moreover, certain hospice organizations have greater existing financial and human resource capacity than others when participating in networking activities. The Alliance will advocate for a sustainable funding source for all hospice organizations in BC.

3. ADVOCATE FOR A PROVINCIAL POLICY AND STRATEGY FOR HOSPICE CARE IN BC.

In the [2013 provincial End-of-Life Care Action Plan](#), the Government of British Columbia sets health system accountability and efficiency as a priority area for future action. The actions highlighted under this priority area include the development of performance measures for end-of-life care, the implementation of improved clinical guidelines, as well as streamlining of policies and processes to improve access to services. The Alliance will advocate for an update to the 2013 Action Plan through the development of a provincial strategy for hospice care in BC. The new provincial strategy should provide the sector with a roadmap for the development of performance measures and highlight opportunities for collaboration that streamline the continuum of care for individuals living with serious illnesses and their caregivers.

4. ESTABLISH A COMMON DEFINITION OF HOSPICE CARE IN BC.

The goal of creating an organization that represents a unified voice of hospice organizations across BC requires that the province adopt a common definition of hospice care. Currently, there are many different iterations of the definition. The roundtable recommended that the first action of the Alliance should be the selection of a single definition for hospice care which can be used across government, industry, not-for-profit, and community in BC.

5. ESTABLISH STANDARDS AND AN ACCREDITATION PROGRAM FOR HOSPICE ORGANIZATIONS TO ENSURE QUALITY AND CONSISTENCY IN HOSPICE SERVICES ACROSS THE PROVINCE.

Hospice organizations are integral to an effective learning health care system where promising practices can be scaled, spread, and tailored to the unique needs of everyone they serve. Currently, there is a lack of common terminology, few opportunities for consistent data collection, and little clarity around what client outcomes best indicate the successful provision of hospice care.

To further the possibilities of collaboration among hospice organizations and to advance learning between organizations, the Alliance will facilitate the development of standards, performance indicators, and an accreditation program for hospice services by forming a working group to determine appropriate performance measurements in hospice care.

6. RAISE PUBLIC AWARENESS OF THE IMPORTANCE OF PERSON-CENTERED CARE AND ADVANCE CARE PLANNING EDUCATION PROVIDED BY HOSPICE ORGANIZATIONS IN BC.

The term “hospice care” carries with it the stigma of end-of-life or death. This connotation, coupled with the absence of a shared definition for hospice care, has resulted in a lack of awareness among the general public regarding the work of hospice organizations and their role in supporting individuals with serious illness to live and die at home and in their communities.

The roundtable recommended the Alliance launch a media strategy to raise awareness and educate the public on the care and services provided by hospice organizations in communities. The strategy will take an approach of leveraging existing networks through mailing lists, community events, and provincial partnerships to communicate the vision and services of hospice care, as well as incorporate a media campaign that fosters empathy and support for the work of not-for-profit hospice organizations.



7. ESTABLISH CORE COMPETENCIES AND A PROVINCIAL EDUCATION PROGRAM FOR HOSPICE STAFF AND VOLUNTEERS.

Current volunteer education and training resources are not standardized or accredited across organizations. The Alliance will establish core competencies and develop a consistent in-person and online training program for hospice staff and volunteers to ensure the highest quality of care for clients.



8. DEVELOP AN EFFECTIVE VOLUNTEER ENGAGEMENT STRATEGY.

Hospice organizations rely heavily on volunteers to support service delivery for individuals living with a serious illness and their families.

Continuing to leverage volunteers as a significant resource presents more opportunities than challenges. However, hospice organizations must ensure that their volunteers continue to be meaningfully engaged and motivated. The Alliance will be responsible for developing a broader, effective volunteer engagement strategy for hospice volunteers.



9. LEVERAGE TECHNOLOGY TO FACILITATE NETWORKING, TRAINING, AND KNOWLEDGE EXCHANGE.

The Alliance will act as the catalyst for knowledge exchange among hospice organizations in BC. The opportunities to collaborate and learn from one another will support an effective learning health care system and elevate the quality of hospice care among organizations in the province.

The roundtable recommended that the Alliance create an online platform to foster ongoing communication, collaboration, and education between hospice organizations and its broader members. The platform should include a directory of members, a hub of resources on promising practices in care, ongoing webinars for knowledge sharing, and more. Furthermore, the online services could be used to support other components of the Alliance's mandate. For example, the platform can be structured as a collaborative workspace where hospice organizations can work jointly on initiatives of mutual interest. Additionally, the platform could support the delivery of a standardized training and accreditation program for hospice organizations.



10. EXPLORE AND FACILITATE OPPORTUNITIES FOR MEANINGFUL PARTNERSHIPS BETWEEN HOSPICE ORGANIZATIONS WITH UNDERSERVED COMMUNITIES IN THE PROVINCE.

Applying an EDI lens is essential to ensuring that hospice care is accessible and appropriate for all British Columbians. Nonetheless, understanding the needs of traditionally underserved populations such as Indigenous Peoples, newcomers, and visible minorities, requires thoughtful and critical listening skills. With many other networks and organizations focusing their energies on developing effective EDI policies, hospice organizations can learn from the experiences of other sectors and leverage that knowledge for meaningful change.

Therefore, the roundtable recommended that the Alliance focus its work on initiating ongoing dialogue with underserved communities to better understand their unmet needs. Furthermore, the Alliance should explore partnership initiatives with institutional leaders in EDI in order to identify opportunities for better meeting the diverse needs of the cultural, linguistic, and ethnic minorities they serve.

The Path Forward

The population of BC is experiencing an important demographic shift. As the proportion of the population over the age of 65 continues to rise, our province's already overburdened health care system will need to adapt in order to meet the needs of individuals living with serious illness and their caregivers.

Community-based, not-for-profit hospice organizations are ready to address the challenge. Hospice organizations are geographically spread out across rural, remote, and urban areas of the province and have strong ties with the communities in which they operate. They employ highly qualified professionals who can effectively deliver psychosocial and practical supports to their clients. They also have a vast network of dedicated and passionate volunteers who are well-trained in the provision of direct care supports and community-based education sessions. Finally, hospice organizations operate with a person-centered philosophy and, as a result, have long standing expertise in working collaboratively with individuals and their

care partners to ensure they receive the supports that matter most to them in the setting of their choice.

Capitalizing on these strengths will result in a future with more accessible, inclusive, sustainable, and integrated hospice care for British Columbians. The 10-step path recommended in this report provides a roadmap for revitalizing the hospice care sector and, most importantly, establishing the leadership needed to drive our province forward.

To achieve this vision, collective action is needed. Hospice organizations, regional health authorities, the Government of British Columbia, community organizations and other key stakeholders must come together to translate our ideas into action. Together, we can overcome some of the challenges that our health care system is currently experiencing and improve quality of life for all British Columbians living with serious illnesses and their caregivers. It is time for collaboration and innovation. Let us begin moving forward together.



Appendix A — Founding Organizations of the Provincial Hospice Working Group

BRITISH COLUMBIA CENTRE FOR PALLIATIVE CARE (BCCPC)

The BCCPC is a provincial organization that was established in 2013 by the Ministry of Health to accelerate improvement in palliative care and support British Columbia's End-of-Life Action Plan. The core work of BCCPC focuses on development innovative solutions and spread of best practices in palliative care and advance care planning, provision of education for health care professionals, assistance with the creation of supportive community networks for patients and families, and empowering British Columbians with the resources they need to make informed decisions for themselves and their loved ones.

Representative: Dr. Eman Hassan, Executive Director

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION (BCHPCA)

The BCHPCA is a not-for-profit membership organization, which has been representing individuals and organizations committed to promoting and delivering hospice care to British Columbians since 1986. Their mission is to spark action through conversations, relationships, and partnerships in order to support dying and grieving well.

Representative: Donna Flood, President

VANCOUVER COMMANDERY OF THE SOVEREIGN ORDER OF ST. JOHN OF JERUSALEM, KNIGHTS HOSPITALIER (SOSJ)

The Vancouver Commandery of SOSJ is a federally constituted not-for-profit corporation dedicated to the support of palliative care in British Columbia. Their vision is to play a leadership role in the funding and delivery of hospice care programs based on embracing three priorities: strengthening compassionate communities of care, training and education, and innovation and excellence.

Representative: Susan Scott Gabe, Director

VANCOUVER ISLAND FEDERATION OF HOSPICES (VIFoH)

VIFoH is a registered BC society of not for profit community hospices committed to providing hospice care to each person that matters most to them. The purpose is to speak with one voice to the government and collaborate to develop and deploy best practices to hospices across Vancouver Island as they offer support and education to people who are living with dying, caregiving and grieving.

Representative: Terri Odeneal, President

VICTORIA HOSPICE

Victoria Hospice has provided quality end-of-life care since 1980. As a registered charity, their mission is to enhance the quality of life for those facing life-limiting illness, death, and bereavement through patient and family-centre care, education, research, and advocacy. Each year, their interdisciplinary staff and 300+ volunteers care for approximately 1,000 patients, whether at home or on their 17-bed inpatient unit in the Royal Jubilee Hospital; 2,500 individuals through grief support and counseling programs; and 900+ individuals through education and training.

Representative: Kevin Harter, Chief Executive Officer

AGE-WELL NATIONAL INNOVATION HUB ADVANCING POLICIES AND PRACTICES IN TECHNOLOGY AND AGING (APPTA) (ROUNDTABLE FACILITATION)

APPTA's vision is drive policy innovation that improves the future of aging in Canada. By mobilizing the power of research & technology, collaboration, and innovation, they aim to advance evidence-informed decision-making that positively impacts the lives of older Canadians.

Facilitator: Candice Ashley Pollack, Executive Director

Appendix B — Roundtable Event

ROUNDTABLE PARTICIPANT LIST

The Provincial Hospice Working Group would like to thank the following individuals for contributing to our Roundtable meeting on November 13, 2019.

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Division)

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Dr. Gloria Gutman

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Barb Maclean

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SMALL TABLE FACILITATORS AND EVENT SUPPORT

The Provincial Hospice Working Group would like to thank the following individuals for volunteering their time and energy to ensure the success of the roundtable.

Jennifer Bond

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Gretchen Hartley

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End Notes

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