BC Centre for
Palliative Care

Facilitating Equitable Access to Palliative and End-Of-Life Care for Underserved Populations in British Columbia: Knowledge Exchange Series (2025)

Summary Report

About this Document

This document summarizes the planning, delivery, and key insights from a three-part virtual learning and knowledge exchange event series hosted by the BC Centre for Palliative Care in Spring 2025. The series' design, topics, and discussions were informed by insights from research, experts, and lived experiences. The series aimed to advance equity-informed approaches by centring the stories of people with lived experience, showcasing promising practices, and exploring the connection between palliative care within the health system and services offered by community organizations. Through presentations, breakout discussions, and group sharing, participants examined barriers and facilitators to access and identified opportunities to strengthen equitable palliative and end-of-life care in BC.

By sharing these insights, we hope to inform practice, guide future research, foster cross-sector collaboration, and support ongoing efforts to improve equitable access to the most-needed care.

How to Cite this Document

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Acknowledgments

Territory Acknowledgement

The BC Centre for Palliative Care works with humility and respect alongside partners across the land colonially known as British Columbia. We acknowledge that our work takes place on the traditional and unceded territories of many distinct First Nations, whose values continue to guide us. We recognize Métis people and Métis Chartered Communities, as well as Inuit and urban Indigenous peoples living across the province on various traditional territories.

We wish to acknowledge that participants of the knowledge exchange series joined in from a wide range of geographic regions, all of which represent traditional territories of many distinct First Nations. These lands have been cared for since time immemorial by Indigenous peoples, whose deep relationships with land, water, and community continue to this day. We continue to benefit from their ongoing stewardship, which made it possible for us to gather, learn and connect.

As settlers and guests, we recognize that we have benefited from the colonial system, as we arrived here and across Turtle Island, uninvited and imposed. The devastating impacts of this colonial system are ongoing and guide our commitment to learning about decolonization, including working towards challenging colonial systems and meaningfully uplifting Indigenous peoples, voices, and rights.

In alignment with the Truth and Reconciliation Commission's Calls to Action in Healthcare (#18-24)[1], which emphasize improving Indigenous health and advancing cultural safety in healthcare, we commit to collectively and continuously grounding our work in respect for Indigenous rights and knowledge systems, and to remain accountable for the responsibilities we hold as guests on these lands. We invite others to join our commitment to challenge the settler privilege we hold and to practice accountability in our relationships with Indigenous communities, peoples, and lands.

Gratitude for Contributors

The BC Centre for Palliative Care (BCCPC) expresses its sincere gratitude and appreciation to everyone who contributed to the planning and delivery of the Knowledge Exchange Series and development of this document. We have included below the contributors who consented to be acknowleged in this report.

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Introduction

Equitable Access to Palliative and End-of-life Care in Canada

In Canada, not everyone has equal access to palliative and end-of-life care.[2,3] In 2021, the Worldwide Hospice Palliative Care Alliance called on governments to make equity a priority by addressing the structural and social conditions that create unfair differences in care.[4] This meant recognizing that people experiencing oftentimes overlapping forms of discrimination (e.g. racism, ageism, classism, colonialism, ableism, sexism, homophobia, transphobia) and social disadvantage (e.g. poverty, homelessness) face extra barriers to palliative care.[4] These inequities often result in more severe symptoms, fewer opportunities to access specialist palliative care, and poorer outcomes towards end of life.[4]

It is important to emphasize that these inequities are not natural or unavoidable; they are the result of unfair social conditions or injustices.[5] The systems we live in (social, cultural, political, and economic) create disadvantage for some groups while giving unearned advantage or social privilege to others.[5,6] Thus, ignoring privilege when discussing inequity leaves the picture incomplete and limits the possible solutions we can create.[5] In palliative care, emerging research shows that inequity can show up in everyday interactions between patients/families and care providers.[6] For example, how a patient or family's knowledge and abilities are judged, which is often influenced by providers' own privilege or assumptions, can affect how that person or family is included in decisions or how easily they can access care.[6] Therefore, addressing inequity means not only supporting those who are underserved but also questioning how those who hold privilege may contribute to keeping existing systems and inequities in place.[6]

Across Canada, communities are developing equity-oriented approaches to palliative care, a growing area of research and practice aimed at improving access and addressing the structural and social conditions that prevent people from receiving high-quality care.[7] While progress has been made, as highlighted in Health Canada's *Framework on Palliative Care in Canada - Five Years Later, 2023*,[8] more work is needed to meet the needs of Canada's diverse populations.

Knowledge Exchange Overview

In Spring 2025, the BC Centre for Palliative Care hosted a three-part virtual Knowledge Exchange Series on Facilitating Equitable Access to Palliative and End-of-Life Care for Underserved Populations in BC. The series' design, topics and discussions were informed by insights from research, experts, and lived experiences.

Purpose

The purpose of the series was to advance an equity-informed approach to palliative care by focusing on several key objectives: exploring the stories of people with lived experience, showcasing promising practices, strengthening the connections between palliative care approaches in the health system and community organizations, and identifying future directions for policy, practice, and research.

Objectives

1. Explore the lived experience of underserved populations when accessing palliative and end-of-life care.
2. Identify and promote promising practices while strengthening connections across sectors.
3. Identify future directions in policy, practice and research to enhance access.

Planning

The planning committee undertook a series of steps to prepare for and deliver the knowledge exchange series. First, they identified the populations of focus. Then, an environmental scan was done to gather existing knowledge on the lived experiences of individuals within these groups. This was followed by targeted literature reviews on select populations to provide additional context and evidence. Insights from both the environmental scan and literature reviews were summarized into population fact sheets, which were shared with participants ahead of the knowledge exchange sessions. After the sessions, participants completed a prioritization survey to identify the most important questions and potential solutions relevant to each underserved population.

Populations of Focus

The underserved populations of focus were decided on by the planning committee through a series of discussions **(See Box 1)**. The term ‘underserved’ was defined as individuals, groups, or communities who do not have adequate access to essential services or opportunities, resulting in unmet needs. Decisions on whether to include a population were informed by the committee members’ expertise and existing literature recognizing these populations as underserved.

Box 1 – Populations selected for the Knowledge Exchange Series
(Highlighted populations were selected for a literature review)

People living with a life-limiting illness:

- Organ failure
- Dementia
- Hematological diagnoses
- Rare diseases

Those experiencing a life-limiting illness and who:

- Reside in rural and remote communities
- Are experiencing unstable housing or who are unhoused
- Are Indigenous
- Are culturally diverse (not Indigenous) including immigrants and refugees
- Have neuro-developmental disabilities
- Are experiencing mental illness
- Are experiencing a substance use disorder
- Are 2SLGBTQ+
- Are justice involved
- Have other disabilities (hearing impaired, limited physical abilities, visually impaired)

Gathering Information

Environmental Scan

An environmental scan survey was distributed in early December 2024. The survey objectives were to:

1. Gather knowledge on the lived experiences of underserved populations in accessing palliative and end-of-life care.
2. Identify current opportunities and connections that support improved equity in access.

This survey was distributed to key informants representing palliative care organizations, health authorities, long-term care regional leadership and palliative care interest groups throughout BC. Additionally, the survey was sent to academic palliative care departments and individual palliative care clinicians and researchers known to the BC Palliative Care Research Collaboration. Lastly, the survey link was distributed through the BC Centre for Palliative Care's monthly newsletter *Centrepoint*.

The survey began with demographic questions to help contextualize responses, followed by a section asking participants to identify which underserved populations (based on a list developed by the planning committee) they have experience working with. For each population, respondents described primary challenges and barriers to equitable access to palliative and end-of-life care (including policies, financial constraints, systemic or institutional limitations, poor awareness of a service, or a lack of cultural competencies). Participants were also asked to identify projects, initiatives, or programs that promote (or seek to promote) improved equity in access for each underserved population.

The final survey question asked respondents if they knew any patient partners or family members from the selected underserved populations who may be interested in sharing their positive or negative lived experiences related to accessing palliative and end-of-life care. Those who responded "yes", were later contacted to learn more about their connection.

The survey was closed at the end of January 2025, after receiving a total of 57 responses. Survey data was analyzed both quantitatively and qualitatively in MS Excel. Qualitative data on the challenges and barriers was summarized, collated and analyzed for themes. These findings, along with the literature reviews described below, informed the content of the knowledge exchange sessions and the development of population-specific fact sheets.

Literature Reviews

Planning committee members also volunteered to conduct literature reviews for selected underserved populations based on their capacity. The review objectives were to:

1. Summarize the lived experiences of each underserved population when accessing palliative and end-of-life care.
2. Describe the barriers and facilitators to access.
3. Identify promising practices that promote equitable access.

Each review followed a three-stage process **(See Figure 1)**

The review findings for each population can be found in their respective chapters, which are accompanying this report. Due to time constraints faced by the planning committee, not all populations underwent a literature review. As a result, there may be missed opportunities to identify existing knowledge or gaps that participants may not have been aware of.

Figure 1 – Literature Review Three-Stage Process

Stage 1:
Preliminary Database Search

Identify peer-reviewed reviews in the white literature.

Identify relevant reviews in the grey literature.

Stage 2:
Supplementary Literature Search

Identify relevant primary research articles that fell outside of the search dates for previously identified literature reviews.

Stage 3:
Summary of Findings

Summarize findings into three main areas: lived experiences, barriers and facilitators, and promising interventions or practices.

Population Fact Sheets

The environmental scan survey and literature reviews informed the development of population-specific fact sheets, which were made available to participants before the first session. Each fact sheet provides a high-level overview of key themes from the literature and perspectives of survey respondents relevant to the knowledge exchange sessions.

A fact sheet for each population is available in their respective chapter.

Knowledge Exchange in Action

The three knowledge exchange sessions were designed to facilitate connection across the whole continuum of care, promote knowledge exchange among attendees, advance the uptake of existing research findings, and shape future research.

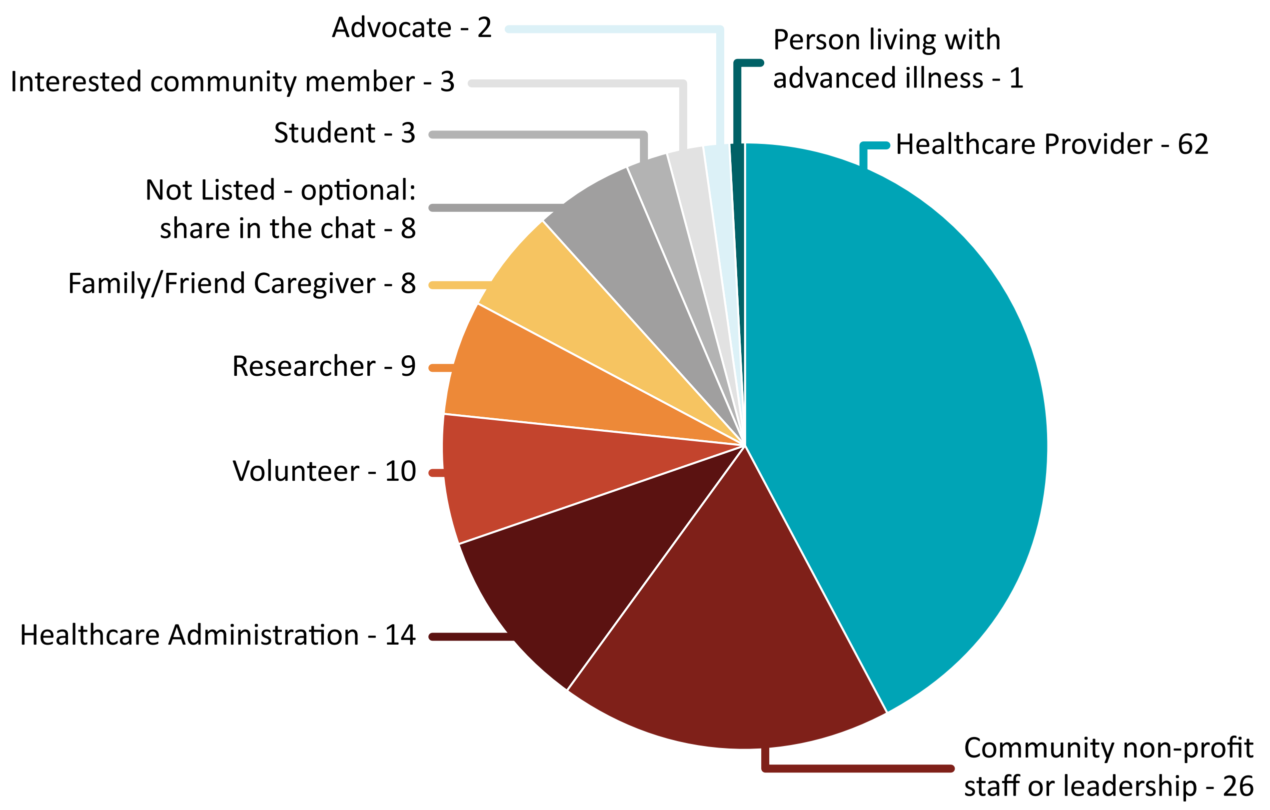
Each session was 2.5 hours long and involved a mix of presentations, small breakout discussions, and larger group sharing. A range of presenters and participants were invited, including people with lived experience, family/friend caregivers, healthcare providers, healthcare administrators, community non-profit staff or leadership, researchers, students, and interested community members.

Session 1: Lived Experience

A total of 189 attendees participated in Session 1, which focused on the lived experiences of underserved populations in accessing palliative and end-of-life care. Through a personal story shared by someone with lived experience, along with small- and large-group discussions, attendees explored common themes, key differences, and gaps in knowledge across these populations. The session achieved the following objectives:

1. Identify gaps in knowledge related to the information presented in the fact sheets.
2. Discuss key similarities or differences across underserved populations.

Figure 2 – Mid Session 1 Poll: Number of Poll Participants (n=146)

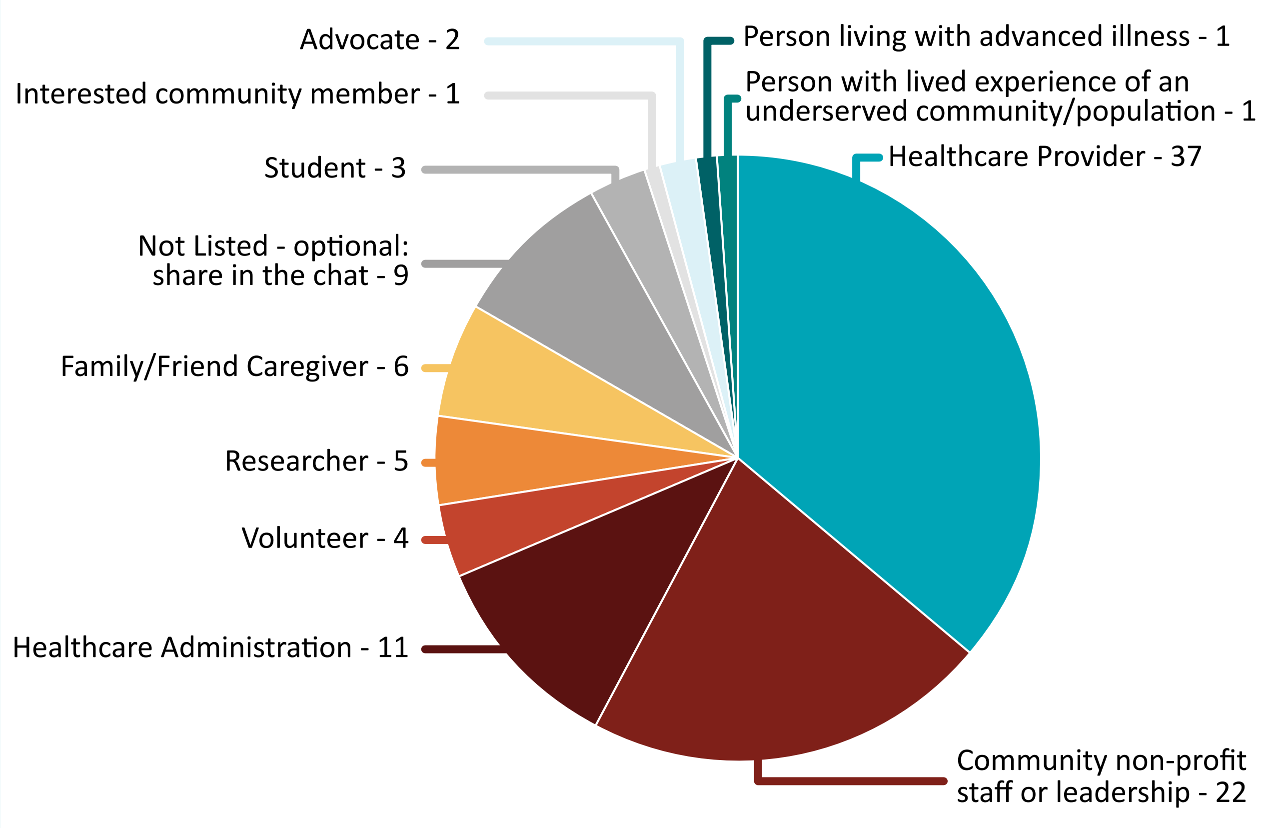


Session 2: Current opportunities

A total of 149 attendees participated in Session 2, of which 70% had attended Session 1. Session 2 focused on identifying current opportunities and connections that support improving equitable access to palliative and end-of-life care. Through a personal story shared by someone with lived experience, along with small- and large-group discussions, attendees identified barriers faced by underserved populations within their own contexts. They also shared ideas and strategies they could implement to begin addressing these challenges. The session achieved the following objectives:

1. Identify barriers identified as a priority to address for each underserved population.
2. Discuss what can be done to address the identified barriers.

Figure 3 – Mid-Session 2 Poll: Number of Poll Participants (n=102)



Session 3: Future opportunities

A total of 67 attendees participated in Session 3, of which 60% had attended both previous sessions, 32% attended one prior session, and 7% joined for the first time. This final session focused on identifying future opportunities for improving access to palliative and end-of-life care. Through small- and large-group discussions, attendees discussed what they would like to know or solve in relation to each underserved population, while also brainstorming potential solutions. To close the session, attendees took part in a poll where they identified one action they plan to take following the series. The session achieved the following objectives:

1. Identify what we want to know or solve in relation to each underserved population.
2. Discuss potential solutions that can be undertaken to address these questions or problems.

Figure 4 – Mid-Session 3 Poll: Number of Poll Participants (n = 40)

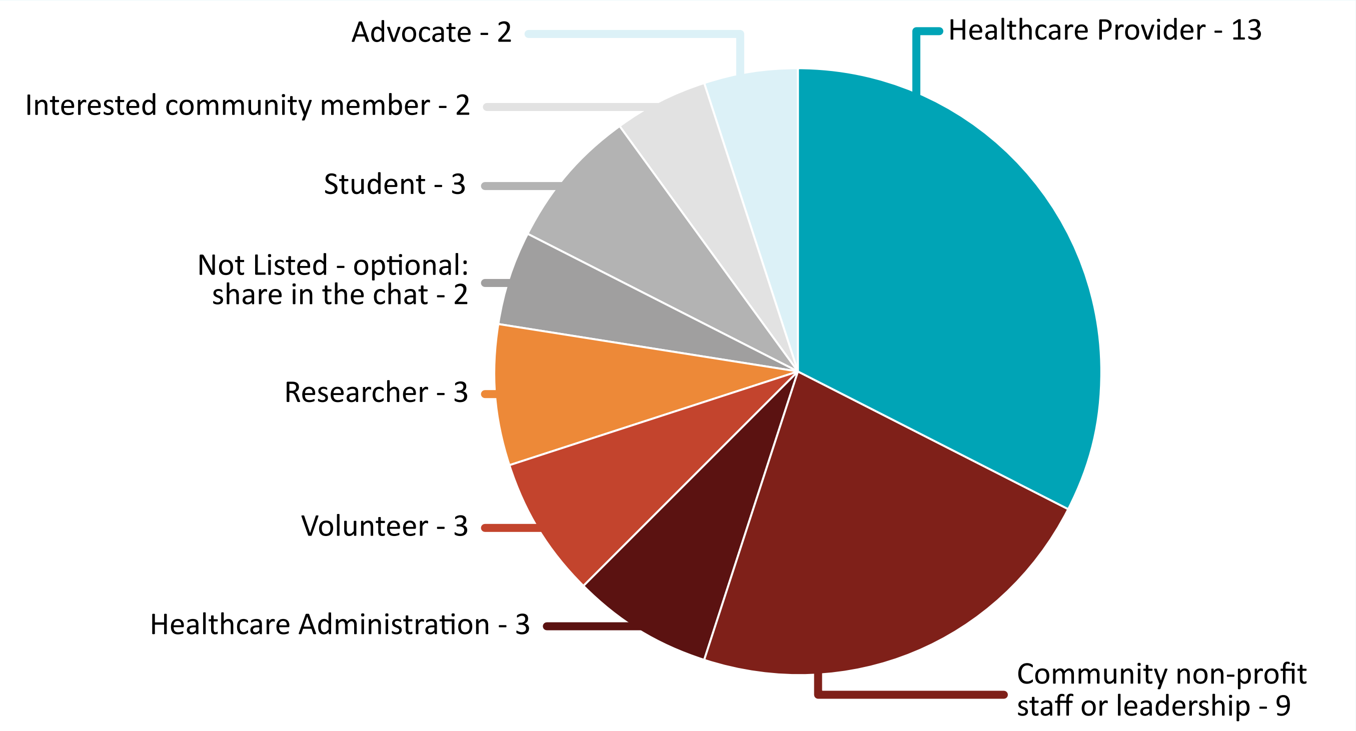


Figure 5 – Post-Session 3 Poll Themes

What is one action you will be taking following these sessions?

Data and Storytelling	Education and Awareness	Collaboration and Networking	Advocacy and System Improvement
“Actively listen to patients’ wishes for what is important for them at end of life.”	“Integrate palliative and end-of-life care education across all levels of schooling - from elementary to university.”	“Continue to offer opportunities that bridge the gap between healthcare providers, palliative care programs, and community organizations.”	“Advocate to streamline exisiting systems and processes.”
“Start gathering first person qualitative data and stories... share this data to show the good, the bad, and the ugly and then foster discussion and action planning.”	“Talk about end of life to help normalize these conversations.”	“Support the continued building of a palliative care provider network by collaborating on funding opportunities.”	“Continue to push forward on networking and education within my organization.”

Prioritizing Actions

Post-series Prioritization Survey

Two months after the final knowledge exchange session (session 3), an online survey was distributed to participants who attended any of the sessions. The survey asked respondents to review and rate a set of questions and proposed solutions pertaining to each population group. These questions and solutions were drawn from ideas shared during session 3.

A total of 65 completed responses were received. Survey data was analyzed both quantitatively and qualitatively in MS Excel. Findings and key insights are summarized and described below.

What we Learned

Similarities and Differences between Underserved Populations

During Session 1, attendees identified common themes and distinct differences among underserved populations. The two visual summaries below highlight the key similarities and differences that emerged from the discussion.

Similarities

1. **Complex patient needs**
   Example: isolation from traditional support networks
2. **Late recognition of palliative care needs**
   Example: late initiation of care planning conversations
3. **Access barriers**
   Example: challenges accessing grief and bereavement support due to language barriers, geographic challenges
4. **Knowledge gaps**
   Example: lack of familiarity with navigating the health system
5. **Stigma and mistrust**
   Example: historical harm/ trauma in care settings
6. **Inadequate systems**
   Example: lack of support for diverse caregiving models in care settings
7. **Cultural safety and trauma-informed practice**
   Example: cultural disconnect between patients and providers
8. **Value of individualized care**
   Example: holistic care that includes appropriate networks of support and meet people where they are at

Differences

1. **Unique social determinants of health**
   Example: stigma may be unique in its nature to each underserved community - for instance, providers unfamiliar with specific behaviours associated with substance use may misinterpret them as aggressive
2. **Unique social determinants of health**
   Example: admission to services often takes a long time for populations experiencing rare diseases
3. **Communication gaps**
   Example: healthcare teams addressing substance use, homelessness and mental health are often siloed and do not always talk to each other
4. **Emerging needs**
   Example: there are not enough resources available for the growing population of older adults

   Example: those who experienced loss during the pandemic experience a unique form of grief that requires more attention

Refer to Session 1 Summary in Appendix for more details.

Barriers, Solutions and Recommended Actions Identified for Each Underserved Population

During Session 2, attendees discussed barriers faced by each underserved population, along with potential solutions and recommended actions. The two visual summaries below highlight key challenges and ideas that emerged from the discussion. Additional details for each population can be found in the population-specific chapters in the Appendix.

	Barriers	Solutions	Recommended Action
People experiencing a substance use disorder	Lack of a public guardianship program makes it difficult for people without family to navigate healthcare; limited mobile care, and insufficient training for caring for people who use substances.	Connect substance use care to broader healthcare, strengthen primary care, and combat stigma using education and training.	Adopting a people-centred approach is essential. This can be done by bringing services to individuals, rather than expecting them to navigate complex systems alone.
People experiencing unstable housing	Lack of safe spaces, inadequate follow-up after discharge, communication gaps, limited care inclusion, and distrust in systems; people without identification/care card may face difficulty entering care systems.	Create safe care spaces, upskill volunteers and providers, raise awareness of hospice, build community trust, promote inclusive housing, and use temporary PHNs to facilitate access to care.	Create flexible, safe care spaces near existing supports to ensure dignity and continuity of care.
Indigenous individuals	Broken trust between Indigenous communities and healthcare systems; lack of clinicians adequately trained on culturally safe care.	Set up safe areas in hospitals/clinics where people can practice their traditions. Increase resources for Indigenous staff and representation, cultivate cultural awareness.	Championing cultural humility and Indigenous rights is essential to building capacity at a larger level and setting a standard for supporting Indigenous communities.
People living in rural and remote areas	Lack of formal supports for caregivers, unequal access to essential services, concerns about privacy and confidentiality in small communities, and worsening inequities (e.g. access to technology).	Assess caregiver capacity regularly, implement wraparound services (transport providers, non-profits, local groups) for care delivery, ensure care models reflect the values of the diverse communities.	Invest in caregiver capacity, and build partnerships across sectors to enhance access to person-centred care.
People who are culturally diverse	Language barriers can lead to miscommunication; cultural differences can make system navigation difficult and isolating, deterring access to care.	Train bilingual volunteers in cultural care, promote cultural humility, and strengthen ties between non-profits and health authorities to improve care navigation.	Enhance resource coordination and navigation support, grounded in cultural humility, to improve access to care.

	Barriers	Solutions	Recommended Action
People living with dementia	Limited caregiver support, lack of advance care planning, and care settings are often not designed for people with dementia or not supportive of family involvement.	Simplify access to respite, expand caregiver education, involve caregivers in planning, and use transition providers to maintain continuity and ease emotional strain of caregivers.	One-on-one education and emotional support is essential to helping caregivers navigate resources and maintain quality of life for all involved.
People living with rare diseases	Limited public and professional awareness of rare diseases and their unique needs can lead to late referrals.	Outreach should be done to raise awareness about palliative care; survey patients using evidence-based tools to identify patient needs early; set care standards to improve provider knowledge and accountability.	Education about palliative care should start earlier, via targeted outreach and community advocacy. Awareness must extend to include all serious illness, including rare diseases.
People living with neurodevelopmental disabilities	Disability and healthcare providers lack access to each other's information, existing clinical tools don't meet the needs of this population, and staff lack training on neurodevelopmental disability.	Hire a dedicated Health Services for Community Living nurse to coordinate care, develop clear plans for adults with complex needs, and adopt ongoing person-to-person education between organizations.	Define healthcare/disability provider roles and create shared protocols to improve access to appropriate care.
People living with severe mental illness	Many clinicians lack awareness of mental illness as a life-limiting illness, and long waitlists can lead to setbacks in patient wellbeing and willingness to seek care again.	Provide ongoing education to break down stigma around mental health, and foster collaboration across health authorities and community providers to build capacity and strengthen a multidisciplinary approach to care.	Advancing a multidisciplinary approach is essential to breaking down silos between services and promoting access to care.
Members of the 2SLGBTQ+ community	Stigma about traditional family structures, discrimination in spiritual care, lack of provider knowledge about 2SLGBTQ+ needs, and non-inclusive language erode dignity and trust, disrupting access to care.	Engage 2SLGBTQ+ individuals in education, planning and policy development to ensure that these processes reflect the lived experiences of 2SLGBTQ+ people.	A cultural shift, via changes in education, training, and policies, is needed to make care feel safe and inclusive.

Top 3 Rated Research Questions to Answer for Each Underserved Population

Following Session 3, attendees completed a survey to prioritize the most important research questions to answer, related to each underserved population, which emerged from the Session 3 discussion. The top three rated questions for each population are presented in the two visual summaries below. Additional details for each population can be found in the population-specific chapters in the Appendix.

People experiencing a substance use disorder	**Practice/Care** How can we bridge silos and gaps between hospice and earlier approaches to palliative care?	**Policy** How do we ensure palliative care is not denied due to substance use and how can policies evolve to reflect this?	**Community Engagement** How can we cultivate communities that truly meet people where they are, such as the way “Moms Stop the Harm” supports parents who have lost children to substance use?
People experiencing unstable housing	**Education/Training** How can we strengthen staff education in de-escalation and trauma-informed care? How can we reduce stigma and stigmatizing language?	**Research** How can we better identify and reach this population in order to engage and support them?	**Practice/Care** How can we better understand the needs and goals of this population?
Indigenous individuals	**Education/Training** How can we train staff to effectively address racist behaviour in a way that educates rather than shames, and how can we invest in ongoing education on cultural humility to foster more respectful, inclusive care environments?	**Policy** How can service funding be structured or expanded to ensure that people can receive culturally safe care closer to home?	**Education/Training** How can we learn more about cultural/traditional healing practices that support palliative care? How might partnering with Indigenous communities help develop culturally grounded resources?
People living in rural and remote areas	**Community Engagement** How can we strengthen community organizations, which are deeply connected to local needs and priorities, to play a greater role in delivering and supporting palliative care services?	**Research** How can we better recognize and address the added barriers (such as for travel and technology use) that rural communities face in accessing and receiving palliative care?	**Practice/Care** How can we explore and improve the role of telehealth in palliative care for rural and remote communities?
People who are culturally diverse	**Practice/Care** How can Elders, spiritual leaders, and cultural knowledge holders be formally recognized and integrated as legitimate members of the care team?	**Education/Training** How can we increase awareness of available community services to support self-referral?	**Education/Training** How can we strengthen patient education on advance care planning and serious illness conversations so that it reflects and respects diverse cultural values?

People living with dementia	**Practice/Care** How can we support people with loved ones that have dementia and are still living at home?	**Education/Training** Do families understand the transitions associated with different stages of dementia? Are healthcare providers explaining these stages to families, such as what to expect as the disease progresses?	**System/Program Planning** How can we streamline documentation processes to avoid siloed records and ensure integrated care planning is implemented across disciplines?
People living with organ failure	**System/Program Planning** How can we proactively identify what resources or supports are needed before a crisis occurs?	**System/Program Planning** How can long-term care settings shift towards robust, individualized goals of care planning for residents with organ failure?	**System/Program Planning** How can we create a single, consistent point of contact to help individuals and caregivers anticipate the next phase of disease, like organ failure, and ensure the right supports are in place of ahead of time?
People living with neurodevelopmental disabilities	**System/Program Planning** How can we strengthen the referral system to prevent service gaps, particularly during critical transitions such as from pediatric to adult care?	**Research** What are the ethical challenges surrounding assent/consent in palliative care for individuals with diminished capacity or complex circumstances, and how can these be navigated responsibly? Are there any legal frameworks guiding end-of-life decisions for this population?	**Practice/Care** How can we integrate disability-informed practices into all types and stages of care?
People living with severe mental illness	**Policy** How can we ensure that palliative care program mandates are grounded in philosophy that meaningfully addresses the unique needs of individuals with mental health challenges ?	**Research** How can we learn more about low-barrier hospice models, and what strategies can be used to navigate or implement low-barrier care within standard hospice settings to better support people who face structural or social barriers?	**Research** What are the ethics of having one site that all individuals needing a low-barrier approach go to versus providing low-barrier service in every community?
Members of the 2SLGBTQ+ community	**Practice/Care** How can those of us in palliative/hospice care re-examine our language to ensure it honours trans identities, chosen families, and diverse communities we serve, especially given the harmful systems many are navigating or resisting?	**Education/Training** How can hospice societies be supported to invest in training for volunteers and staff to provide inclusive, affirming care for 2SLGBTQ+ clients?	**System/Program Planning** How are long-term care facilities held accountable for ensuring that 2SLGBTQ+ older adults are met with dignity, authenticity, and celebration?

Top 3 Rated Promising Solutions to Address for Each Underserved Population

In the post-session 3 survey, participants also prioritized the most promising solutions to improve access to palliative and end-of-life care for each underserved population, based on ideas generated during Session 3. The top three rated solutions for each population are presented in the two visual summaries below. Additional details for each population can be found in the population-specific chapters in the Appendix.

People experiencing a substance use disorder	**Education/Training** Knowledge sharing and facilitating dialogue on gaps and best practices.	**System/Program Planning** A health region could co-develop a pilot program: placing a nurse practitioner with palliative care expertise on an overdose outreach team to identify clients with life-limiting illness early, offer advance care planning, and bridge to hospice services when needed.	**Community Engagement** Community partnerships, for example building supportive networks, leveraging local centres, and cultivating presence and capacity in the community.
People experiencing unstable housing	**System/Program Planning** Cultivating access to safe spaces to meet the population where they are.	**Education/Training** Education for staff on cultural differences, differences in communication, and history of trauma.	**Education/Training** Education for patients around system navigation and palliative care literacy.
Indigenous individuals	**Community Engagement** Community outreach to improve connections and grow trust.	**Education/Training** Engage Indigenous populations in the development of expanded clinician education focused on cultural safety, colonization, and effective care approaches. Perhaps we can create a checklist of considerations for all equity populations.	**Policy** Establish advocacy groups that help move solutions forward.
People living in rural and remote areas	**Education/Training** Cross-sector knowledge sharing and opportunities for public education on palliative care for rural populations.	**Research** Research on the successes and challenges of delivering palliative care in rural and remote settings.	**Community Engagement** Foster community dialogue and establish spaces for community-led conversation.
People who are culturally diverse	**Community Engagement** Promote community-based services, strengthen organizational partnerships, and grow patient navigator roles. Support coordination by sharing contact information with public health offices and primary care networks and creating central intake points.	**Practice/Care** Establish protocols for checking patient and family preferences around disclosure and rituals. Implement routine cultural safety check-ins during care transitions and family meetings.	**Practice/Care** Establish clear clinician roles and assign responsible care providers.

People living with dementia	**Education/Training** Include palliative care in nursing programs and orientation sessions when employees start working in health authorities.	**Community Engagement** Outreach with the community to promote awareness about what community services are available.	**Practice/Care** Create a standardized operating procedure on when conversations about goals of care, disease progression, etc. should happen, and how often regular updates should be provided.
People living with organ failure	**System/Program Planning** Fund more outpatient clinics focusing on advance care planning and symptom management to avoid hospitalizations and deaths.	**Policy** Increase funding for social workers or support staff that could alleviate the pressure of competing responsibilities on nurses.	**Research** Increase funding for cross-discipline palliative care research in organ failure.
People living with neurodevelopmental disabilities	**System/Program Planning** People need support in navigating and knowing what is possible, such as available services.	**Practice/Care** Update the protocol for when healthcare is responsible and when Community Living BC is responsible. Perhaps this protocol can include information about what each player can bring to the table collaboratively, rather than making it a handoff between organizations.	**Education/Training** Normalize advance care planning conversations through a national campaign or leveraging some clever tools to enable regular conversation.
People living with severe mental illness	**Education/Training** Shift current staff understanding in hospice settings to better support individuals from mental health and substance use or prison-involved populations, and ensure that a trauma-informed lens is embedded in staff education and practice.		
Members of the 2SLGBTQ+ community	**System/Program Planning** Establish cultural safety navigators to help 2SLGBTQ+, unhoused, people who use substances, new Canadians/refugees and other groups to navigate the healthcare system and advocate for them.		

Participant Feedback

Knowledge sharing/discussion across diverse perspectives
There was a strong appreciation for the diversity of backgrounds, lived experiences, and disciplines among participants.

> *"The chance to hear from a variety of people involved in the care of those with serious illness and those with lived experience from some of these underserved groups. I felt people were incredibly respectful and listened to learn from others which was beautiful to be a part of."*

Making connections
Participants enjoyed the chance to connect with others and continue collaborating beyond the knowledge exchange.

> *"See all the people from across the spectrum of care coming together and eager to have more opportunities to connect."*

Session design and delivery
Participants expressed positive feedback on the structure and delivery of the sessions, including the mix of presentations and interactive elements of the sessions.

> *"I enjoyed the discussion among the small groups and the ability to choose topics that we wanted to learn about the most."*

Session Length
Participants felt that the sessions were too short and would have benefited from being full-day events. Several noted a lack of time particularly in the breakout sessions.

> *"Too short. We need more discussion and action. Let's keep this good work up."*

Virtual Format Challenges
Some participants experienced technical challenges and expressed fatigue with online presentations.

> *"I'm getting tired of online presentations - but this was quite engaging."*

Need for Clearer Goals
There was some confusion about the overall intent of the research. Clearer communication of objectives and expectations was suggested.

> *"It was never entirely clear what the purpose was of the research. I initially went in thinking it was a learning opportunity for me; however, it was people in community sharing their learning with the researchers."*

Content suggestions
Participants highlighted the need for a broader definition of vulnerability and some concerns were raised about the lack of attention to complex issues, such as assessing pain in cognitively impaired individuals.

> *"Need to have a broader concept of vulnerable. Some particularly older individuals are marginally housed and neglected."*

Successes

The Knowledge Exchange Series, grounded in research and lived experience, exemplified a successful collaboration across multiple sectors in BC to improve palliative and end-of-life care for underserved populations.

By bringing together researchers and research users from both the health system and community sectors, the series created a space to collectively identify evidence-informed solutions to gaps in palliative care delivery and research; solutions with potential to improve equitable access to care.

The event engaged a wide array of participants in the planning and implementation of knowledge translation activities for existing research —an innovative approach to enhancing the real-world impact of research findings.

Partnership opportunities fostered through this event enabled new and meaningful connections between researchers and research-users. As a result of this collaborative process, we now have strong foundation of future research directions to refer to as we continue working towards improving access to palliative care for people from underserved populations living in BC.

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Appendix

Population Specific Chapters

- People Living with a Life-Limiting Illness and Experiencing a Substance Use Disorder
- People Living with a Life-Limiting Illness and Experiencing Unstable Housing or Homelessness
- Indigenous Individuals Living with a Life-Limiting Illness
- People Living with a Life-Limiting Illness in Rural and Remote Areas
- Culturally Diverse Individuals Living with a Life-Limiting Illness
- People Living with Dementia
- People Living with Organ Failure
- People Living with Rare Diseases or Hematological Disorders
- People Living with a Life-Limiting Illness and Neurodevelopmental Disabilities
- People Living with a Life-Limiting Illness and Severe Mental Illness
- 2SLGBTQ+ Individuals Living with a Life-Limiting Illness
- Justice-Involved Individuals Living with a Life-Limiting Illness

Session 1 Summary:
A deep dive into the similarities and differences between underserved populations

Similarities

Complex patient needs

- Individuals often face overwhelming transitions into hospice and palliative care e.g. adjusting to a new environment, navigating lifestyle changes, accepting care, overcoming shame.
- People from underserved populations experience significant emotional/cognitive burdens due to challenges navigating the system, which negatively affects their access to care.
- Many individuals experience separation or isolation from biological families or conventional social networks that are traditionally prioritized in legal frameworks or advance care planning conversations.
- Grief and trauma impact all underserved populations, yet there is limited training for providers in addressing these issues. After a loss, underserved communities often receive even less follow-up support compared to other groups.
- Many of these underserved categories intersect, so we need to be empathetic to acknowledge the different backgrounds. This layering of disparities can make it more difficult for someone to get the care they need, and this must be acknowledged. We need to see the whole person.

Late recognition of palliative care needs

- Lack of early diagnosis results in delays in treatment for these populations.
- Late initiation of care planning conversations and recognition of palliative care needs by clinicians.
- Clinicians often wait for a patient to be symptomatic before referral (for example, referrals to home nursing), which can delay access to appropriate care.

Access barriers

- There are barriers to accessing grief and bereavement supports among underserved populations (e.g. lack of trained providers, language barriers, etc.)
- Geographic challenges create barriers to access for many of these populations, including rural and remote communities, Indigenous groups, etc. These barriers impact care options and service availability.

Knowledge Gaps

- Many health systems or programs are difficult to navigate or learn about for people unfamiliar with them.
- Lack of knowledge and competence in serving these populations across the health disciplines.
- Knowledge gaps in providers could be addressed by providing education or sometimes more research.
- There is a real value in looking at our education systems and understanding how we are training providers. What are we teaching people who are coming into this?
- Healthcare providers need to support or collaborate with providers with different expertise to address the diverse care needs that arise from the overlapping (intersectional) aspects of a person's identity.

Stigma and mistrust

- People may doubt that providers will meet their needs. Those who have experienced trauma may have a particularly difficult time building trust in the healthcare system. It can take a lot of time to build this trust.
- Healthcare settings can be stigmatizing places for people, and some groups have historical or generational trauma leading to under-utilization of services.
- The labelling of "hospice" suggests it is only for elderly individuals, but it is essential to communicate that hospice care and services are not limited to this specific demographic.

Inadequate systems

- The health systems are designed for the privileged, making it more difficult for individuals with fewer resources or supports to navigate the system. For example, policies are typically targeted to middle-class populations that have economic capital and literacy. Making the system easier to navigate will serve more people and promote equity.
- There is an implicit expectation from the healthcare system that individuals need to navigate the system by themselves, which also requires a substantial amount of self-advocacy. This expectation is hard to manage for many underserved populations. There is a need for the healthcare system or providers to take that responsibility rather than imposing it on patients/families that are already overburdened.
- Western caregiving models often exclude groups that rely on extended family structures, making it more difficult for populations with unconventional networks to receive appropriate support.
- Home support is stretched… continuity and relationship building are so important but difficult to create in these settings.

Cultural safety and trauma-informed practice

- Cultural disconnect: a lack of cultural understanding between patients and providers makes it difficult to access specialized care.
- When we think of culturally diverse, we think of ethnicity, but forget queer culture or other groups that are not as dominant, and how we can ask and listen to clients and families.
- Cultural and emotional safety is a shared priority across all groups. There's a risk of dehumanization when patients are seen only through the lens of their condition.
- There is a need for trauma-informed practices and interventions. We need to be aware of historical and other characteristics that people collectively went through, in addition to individualizing care according to their needs.

Importance of family/community/networks of support

- Families must advocate heavily to get access to what is needed. Families feel they need to be there all the time to get the same level of attention/understanding. It's not sustainable.
- People want care that includes family, community, and support networks, not just clinical treatment.

Individualized care

- Non-patient-centered care: treatments often don't align with what patients truly need or want, leading to unnecessary suffering.
- There is a need to emphasize patient autonomy and start care planning early.
- Instead of categorizing people into groups, it would be helpful to just be open-minded and not presume that a certain group would need x and y.
- Patient-centered, whole-person care is essential and must acknowledge intersectional identities, the overlapping aspects of someone's identity that create unique experiences of discrimination, disadvantage or privilege.
- Many experience fragmented care, but for patients, everything is connected. A true seat at the table means centering the individual voice — especially those who often go unheard.
- Volunteers can have a key role in meeting people where they are, and understanding information exactly as the patient presents it.
- Assumptions about what makes life worthwhile can be deeply harmful. Rural residents may choose not to relocate. Individuals with mental illness or disabilities can experience joy, meaning, and good quality of life. Care should meet people where they are, not where others believe they should be.

Differences

Unique social determinants of health

- Stigma may be unique in its nature to each underserved community. Trans people can suffer more from stigma in rural and remote areas, which may require them to travel to urban areas.
- The severity of someone's health/personal situation may be underestimated depending on what community they belong to. Example: The severity of alcohol addiction is often downplayed.
- Providers unfamiliar with specific behaviours associated with substance use may misinterpret them as aggressive or verbally abusive.
- "Street families" (chosen families within marginalized communities) play a crucial role in emotional and practical support. However, they often lack legal recognition in matters such as decision-making and estate claims.
- There is a sense that unhoused populations have less access to hospice due to legalities (e.g., Who is the next of kin? Who has access to patient information?)
- Lived experience also shows that some unhoused individuals do not want to access this service, either from personal preference or feelings of not belonging in that environment.
- For populations experiencing rare diseases, it often takes a long time to get admission, and patients do not have adequate resources to access services.
- Incarcerated people may have particularly difficult access challenges.
- Truth and Reconciliation approaches and actions pertain uniquely to Indigenous communities. It is important to differentiate our responsibilities to Indigenous communities from those to other culturally diverse groups. They should not be grouped together.

Communication gaps

- Lack of clear communication can delay care, especially for those with neurodevelopmental disabilities or dementia.
- Individuals who have difficulty communicating may encounter providers who are hesitant to engage with them. For example, early loss of voice is common in conditions like dementia due to decisions being made without patient input.
- Loneliness and weak family networks: some individuals have fewer advocates.
- For populations affected by substance use, homelessness, or poor mental health, teams are often siloed and do not always talk to each other.

Emerging needs

- Seniors are seen as just "getting old", or "at end of life anyways". There are not enough resources available to get to them i.e. referrals or interventions/medications.
- Seniors often lack advocates, especially when they have no nearby family or friends to support them, leaving their voices unheard.
- Many individuals from diverse communities are only now beginning to be recognized and are starting to self-identify. Example: substance use has increased significantly in Canada since the pandemic. Those who have experienced loss during the pandemic experience a unique form of grief. More attention is needed to address these populations' unique needs.

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