



Covenant Health
Palliative Institute

Building Compassionate Communities: Raising Awareness of Palliative Care and Advance Care Planning in Alberta

An Action Planning Report

June 2022

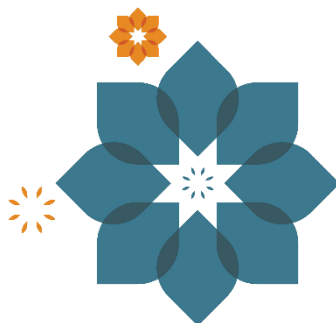


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Land Acknowledgement

We are on Treaty 4, 6, 7, 8 and 10 territories within Alberta. We acknowledge the many First Nations, Métis and Inuit whose footsteps have marked these lands for generations. We are grateful for the traditional Knowledge Keepers and Elders who are still with us today and those who have gone before us. We recognize the land as an act of reconciliation and gratitude to those whose territory we reside on or are visiting. We honour the Indigenous knowledge and ways of care for the land that provide us with a model of living well in connected and interdependent communities.

Reflection

Our theme, and the gathering today, reminds me how it takes a community working together to influence and build a future where its members can flourish. When we come together with a diversity of perspectives and our unique lived experiences – together we can best consider how to build the Compassionate Communities that we need and want throughout our lives – and are essential during times of illness or as we approach the end of our life.

It requires that we honour our past, honestly recognize our realities today and consider how we can all participate to help create the future we desire.

"We inhabit the world we choose to see; may we not lose sight of love today. As we feel the depths of war, may we also remember the possibilities for peace. When we see someone suffer, may we not forget how many people we can help. May hope and faith in possible tomorrows inform our views of today. If we see fear, and work for love; fear will always fall away". [Marianne Williamson, May We Not Lose Sight of Love Today]

May we commit to actions that nourish and support our well-being and health.

May we each be blessed with peace of mind and heart.

May we be renewed and strengthened in faith and in community.

May we have the grace, wisdom and courage to do whatever we are called to do today.

May we offer support to one another as sensitive topics are explored.

May we be inspired to continue to support, advocate and provide care in the places we have opportunity to serve.

May we not lose sight of love today.





Konrad Fassbender
Scientific Director
Covenant Health Palliative Institute



Louise Kashuba
Corporate Director
Covenant Health Palliative Institute

On behalf of the Scientific and Organizing Committees, we are grateful to everyone who registered and participated in our Compassionate Communities Forum on March 19, 2022. It has been conceived as the first of three planned annual meetings reflecting the themes of **building**, **growing** and **sustaining** Compassionate Communities in Alberta.

As defined by *Public Health Palliative Care International*, “death, dying, loss and care is everyone’s responsibility.” Compassionate Communities is an innovative public health approach that regards the community as an equal partner in caring for those who are seriously ill, dying, caregiving and grieving. Our contribution to this global movement is to recognize the need for early awareness by community organizations and the public as a necessary foundation upon which Compassionate Communities are built. At this meeting, we explored the intertwined roles of advance care planning and palliative care; we also broadened the scope of advance care planning beyond health to include legal, financial and personal considerations.

This report arises from an effort to identify, understand and engage stakeholders with a shared interest in Compassionate Communities. Through a series of systematic reviews, environmental scans and surveys, we have identified resources to help individuals and organizations support the public, patients and families in preparing for and living with serious illness. In our work, we identify best practices, organizations and resources that promote Compassionate Communities across Alberta, Canada and the world. A comprehensive communications and marketing strategy has been designed to promote resources to help Albertans prepare and cope with serious illness.





The forum set out to accomplish three objectives:

1. To better understand the Compassionate Community concept through a series of speakers who shared learnings on the implementation of Compassionate Communities across Canada and globally. The speakers and presentations were not meant to be exhaustive but rather to help achieve a common understanding and vision for working together.
2. To highlight the five resources the Palliative Institute is implementing across Alberta through five corresponding workshops.
3. In order to listen, understand and generate an action plan, hold a series of world cafes; the resulting recommendations from which will guide the Covenant Health Palliative Institute.

Acknowledgements

The Covenant Health Palliative Institute acknowledges the Compassionate Communities Forum Scientific and Organizing committees: Dr. Konrad Fassbender, Dr. Mary-Ann Shantz, Dr. Sheree Kwong See, Dr. Martin LaBrie, Dr. Esha Ray Chaudhuri, Louise Kashuba, Hussain Maqbool Ahmed, Maril Murray, Melanie Doiron, Michelle Goonasekera, Tyler Hamil, and Daina Sparling.

We thank keynote speakers Dr. Allan Kellehear, Dr. Cathy Payne and Shyla Mills; Canadian panel speakers Dr. Eman Hassan, Dr. Hsien Seow and Bonnie Tompkins; and all those who offered welcoming remarks: Jason Copping, Alberta's Minister of Health; Patrick Dumelie, Chief Executive Officer at Covenant Health, Covenant Care and Covenant Living; Conny Avila, Covenant Health Chief Innovation Officer; and Bonnie Tejada, Covenant Health Director of Mission and Spirituality.

This project would not be possible without the agreements from the following organizations who have shared their tools for adaptation (selected) and promotion: Canadian Virtual Hospice & Elders Circle, All-Ireland Institute of Hospice and Palliative Care, Palliative Care Queensland, Death Cafe, and the Government of Alberta: Ministry of Seniors and Housing.

We are grateful to BUKSA Conferences + Associations for event management and logistics support, and to all members of the Covenant Health Palliative Institute and extended Covenant family who contributed to this event's success.

Lastly, thank you to all participants and those who expressed interest in Covenant Health Palliative Institute's inaugural Compassionate Communities Forum. Without your involvement and continued support, this report and its recommendations would not have been possible.





Covenant Health & the Palliative Institute

Covenant Health

Palliative care is a part of Covenant Health's heritage and continues to be a priority today. This began with the Sisters of Charity (Grey Nuns) of Montreal who came to Alberta in 1863 with a calling to dedicate their lives to caring for the sick and vulnerable.

The Grey Nuns recognized the need for palliative care and established the Edmonton's first hospital-based program at the Edmonton General in 1985. The program grew out of an identified need for more all-encompassing, trans-disciplinary approaches, and a better understanding of the complex and evolving nature of pain.

In 1988, the Tertiary Palliative Care Unit at the Grey Nuns Community Hospital was established and it has evolved into a world-class, multi-disciplinary program for practitioners, students and researchers from around the world.

The Grey Nuns were also instrumental in the creation of a regional palliative care program in 1995 (now known as the Edmonton Zone Palliative Care Program) and the Annual Palliative Education & Research Day conference, now hosted by the Palliative Institute.

The Institute

In 2012, Covenant Health launched the Palliative Institute, envisioning a future where every Albertan is able to make informed choices about their present and future health care, and where caregivers have the knowledge, expertise and resources to support them.

The goals of the Palliative Institute are to increase palliative care capacity to address gaps in service within Canada, increase the use of advance care planning and advocate for a robust national palliative and end-of-life care system.

The five pillars of the Palliative Institute are:

1. **Policy:** Influencing the development of policies that will improve the quality of palliative care through research on best practices and education.
2. **Education:** Promoting palliative and end-of-life care learning and education.
3. **Clinical support:** Influencing clinical practices based on leading practice and utilizing knowledge obtained through research to improve the quality and comprehensiveness of palliative and end-of-life services
4. **Research:** Developing knowledge through research.
5. **Community outreach:** Developing and strengthening partnerships and engaging related communities in support of palliative and end-of-life care.

Further information about the Covenant Health Palliative Institute and its projects can be found [here](#). More information on palliative care, advance care planning and compassionate communities, including definitions are included.





Compassionate Communities Forum

The following recordings and presentations from this event can be review by visiting our Forum website at CompassionateCommunities.care and using the password “Palliative22”.

Program Summary

Opening comments were made by Alberta’s Minister of Health Jason Copping, Covenant Health, Covenant Care and Covenant Living Chief Executive Officer Patrick Dumelie, Chief Innovation Officer Conny Avila, and Covenant Health Director of Mission and Spirituality Bonnie Tejada.

To draw large and diverse participation from those invited, the event had an engaging program that included keynote addresses by topic experts from the United States, Ireland and Australia, and a panel discussion with Canadian leaders on palliative care and advance care planning.

Dr. Allan Kellehear, founder and one of the leading advocates of the Compassionate Communities Approach to palliative care, provided the opening keynote address with the history, evolution and continued importance of the movement.

Shyla Mills of Palliative Care Queensland and Dr. Cathy Payne of the All Ireland Institute of Hospice and Palliative Care each provided remarks and answered questions on innovative initiatives each of their organizations are engaged in to increase palliative public awareness.

A Canadian panel discussion was moderated by Dr. Martin LaBrie, clinical professor with the University of Calgary’s Division of Palliative Medicine. The panel illustrated innovative Canadian approaches with highlights provided by: Dr. Eman Hassan ([British Columbia Centre for Palliative Care](#)), Dr. Bonnie Tompkins ([Pallium Canada](#)) and Dr. Hsien Seow ([Waiting Room Revolution](#)).



A common vision and exemplars of the Compassionate Communities movement was followed by a high-level presentation and summary of the Palliative Institute Grants, which provided the context for the workshops and world cafes.





Resource Workshops: Participants were invited to attend one of five resource workshops, the tools of which are designed to increase public awareness of palliative care and advance care planning in Alberta. The full citations for these five tools can be found in the Key References section at the end of this document.

For each workshop, participants were asked questions, provided suggestions and commented on adoption, adaptation and/or promotion of these resources across Alberta. The focal areas, resources and descriptions are summarized as follows:

Focal Area	Tool	Tool Description
Increasing comfort talking about death and dying	Death Cafe	A café-style event that provides a safe space for conversations about death and dying with no agenda, objective or themes.
Improving understanding of palliative care	Introduction to Palliative Care	A free self-directed online course to help members of the public better understand palliative care.
Building community support for palliative care	PalliLearn	A series of short educational courses aimed at building community knowledge and capacity.
Encouraging planning ahead	Coming Full Circle Workbook	An interactive workbook to prompt reflection and conversation about wishes for future health care.
	Advance Care Planning Alberta Toolkit	Comprehensive Alberta-specific resource that ties advance care planning with legal and financial concepts.

World Cafes: Participants were invited to attend world cafe sessions to discuss opportunities, challenges and to make recommendations from the perspective of the following communities:

- Legal, financial planning & insurance providers
- Hospice & palliative care societies
- Libraries
- Senior serving organizations
- Faith and cultural communities

The focus of the current report is to capture and synthesize recommendations emanating from those discussions.

The conference concluded with a high-level summary of the action plan, a preliminary overview of a commensurate website, an invitation to review this report and to announce next year’s Forum.





Recommendations

The purpose of the 2022 Compassionate Communities Forum was to meet with key stakeholders and community partners to facilitate dialogue and exchange ideas that would inform a series of concrete actions. Through action planning, the Palliative Institute has synthesized the feedback attendees provided into measurable and achievable actions. Through structured, thematic synthesis of participant discussion, a series of recommendations was identified. Where possible, the role of community partners and key stakeholders were highlighted.

Recommendations are aggregated and prioritized as follows:

- Level 1:** Recommendations directly related to the Advance Care Planning Alberta or Palliative Care Public Awareness projects' ongoing or planned activities led by the Palliative Institute.
- Level 2:** Recommendations aligned with the Advance Care Planning Alberta or Palliative Care Public Awareness projects' objectives led by partners and stakeholders with support by the Palliative Institute.

Legal, Financial Planning & Insurance Professionals

Recommendation 1: Encourage the use of five resource and educational tools by legal, financial planning and insurance sector professionals

Goal: Support professionals from the legal, financial and insurance sectors as they interact with their clients and colleagues on the topics of palliative care and advance care planning. Leverage opportunities to promote the five tools under development by the Palliative Institute and adapt content to these professionals for future adaptations.

Level: 1

- **Action:** Provide existing key stakeholders from the legal, financial, and insurance sectors with adaptations of Advance Care Planning AB Toolkit, Death Cafe, Coming Full Circle Workbook, PalliLearn, and Introduction to Palliative Care as client tools.
- **Action:** Expand legal, financial, and insurance planning stakeholder list to reach a broader audience





Recommendation 2: Promote the benefits of having conversations about wishes, values and beliefs between Albertans and legal, financial planning and insurance sector professionals

Goal: Challenge the timing at which the typical Albertan has advance care planning discussions by adapting the mechanisms used to disseminate public legal information and increase public awareness.

Level: 1

- **Action:** Create a one- to two-page discussion guide that synthesizes the key messages of the five tools and assists lawyers, financial planners, and insurance professionals in clarifying their clients' wishes, values, and beliefs before outlining options for advance care planning documentation.
- **Action:** Establish working relationships with key stakeholders from these sectors to seek formal agreement to promote their independent educational resources on the new Palliative Institute website.

Recommendation 3: Clarify what is essential advance care planning documentation in Alberta

Goal: Provide clarity to the Alberta public and community organizations of what constitutes essential advance care planning documentation.

Level: 1

- **Action:** Create a resource guide that delineates which legal documents are (a) necessary and (b) optional when completing advance care planning with a lawyer or financial planner.

Recommendation 4: Move discussions of advance care planning and legal documentation upstream

Goal: Have Albertans discuss legal documentation and advance care planning before the onset of any serious, life-limiting illness.

Level: 1

- **Action:** Create an early-intervention resource guide that addresses the need for legal documentation before diagnosis of serious illness or loss of capacity.
- **Action:** With involvement and support from key stakeholders, design, distribute and encourage messaging that encourages adult Albertans of all ages and stages of life to engage in advance care planning. This will allow Albertans to think ahead to the financial implications associated with palliative and end-of-life care, incapacitation or death.





Recommendation 5: Amplify information and resources to key allied professionals

Goal: Pursue strategic partnerships with allied health and adjacent professionals to provide education. Act as an intermediary resource for advance care planning materials related to the legal, financial, and insurance sectors.

Level: 2

- **Action:** Connect with Family and Community Support Services (FCSS) to introduce Palliative Institute projects and promote the benefit of providing palliative care and advance care planning information and resources. Leverage the important role of social workers as professionals working in health, social service and legal settings.
- **Action:** Outreach to the Alberta College of Social Workers to advocate for equipping social workers with palliative care and advance care planning information and resources.
- **Action:** Engagement with the funeral planning industry and faith leaders that support end-of-life planning. Understand their role and provide them access to legal, financial and other advance care planning-related resources that would support these interactions.
- **Action:** Explore and pursue both formal and informal opportunities to provide information and education to interested groups, sectors and professionals with an end goal of educating the public.





Hospices & Hospice Palliative Care Societies

Recommendation 6: Engage lesser-known but involved palliative care support groups recommended by participants

Goal: Engage lesser-known groups throughout Alberta involved in palliative, end-of-life and hospice care, and their related support networks. Promote Compassionate Communities as a means to help address their specific needs.

Level: 1

- **Action:** Establish working relationships with key stakeholders from lesser-known groups, including end-of-life doulas, mental health groups, Death Cafes, caregiver associations, groups that support patients to die in their homes, and men's support groups focusing on death, dying and grief.
- **Action:** Review and adapt the Palliative Institute's existing equity, diversity and inclusion protocol to specifically address engaging these lesser-known groups

Recommendation 7: Cross-community elevation of existing initiatives and events to promote and foster the Compassionate Communities movement

Goal: To share existing community activities that can stimulate cross-community connections, increase public understanding of Compassionate Communities and create pride in fostering a caring environment in Alberta.

Level: 2

- **Action:** Engage existing partners and key stakeholders with provincial reach (ie. Alberta Hospice Palliative Care Association) and request that they amplify community activities on their existing event listings pages.
- **Action:** Create an online communication framework for community groups to access and provide event details intended to streamline dissemination to partners and stakeholders who agree to amplify community events on their existing webpages.





Libraries

Recommendation 8: Leverage the role of libraries as community hubs and librarians as community facilitators

Goal: Capitalize on the role of libraries and librarians as intermediaries for the public to learn about and access community resources, activities and networks. Enable libraries to more effectively deliver palliative care and advance care planning information and resources.

Level: 1

- **Action:** Explore and pursue opportunities to provide education and support to librarians. Deepen their knowledge and understanding of palliative care and advance care planning and awareness of educational resources. Librarians provide valuable one-on-one support to patrons and assist in resource access and navigation of health care services.
- **Action:** Engage and collaborate with libraries to deliver the Palliative Institute's five tools to communities across Alberta. Libraries are community hubs that provide neutral, accessible, public space for diverse communities.
- **Action:** Engage and collaborate with libraries to promote the five resource and educational tools and the Palliative Institute website. Libraries promote educational resources and events via newsletter and by their online web presence and social media platforms.
- **Action:** Collaborate with libraries to explore opportunities to make physical materials available to local communities across Alberta through interlibrary loans. Libraries offer books and technological support for patrons to meet their needs.
- **Action:** Together with libraries, co-create book lists related to palliative care, advance care planning, grief, loss and dying tailored to different groups and audiences.
- **Action:** Introduce existing palliative care stakeholders to their local libraries. Help facilitate working relationships with palliative care experts, Compassionate Community organizations and lesser known groups involved in palliative care to deliver related public education to the community.





Senior Serving Organizations

Recommendation 9: Identify and pursue opportunities with other potential community facilitators recommended by participants

Goal: Expand opportunities for the public to access palliative care and advance care planning education and resources within their communities by identifying and leveraging additional community facilitators.

Level: 2

- **Action:** Pursue a closer working relationship with Healthy Aging CORE Alberta and similar Alberta-based organizations dedicated to amplifying opportunities and resources for community-based senior serving organizations. Propose the creation of space on their websites for palliative care, advance care planning or Compassionate Communities discussions and resources.
- **Action:** Explore ‘wellness fairs’ taking place in communities across Alberta; determine if, and to what extent, palliative care and advance care planning information and resources could be elevated at these events.
- **Action:** Communicate funding and other opportunities for smaller organizations and informal groups intended to fill gaps that exist in community education. For example, explore and share opportunities with the Multicultural Health Brokers Co-Op to expand their existing seniors program to further include palliative care and advance care planning information.
- **Action:** Engage organizations that support persons living with dementia, including lesser-known groups involved in palliative care. Understand and better support their role in caring and providing crucial information to a population whose diagnosis presents unique trajectories and challenges for advance care planning and palliative care.





Culture & Faith Communities

Recommendation 10: Proactively engage and meaningfully involve Indigenous communities, diverse faith communities, and non-religious Albertans.

Goal: Ensure that the Palliative Care Public Awareness and Advance Care Planning Alberta project deliverables reflect the perspectives and address the needs of diverse communities across Alberta.

Level: 1

- **Action:** Expanded outreach to Elders, Indigenous community leaders and Indigenous scholars on Palliative Care Public Awareness and Advance Care Planning Alberta project activities and scholarly byproducts.
- **Action:** Connect with religious leaders of diverse groups, including newcomers, to better understand and address specific need and perspectives.
- **Action:** Encourage a patient-centric approach to understanding and addressing palliative care and advance care planning, weighing patient values, wishes and beliefs above that of cultural norms and standard practices. Accept and promote alternative perspectives and approaches to deliver knowledge and resources to specific communities.

Recommendation 11: Elevate training opportunities for faith leaders, volunteers and end-of-life doulas

Goal: Equip those performing supportive roles for those living with life-limiting illness, death, dying, loss and grief within specific communities, such as faith leaders, cultural community volunteers and end-of-life doulas, with the skills and training to provide effective support.

Level: 2

- **Action:** Provide a forum for faith communities to gather and discuss key considerations for the five resource and educational tools, such as what content should be included in any adaptations of the PalliLearn Community Education modules.
- **Action:** Connect and foster closer relationships between end-of-life doulas and faith community stakeholder groups such as prayer teams to facilitate the sharing of resources and knowledge between those in similar supportive roles.



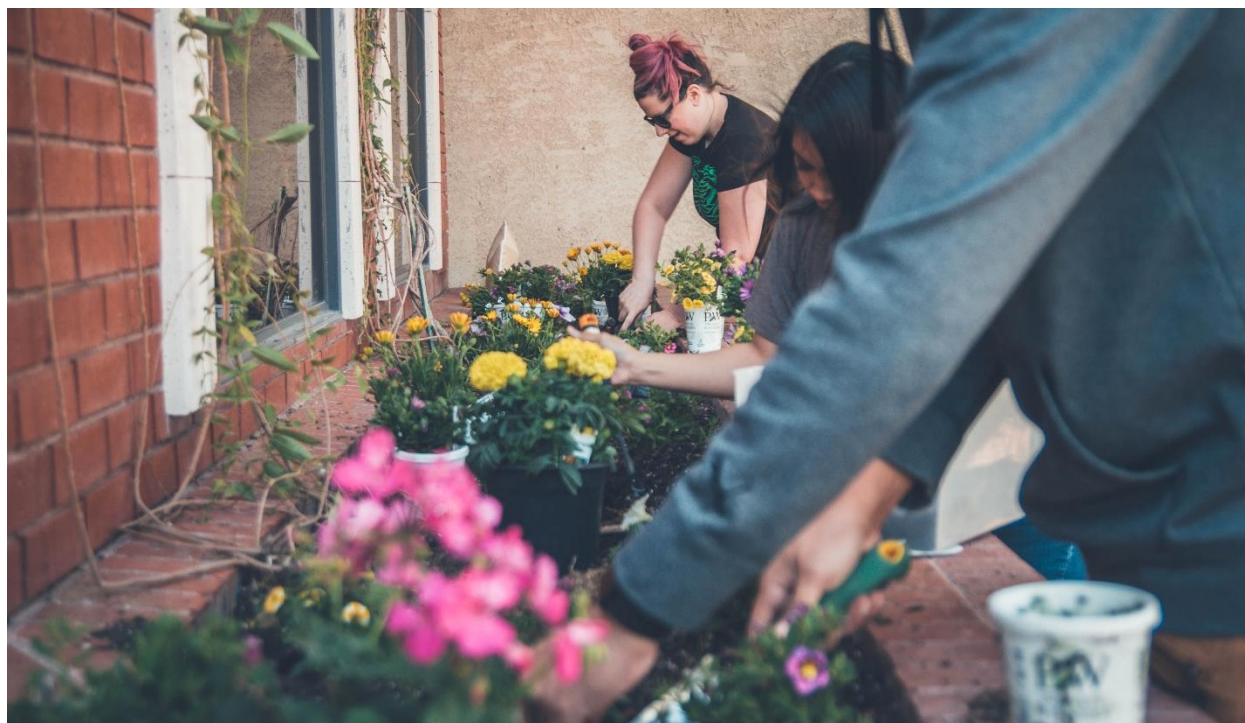


Next Steps

The recommendations contained in this report will guide the work by the Palliative Institute and stakeholders over the next year. They will be used by the advisory committees and working groups to characterize and prioritize work plans and deliverables. We hope that these recommendations serve to recognize and advocate for the importance and role of stakeholder organizations.

The World Cafe template will be used to guide further discussions with Compassionate Communities partners. At the time of this report, World Cafes and ensuing recommendations have arisen from engagement of CORE Alberta and Covenant Health Community Boards. Additional discussions will provide an opportunity to reinforce and build upon this work. Additional recommendations will supplement the 11 contained in this report.

Our next Compassionate Communities Forum will take place in 2023! We will use this opportunity to provide a report card on our progress related to the recommendations. The theme of next year's Forum (Growing Compassionate Communities in Alberta) will build on our inaugural efforts.





Covenant Health is proud to continue our mission to seek out and respond to the palliative care needs of vulnerable populations. Following two decades of establishing an international reputation, Covenant Health launched the Palliative Institute in October 2012 with a strategic plan to “be leaders in robust palliative and end-of-life care and advocate for it to be an essential part of the health system.”

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To obtain additional information, please contact the Covenant Health Palliative Institute.

Corresponding authors: Tyler Hamil, MPA, Mary-Ann Shantz, PhD, Abisola Omoniyi, MPH, Michelle Goonasekera, BSc, Patricia Biondo, PhD, Louise Kashuba, MN, Konrad Fassbender, PhD.

Address: Covenant Health Palliative Institute, c/o Grey Nuns Community Hospital, Rm 416, St. Marguerite Health Services Centre, 1090 Youville Drive West, Edmonton, AB T6L 0A3

Phone: 780-735-9637

Fax: 780-735-7302

E-mail: Palliative.Institute@covenanthealth.ca

Website: <https://www.covenanthealth.ca/innovations/palliative-institute>

Social Media: Twitter: [@CHPalliative](https://twitter.com/CHPalliative); LinkedIn: [@Palliative Institute](https://www.linkedin.com/company/palliative-institute); Facebook: [/Covenant-Health-Palliative-Institute](https://www.facebook.com/Covenant-Health-Palliative-Institute)

Disclaimer: Participation in the Forum was voluntary. Recommendations arising from the World Cafes are confidential. Quotations and attributions are anonymous. The views and opinions expressed in this presentation are those of the authors and do not necessarily reflect Covenant Health, the participants nor institutional stakeholders.





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Palliative Care Queensland. [PalliLearn](#) Community Education Program. This innovative series of courses is aimed at educating the public, building community capacity on issues related to dying, death and bereavement and supporting caregivers. Contact: Level 8, 135 Wickham Terrace, Spring Hill, Brisbane





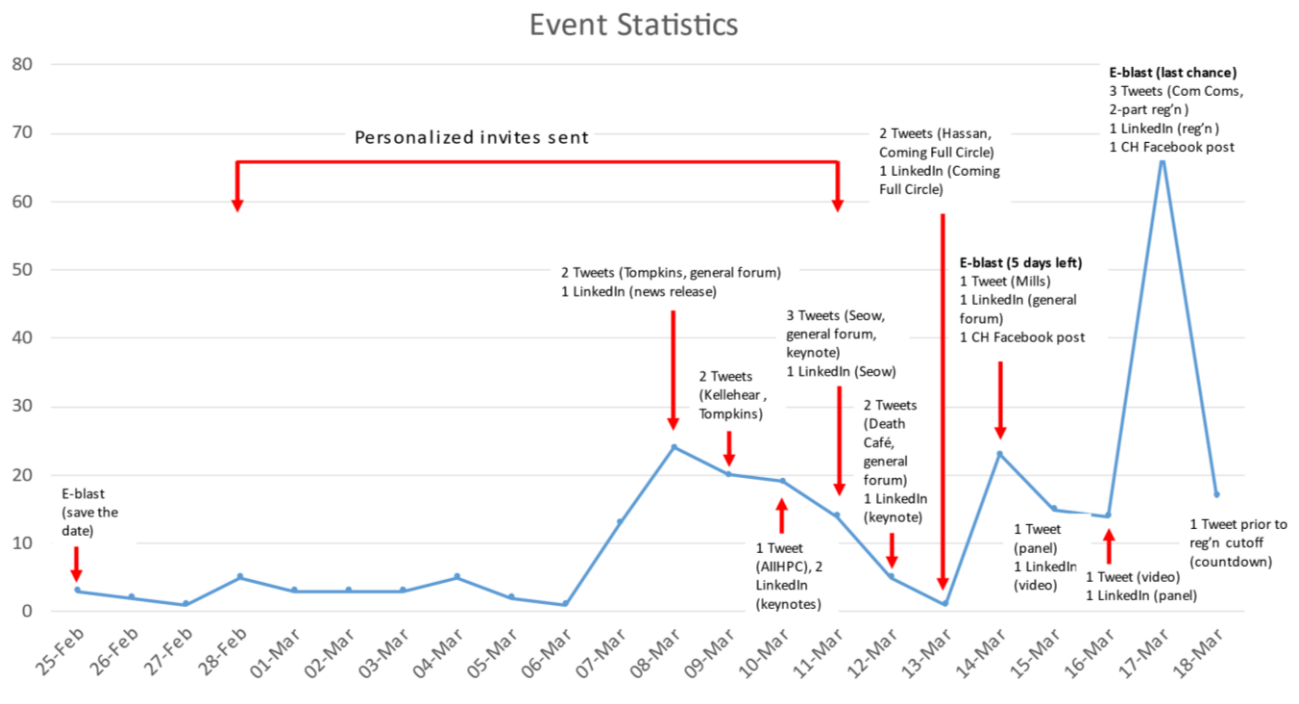
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Appendix 1: Forum Statistics & Audience



The Forum was conceived and organized to support conversations, understanding and action planning for the five key communities (**bolded below**).

Six registrants belonged to the key community of **legal, financial planning and insurance professionals**: three from the legal sector and three financial planners, two of whom were from banking and credit institutions. Due to some participants attending but not registering, attendees from this group included four legal professionals and two financial planners, one of whom was from the banking sector. The legal professionals who attended included three legal firm attorneys and an executive with a provincial non-profit representing the legal profession in Alberta.

Hospices and hospice palliative care societies represented the largest number of Forum participants: 29 registrants, 20 of whom attended the event. These included eight with positions on the executive or board level, eight with management or operations roles, three health care professionals, a social worker and two volunteers.

Three individuals with **libraries** expressed interest in the Forum: two registered but could not attend, while another attended the day of the event. Their roles included library director, library assistant and community engagement coordinator.





Twelve registrants and eight attendees were identified as having roles with **senior serving organizations**. These included community support organizations, disability and social service associations as well as groups supporting seniors and retirement communities. Seven participants' occupied executive or board roles, two were operations staff, one was a volunteer and another a retired social worker.

Among the fifth key communities identified ahead of the event, there were seven registrants representing the following **faith-based communities**: Catholic, Hindu, Muslim and Unitarian communities; two ultimately were able to attend the Forum. Their roles included priests and chaplains, executives from religious affiliated associations and organizations staff such as managers and coordinators.

Among participants who did not fall into one of these five key communities, health care professionals had the largest representation with 70 registrants and 24 attendees. Another 14 registrants, 9 of whom attended, had roles in health and end-of-life consulting including as end-of-life and death doulas. International medical graduates and member of associated Alberta-based organizations were also significantly represented with 27 registrants and 15 attendees. The 63 registrants and 27 attendees who did not provide an organization affiliation or role were assumed to be attending on behalf of the general public.





Appendix 2: Forum Evaluation

A total of 194 individuals (72% of registrants) attended the event. An evaluation of the Forum was completed by 32 individuals and summarized below.

