Facilitating equitable access to palliative and end-of-life care for underserved populations

Knowledge Exchange and Learning Series *hosted by the BC Palliative Care Research Collaborative*

Session 3, Themes:
Sharing Ideas for Potential Solutions

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BC Centre for Palliative Care

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Substance Use

What do we want to know or solve (Breakout 1)

- **Community support tailored to needs:** How do we create community and support that meets this population where they are at? For example, the Moms Stop Harm group helps to create a community for people who don't often fit in the palliative care community. It is a group meant for parents who have lost kids to substance use.

- **Integrated, broader palliative approach to care:** The term "hospice" fails to capture the needs of individuals affected by sudden deaths, such as those in the substance use community, who are often overlooked in traditional palliative care. In addition, overemphasizing hospice care narrows the scope of palliative care, limiting its potential to address grief, loss, and whole-person support. We need broader pushes to broader palliative approaches to care, including earlier support that addresses people's emotional, social, and mental need. Currently health professionals are advancing wraparound approaches to chronic disease. One could argue that substance use is also a chronic disease and requires this wraparound care.
    - How do we integrate this approach for people who use substances?
    - How do we bridge siloes and gaps between hospice and earlier approaches to palliative care?
    - Potential partner: FactBC – Federation of Associations for Counselling Therapists in BC is interested in being in a regulated space

- **Education for staff:** providing better education for care providers, such as how to approach issues of pain management.

- **Harm reduction:** A key question to address is, how do we make harm reduction an integrated part of the care environment? We need health promotion at a community level and systems level, especially for equity-seeking groups. It is about affirmation, dignity, and care.

What could potentially be done right now, and by who? (Breakout 2)

- **Community partnerships**: create a community of practice to facilitate regular ways of engagement. An example model we can look to is Moms Stop the Harm. Linking these kinds of groups/communities to hospice organizations can help build capacity across the system via training, advocacy, and mutual support.

- **Peer connection/street outreach**: get to know all the people that we provide care for through street outreach.

- **Knowledge sharing and advocacy:** bring people together at the community, regional, and provincial level to engage in conversation and learning (for example, identifying gaps and opportunities collaboratively). We need to centre things around what community is already doing, finding ways to support appropriately.
    - There are lessons we can learn from the AIDS crisis – about access to advocacy, access to palliative care, etc. We can learn lessons from those who have come before us – such as how to challenge health authorities on their risk aversion strategies that in turn prevent equitable and safe delivery of care.

- **Social prescription**: We can use social prescription (a healthcare approach where providers connect patients with non-medical services and community supports to improve their wellbeing) to ensure people are aware of the holistic supports that are available. This may require reallocation of resources into a broader framework of wellness that includes social, emotional, and practical needs.

Key Priority and Strategy for Action

Populations living with substance use often face conflicting priorities and limited access to traditional spaces, which create huge barriers to care. Adopting a people-centred approach and meeting these individuals where they are is essential to address these barriers to care. Key strategies include implementing street outreach to better understand the needs of those receiving care (as well as fostering trust and connection) and strengthening existing community supports to foster regular engagement and shared learning in spaces that feel safe and accessible to this population.

Unhoused

What do we want to know or solve (Breakout 1)

- **Affordable housing:** The decline in affordable housing has led to a significant reduction in the number of housing advocates that once championed the rights of people seeking safe and affordable places to live. As a result, individuals experiencing homelessness are often left to advocate for themselves, navigating complex systems, facing discrimination, and struggling to access essential services without knowledgeable support. How can we address this problem?

- **Transportation:** Is there infrastructure to have virtual appointments available, as appropriate? Transportation barriers make it difficult for unhoused people to get to and from appointments. One solution currently in place is the SOS care team providers, who go into communities and provide medical care and prescriptions. In the summer, this can be more difficult due to the lack of warming centres, which usually act as central hubs during the winter. In the summer, unhoused people tend to live in encampments, which are more difficult for providers to access.

- **Communication challenges:** How can we help hospices and outreach teams build skills in de-escalation and understanding that how someone speaks doesn't always mean disrespect? Unhoused people may use strong language, have low health literacy, or express frustration, which can sometimes be seen as aggression. If their way of speaking is misunderstood, it can lead to stigma, making it harder for them to get the care they need and leading to worse health outcomes.
    - How can we facilitate a shared understanding of the unhoused patient's condition? Oftentimes, healthcare provider language can be misinterpreted by unhoused patients (for example, "you're doing great" can mean something totally different to the patient than the provider – the provider might mean they are doing great with respect to where they are in their disease progression, while the patient might perceive it as they are cured or doing better).

- **Aligning goals:** How can care providers better understand the needs and goals of this population? When working with this population, healthcare teams may have a desire for benevolence, such as thinking that people want to be brought into a space like hospice that is clean and tidy. But that kind of space may not be what the individual values (for example, going into hospice may take them away from their chosen family). As a result, these facilities may impose expectations in language use and action that do not resonate with this population.

- **Knowledge sharing:** around the province, there are initiatives underway that work to help people get the care they need in non-traditional ways (for example, open houses). How can different hospices around the province connect to share innovative ideas, so that we are not separately inventing the wheel?

- **Defining good care:** What is good care and how do we measure it? Good palliative care is not a one-size-fits all practice. Everyone has different meanings of home. Being away from home might not be someone's wish at end-of-life. There is a need to define what good care means, including identifying and using standardized metrics to monitor and track improvement.

- **Patient identification:** When is the right time? This population has chronic conditions and often dies younger, so they could benefit from palliative services earlier, but do they even want these services? This population is also used to being incredibly independent or interdependent on each other – palliative care might come with sacrifice (for example, location, community, substance use, structured time, etc.) so more research and conversations around this could be helpful.

  - How do we identify patients who are not accessing regular care? We could identify people at warming centers or places where people can just come to hang out and chat without expectations. This could let us learn a lot about people there and what their values, understanding of health, and wishes are. This could be an area to boost training in advance care planning (ACP). Some community facilities could have a set day each month to discuss wishes and ACP in more comfortable setting – then when they do need to access healthcare in the future, we have that documentation (next, how will this information be communicated or passed on to health institutions?)

- **Advance care planning and serious illness conversations**: How do we discuss what this population needs a week or 6 months from now, when they may be focused on what they need today, in this moment? When these conversations do happen, what can we do with the information? There is an extra layer of complexity to consider when the individual does not have an address in a traditional sense.

- **Leveraging community supports:** a lack of documentation, such as care cards, can make it hard for this population to access care. This population also tends to have a difficult time accessing computers, or putting themselves on the housing registry, etc. At the same time, we know that libraries are often used by this population as a place to warm up, access the internet, and sleep. How can settings like libraries be leveraged to support this population?

- **Lack of understanding about the population**: How much do we even know about this population? How many people are there? Where are they? Where do they get their care? Who wants care? There is a community action team in Duncan made of peers and community partners working together to learn more about unhoused people in their community. What can be done to gather information about this population and foster a better understanding of their lived experiences?

What could potentially be done right now, and by who? (Breakout 2)

- **Foster information sharing**: The BCCPC could host information sharing sessions or roundtables across the province or country. This can facilitate information exchange, advance the dissemination of best practices and provide opportunities for interested parties to come together and build lasting relationships.

- **Cultivate accessible safe spaces:** Meet this population where they are at by providing accessible locations to gather. Find out where this population meets to learn (for example, libraries, warming centres, community locations, etc). Create spaces that help us understand what their needs are and how we can support them. A key priority would be to help people learn how they can get involved with care when they are ready for it – provide them with tools to make informed, independent choices.

- **Improve training for clinicians**: Continuing education should be offered during schooling through to when individuals begin working in their respective fields. Training on cultural safety should be expanded: learn about cultural differences, differences in communication, history of trauma experienced by individuals in this population and what trauma can look like during patient-provider interactions. There needs to be communication tools available and better training on how to support individuals who are marginalized in more than one way. Training should be extended to people beyond the traditional healthcare field: including community programs like warming shelters, volunteers, library, etc.

- **Building presence in the community:** Many people in BC, and particularly in this population, do not have a general practitioner (GP). We could create a rule that GPs need to see X amount of clients per year that are unhoused to promote this population's access to GPs. We could invest in community development for those who provide care to this population (for example, death doula, grief professionals, volunteers, peers, social workers, etc) The key priority should be to learn who is already a part of these communities and having advance care planning and serious illness conversations with them. Communities provide care – all types of people can, and already are, doing this. We should help these people recognize their scope and work within their scope. For example, having training for advance care planning and serious illness conversations for people not traditionally in health care provider roles.

- **Patient Education:** Provide education about how to navigate the system, so individuals know where and how to access care. Education about what palliative care can reduce stigma and misconceptions. Boosting health literacy and understanding of systems can empower this population to make informed choices about the care they wish to receive.

Key Priority and Strategy for Action

We need to understand the unhoused population's needs and goals, where they can be reached, and how to communicate effectively with them. By developing this understanding, we can better identify accessible safe spaces and ways of communicating that better reach this population where and as they are. These spaces should be located near existing supports and tailored to individual needs to promote dignity, safety, and continuity of care. A key priority would be to help people learn how they can get involved with care when they are ready for it – providing them with tools to make informed, independent choices.

Neurodevelopmental disabilities

What do we want to know or solve (Breakout 1)

- **Ethical challenges:** How can we address complexities around assent and consent for individuals with neurodevelopmental disabilities?
- **Integrated care**: How can we integrate disability care into all types and stages of care provided? How can we better incorporate best practices for care into existing care pathways? How do we begin these conversations?
- **Inadequate service models**: existing service models for people with neurodevelopmental disabilities in BC are inadequate. How can the referral system be strengthened to ensure this population does not fall through service gaps?
    - How can we address existing gaps in support for individuals transitioning from pediatric to adult care systems?

What could potentially be done right now, and by who? (Breakout 2)

- **Advance care planning:** We need to normalize advanced care planning conversations through either a national campaign or through leveraging some clever tools to enable regular conversation. For example, there is an Australian card game that helps engage people in these conversations.
- **Service navigation:** People need more support in navigating and knowing what is possible, such as what services are available.
- **Standardized protocols**: There is a deep need to update the protocol for when healthcare is responsible and when Community Living BC (CLBC) is responsible. Perhaps this protocol can include information about how each of these players can contribute and bring to the table collaboratively, rather than making it a handoff between organizations.

Key Priority and Strategy for Action

A key priority identified is normalizing advance care planning conversations for people with neurodevelopmental disabilities. In addition, confusion about roles and responsibilities in healthcare and community systems leads to gaps in support for individuals with neurodevelopmental disabilities. Clear protocols that define the roles of healthcare providers, Community Living BC (CLBC), and other stakeholders are essential for improving access to appropriate care. By fostering person-centred, team-based care and ensuring collaborative communication, we can bridge the disconnect between hospice/palliative care and disability care systems, making support more seamless and effective for individuals and families.

Indigenous Populations

What do we want to know or solve (Breakout 1)

- **Exclusion of Indigenous populations**: Why are Indigenous peoples not included in regular health care? This population still faces huge challenges: segregation, prejudice, lack of cultural safety. When health care providers request to Indigenize their work, potential solutions are often separated from mainstream services. There is a need to open up the conversation and talk about what effective approaches and policies to include Indigenous populations look like (for example, there is a need for funding to improve health care provider education).

- **Indigenous support worker or liaison services**: How do we address barriers to providing Indigenous support worker services? One barrier is the lack of voice these workers have in the healthcare system.

- **System bias:** How do we address funding challenges that limit a person's options to receive care closer at home? For example, regional health authorities are not servicing Vancouver Island. Instead, there is a health centre providing services. Due to funding limitations at these centres, the patient may be relegated to a care location that is isolating, does not feel culturally safe, etc. Separate service funding for regional health authorities and health service centres is needed.

- **Power imbalances:** In the hospital, it is often about money and not care. People who have money to donate seem to get attention and power to make decisions. Governing bodies (doctors, funeral home) hold the licensing power. If Indigenous populations had support for knowledge and education on licensing and building their own policies and traditional methods, they could push back and enforce equality by telling the hospital system to change or lose services/business from nations. For example, Terrace BC is building their own hospital to shake up the existing hospital's power or control.

- **Funeral funding and support options:** How can funeral methods better honor people's cultural wishes? Too many are forced to cremate, which is often at odds with people's cultures. For many Indigenous people, they are taught to depend on family, so what does palliative care mean or look like in the context of their ways of knowledge? Using knowledge or terminology that aligns with their culture can help create a bridge for appropriate resource navigation and access to supports.

- **Expand life-limiting conditions eligible for palliative care:** How can the dying/PPS score better include all who need access to inpatient beds? Can community-based hospice beds be used to support patients who are not at less than PPS 40%? What kinds of supports can be provided to people at home who need additional support, but don't meet the PPS score requirement? There is a need for community-based congregate living that leverages a role for hospice, which can bridge the home-palliative care gap, facilitating seamless access to care.

What could potentially be done right now, and by who? (Breakout 2)

- **Education for staff**: staff training and education across the system is necessary – in order to ensure everyone is treated with care and compassion. There is a need to educate on the taboos related to colonization (such as Christian influences) and strategies on how to navigate these conversations in a culturally appropriate way.

- **Building relationships:** due to a history of trauma and mistrust, it will take time to build back trust. The best way to do is this to come together, such as going on Reserve, talking to the Chief, and asking if they want to talk about end-of-life care. Nations are diverse, so understanding how to engage and support them will mean learning about how they deal with things, according to their own traditions.

- **Create a list and contact sheet for palliative care supports**: create a list of resources that help with navigation, including a list of supports/services. This information can be displayed as posters in ER waiting rooms. Encouraging Indigenous communities to share this information by word of mouth will be effective for spreading awareness.

- **Advocacy groups**: Could the BCCPC create policy briefs and action/advocacy task groups that come together to move this work forward? How we can systematize what can be done?

Key Priority and Strategy for Action

Indigenous populations face exclusion from regular healthcare due to segregation, prejudice, and lack of cultural safety, with solutions often separated from mainstream services. There is a need for inclusive policies, better education for providers, and empowering Indigenous support workers who currently lack a voice in the healthcare system. Building trust with Indigenous communities requires time and meaningful relationship-building, starting with direct engagement—such as speaking with Chiefs and understanding their traditions around end-of-life care. Effective support begins with learning how each Nation approaches these issues in alignment with their cultural practices.

Rural and Remote

What do we want to know or solve (Breakout 1)

- **Funding barriers:** Despite announcements of increased funding, rural and remote communities often never receive support directly. This raises a few key questions: Will funding directly help break down barriers? Where does the funding actually go? Ideally, funding should be directed to community-based programs, allowing them to allocate resources where they are most needed. There needs to be greater transparency about where decisions get held up, who the key stakeholders are, and the sources of information that drive policy and institutional changes.
    - Is the Ministry of Health aware of the current barriers to accessing palliative care? There is limited awareness that the primary barrier to rural healthcare support is budget constraints, not a lack of staff. Urban policies should not be directly applied to rural and remote communities. These communities require tailored policies developed in collaboration with community members who understand their unique needs and contexts.
- **Role of telehealth:** Are telehealth options being encouraged at the physician level? Physicians should rotate through hub centers in remote areas for scheduled periods of time to perform procedures and meet with patients—helping to overcome technological barriers. Cross-provincial healthcare services should also be reinstated, as many remote communities are geographically closer to Alberta towns than major centers in B.C. Physicians should be encouraged to better understand the practical barriers patients face—such as travel challenges—and recognize that, in some cases, support can be given through a phone call.
    - At the same time, technology can be confusing and difficult to navigate, and many clients in these communities lack access to phones or other digital devices due to cost and availability. Are there solutions beyond Telehealth?
- **Recognizing intersectionality:** What is being done to recognize the intersectionality in palliative care, including recognition of disabilities? For individuals with physical disabilities, travel poses significant challenges, while those with sensory disabilities often face barriers to using technology. These disabilities add important layers of intersectionality that must be considered in the design and delivery of healthcare services.

- **Travel challenges for staff**: Why is the travel required of nurses to provide care in rural and remote communities not being recognized? Nurses often travel long distances to reach patients, spending many of their working hours commuting rather than delivering care. The Ministry of Health frequently underestimates the amount of work required to serve rural and remote communities, resulting in funding that does not accurately reflect the scope of their responsibilities. Meanwhile, most funding continues to be directed toward acute care services.
- **Lack of awareness of palliative care resources**: Why is there a lack of awareness of palliative care and its resources? Health professionals who do not live in rural areas are often unaware of the barriers these communities face. Before providing service, there should be a proper debriefing on existing challenges and available services. This ensures that health professionals do not unintentionally overpromise resources that are not currently in place.

  - For patients and families: Colleges and community centers play an important role by offering educational sessions on palliative care. It is important to recognize and celebrate the progress made so far, despite ongoing challenges. Death is a universal experience, and children should be introduced to concepts of death and palliative care within the education system—even at the elementary level. Doing so would help build early health literacy and foster more compassionate communities.

- **Building capacity:** Why is hospice volunteer training in palliative care not recognized or transferable across many organizations? Training could be standardized and made more accessible across communities, enabling volunteers to offer their services throughout B.C.

What could potentially be done right now, and by who? (Breakout 2)

- **Foster community dialogue:** Community-led conversations empower individuals to share lived experiences, highlight unmet needs, and strengthen local support networks. Creating inclusive, accessible spaces—both in-person and virtual—can enable broader participation from diverse voices, including patients, caregivers, and underserved populations. As more people join the dialogue, momentum builds for systemic change, increased awareness, and policy responsiveness. These conversations can also inform service design, advocacy efforts, and educational initiatives tailored to specific communities.

  - **Elevating patient stories**: Amplify emotional connection and patient stories by integrating qualitative data and lived experiences into healthcare decision-making processes. Funding decisions driven solely by quantitative metrics often fail to capture the real, human needs behind the numbers. Facilitating regular conversations—both in-person and via Zoom—for individuals to share their stories can foster empathy, community engagement, and more responsive care models. Highlighting patient narratives also helps policymakers and funders understand the emotional and practical realities behind palliative care in rural/remote communities. Qualitative data, such as testimonials and case studies, should be valued alongside statistics when shaping programs and allocating resources.

- **Strengthen community organizations/centres**: Allow community centers to have direct access to funding and empower them to distribute it to community members. This recognizes that community centres have a deeper understanding of local needs and priorities. It promotes flexibility, reduces delays, and increases the efficiency of resource allocation. It also ensures that funding reaches underserved individuals and groups more equitably.

- **Enhance cross-sector collaboration**: create facilitated group discussions between community and acute care educators to share knowledge and reach consensus on patient-centred care strategies. This enhances collaboration and understanding between sectors.

- **Research**: collect data on successes and challenges of delivering palliative care in rural and remote communities. This provides qualitative and quantitative evidence to inform policy improvements and resource allocation. It also ensures that initiatives are grounded in lived experience and real-world outcomes.

- **Engage physicians:** Unfortunately, action and change are more often seen when physicians lead important conversations, compared to when nurses take the lead. So it is important to promote physician buy-in.

- **Education/Advocacy:** Raising awareness of the diverse members on an interdisciplinary palliative care team helps the public and policymakers better understand the holistic and collaborative nature of palliative care. Leverage educational programs that explain the different sectors of palliative care, including what it is, how to support it, and how to effectively share information.
    - Relocate rural and remote health conferences to actual rural or remote communities rather than urban or resort locations like Whistler. Hosting such conferences in remote communities increases authenticity, promotes local engagement, and offers attendees first-hand insight into the challenges these areas face. It provides an opportunity to directly involve local healthcare providers, patients, and leaders who may not have the resources to travel. Rural and remote communities are continually expected to travel, despite consistently voicing that travel is one of their greatest barriers.

Key Priority and Strategy for Action

Rural and remote populations face challenges in accessing palliative care due to a lack of understanding among care providers and government about their unique needs and circumstances. Fostering community dialogue by bringing groups together can help develop tailored policies in collaboration with community members who best understand their unique needs and contexts. By creating inclusive spaces for open discussion at the individual level, we empower individuals to share experiences, identify needs, and build momentum – strengthening local networks and advancing systems-levels change (for example, additional funding allocated to appropriate areas) The more these dialogues are initiated, the more voices join—and with collective participation comes the potential for transformative impact.

Culturally Diverse

What do we want to know or solve? (Breakout 1)

- **Research:** What is the impact of culturally tailoring conversations on uptake of Advanced Care Planning for culturally diverse populations? What opportunities or priorities are there to facilitate participatory research around this topic?

- **Translation vs Interpretation:** How can we provide an appropriate level of support for cultural understanding and address language barriers? Who is appropriate to have present? (a representative? Doula?) Perhaps this involves looking at other systems around the world and exploring what kinds of best practices exist: what are effective models we can learn from or adapt?

- **Strengthen community partnership:** we should partner with organizations that speak the language of our diverse cultures and have an interest in providing that education. We can leverage cultural centres, centres for newcomers, and informally invite people to sessions that are free and attractive (low-barrier opportunities). We should think about who should be taking the initiative to start those partnerships (for example, health authorities reaching out to community organizations). Who in the health authority would take leadership in making those connections?

- **Strengthening systems:** What are the goods and bads of the system – in order to identify the effective areas to target to advance improvement and strengthen what we have.

- **Self-referral to community services**: this is a gap that many people are not aware of. We need an available resource that anyone can access. The resource should list all the community-based organizations that they can reach out to. People move around, so having something that lives on a website is helpful – suggestion for a provincial hub for information and resources, including direction on what the person can do next with the information. Pathways has some valuable information but it is not comprehensive.

What could potentially be done right now, and by who? (Breakout 2)

- **Promote community-based organizations and partnerships:** health authorities, BC Cancer Agency, and other partners should promote community health services offered by surrounding organizations. Examples of actions that can be taken include:
    - Providing public health offices or primary care networks with contact information and designated spot for central intake to remind them of available community-based organizations
    - Leveraging community navigators by strengthening their capacity – this can be done by connecting them to partners. An example is the current partnership between the NavCare Program and Compassionate Communities Program, a collaboration funded by the Canadian Institute for Health Research.
    - Digital marketing should be used to raise awareness of community health services/programs and reach a wider audience
    - There needs to be funding from the federal government to support community-based organizations to advance these programs in community.

- **Establish the most responsible clinician** so that the person and family know the one central person they can go to for information or support. Vancouver Coastal Health is currently working on this – the ministry wants to have the most responsible clinician identified as the sole contact to match the person/family to additional resources or practitioners.

- **Address language barriers and interpretation concerns**: create a glossary of terms (for example, what certain words may mean in another person's language), and a script for the interpreter, such as for advance care planning.

- **Create a lookup tool for palliative care benefits**: there are a lot of questions around what palliative care benefits are or are not available. Establishing a lookup tool can make it easier for all to access this information more easily, informing subsequent decisions.

Key Priority and Strategy for Action

Culturally diverse populations may struggle to access culturally appropriate services that they trust. However, there are often existing organizations in the community who may know how to communicate meaningfully with these patients and families, developing trust and familiarity. Leveraging these organizations is crucial to help this population access what they need, in their own language and informed by their own culture. Thus, promoting community-based organizations and services through strong partnership with health authorities and BC Cancer Agency will facilitate access to these essential supports for culturally diverse individuals and families.

Dementia

What do we want to know or solve? (Breakout 1)

- **Understanding the needs of LTC residents**: wanting to know if residents in LTC homes are receiving adequate palliative and end-of-life care. Do nurses know how to care for these end-of-life symptoms? We want to see nursing teams assessing and ensuring residents are receiving appropriate care and symptom management, alleviation of suffering, etc.
- **Role of primary care providers:** What is and what should be the role of primary care providers in supporting patients living with dementia in the community? Currently, their involvement often seems to be minimal.
- **Patient education:** wanting to ensure all patients know what palliative care actually is and what is encompasses. For example, this would involve differentiating palliative care as a service vs palliative care as an approach.
- **Family education**: 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? Within the context of your clinician role, can you spot families who have or have not received this education? When is this education best delivered? Two recreational therapists from 100 Mile provide this education upon admission via a survey but are unsure how to communicate this information and what they know with the nursing staff. They find that they are often “kicked out” when it comes to palliative care units – how can these kinds of conversations be done across teams to ensure patients are able to access valuable supports (for example, music) ?
- **Inter-team collaboration:** there is a lack of inter-team communication and collaboration that can prevent the creation of a uniform care plan. How do we open or facilitate this communication between different teams (for example, nurses, care aids, recreation therapists)? How do we improve the frequency and effectiveness of this communication? Recreation therapists shared that their current communication system consists of a wire-bound notebook. They talk to each other directly, but the communication doesn’t go up the care team ladder so things relevant to a patient’s care and wellbeing can get ignored for too long. To communicate these things with patients/families, they have to go above their pay grade and risk stepping on toes.
- **Documentation needs:** currently, care teams chart in their own areas and forms, in isolation from one another. The documentation piece is symbolic of the separation between care teams. How can we address this issue? It is important to have the same footing for documentation to cultivate more cohesive teams and facilitate patient-centred care.
- **Role of families in team-based care**: Where do families fit into team-based care? Goals of care/ anticipatory planning conversations need to happen earlier on when people have more agency. Earlier conversations, especially with dementia, are essential and can be protective against ethical dilemmas down the road. Can we address this problem through better funding for and access to patient navigators on site? Based on the experience of recreation therapists in 100 mile, their patient navigators is an hour away and often not onsite so they do not know the community in the same way.

- **Leveraging existing resources, tools, and services**: We have a depth of resources and tools in BC but not everyone finds them accessible. How do we get them into people's hands to use them? What are the most critical resources to put patients and families in touch with when they receive a diagnosis? We don't need to re-invent the wheel but we need to implement the wheel. Could a potential solution be having a "marketing team" or clinical nurse educator ensure staff know this critical information?

What could potentially be done right now, and by who? (Breakout 2)

- **Implement structured team reports:** integrating communication into existing workflows in a systematic way is essential. Where can we leverage existing systems to bring conversations to the forefront?
- **Create a standardized operating procedure on goals of care** for when we should be having conversations about goals of care, disease progression, etc and how often we should be providing these regular updates. We as health providers, need to provide soft communication over time when health status changes. We need to be expressing the slight, little changes in health status and not just the big notable changes or "milestones.
- **Leverage advertising or communications** for resources such as 8-1-1 and 2-1-1.
- **Outreach:** going out into the community to teach about what community services are available, etc. An example discussed was of a palliative physician who did a talk with the local police force. The police were surprised to learn of how many people die at home. Other methods include printing out resources and placing them in areas accessible to patients and families.

Key Priority and Strategy for Action

There is a need to strengthen family involvement in team-based care and ensure early goals-of-care discussions for dementia patients. Ensuring these conversations happen early is essential for enhancing care planning and preventing ethical dilemmas down the road. Inter-team communication and documentation are currently fragmented, with care teams often working in isolation, which can hinder consistent care planning. A key strategy for action will be creating structured team reports and standardizing communication about goals of care to enhance care coordination and ensure patients and families are better supported.

LGBTQIA+

The following ideas were submitted by participants who were not able to participate in the final learning exchange session.

What do we want to know or solve? (Breakout 1)

- **Policy without people is inadequate:** Why do administrators feel that focusing on policy is so important considering that policy makers (boards, senior staff) don't always understand the issues about which they are making policy? Policy without a plan that is informed by people with lived/living experience is a tool of colonialism. Policy has never moved the dial, only small groups of people have.
- **Training volunteers**: I want more hospice societies to invest in training volunteers and staff to support LGBTQIA+ clients because not only does it help them learn about this community, it actually helps them to develop important skills that can be applied to all - listening, gentle curiosity, non-judgement.
- **Support for LGBTQIA+ older adults:** How is LTC held to account in ensuring that LGBTQIA+ older adults are met in their fullness and celebrated? This is essential to prevent older adults from being 'forced' back into the closet in their 4th season of life.
- **Understanding unique needs**: How do members of the LGBTQIA+ community navigate a palliative diagnosis, ACP, caregiving and EOL? Does their approach differ from cis/het people? I want us to consider that intersectionality within the LGBTQIA+ community is a frequent occurrence and that LGBTQIA+ people - like all 'marginalized' communities - aren't a monolith.
- **Appropriate language:** I want everyone involved in palliative and hospice care to reconsider the language we use. For example, asking for a "legal name" may not respect a trans person's chosen name, and referring to "family" may not reflect the reality for many—some may find their closest support in a barista or grocery clerk. Language matters, and much of ours is rooted in white supremacist, patriarchal, and capitalist systems that have harmed many of the people we serve. Many are showing us ways to live outside these systems. How can we best honor that?

What could potentially be done right now, and by who? (Breakout 2)

- **System navigation:** I would love to see VCH hire a cultural safety navigator in each jurisdiction to help LGBTQIA+, unhoused, substance users, new Canadians/refugees and the other groups discussed, navigate the healthcare system and advocate for them. There is no one consistently advocating for people from 'marginalized communities' unless FNHA hires an Indigenous Patient Navigator. It's a fairly inexpensive investment and means the policies being developed in an office somewhere are actually applied in meaningful ways that don't contribute to or cause harm.
- **Community engagement:** Our small hospice has been making changes over the last 18 months to support volunteers, and engage community in conversation. We work with the local shelter, an organization that supports adults with developmental disabilities, and are offering a trauma-informed 8 week grief group for frontline workers later this year. We are a part of a provincial group who will offer an ECHO series on grief/palliative support for people who are unhoused/precariously housed. We still have work to do when it comes to ACP for people who are unhoused, people who live with neurodevelopmental disability, and

members of the LGBTQIA+ community (although planning an ACP workshop specifically for this community in late 2025). What is in our ability is to remind staff, volunteers and the community that we are dedicated to the core intent of hospice work, which is that every person deserves to be met with humanity, care and in their fullness no matter their choices, circumstances or ways of being in the world, when nearing end of life.

Key Priority and Strategy for Action

A key priority is to ensure LGBTQIA+ individuals receive care that reflects their unique experiences—particularly in the context of serious illness, caregiving, and end-of-life. This includes investing in training for hospice volunteers and staff, not only to better support LGBTQIA+ clients but also to build universally applicable skills such as active listening and non-judgment. To improve system navigation and reduce barriers, health authorities should fund cultural safety navigators in each jurisdiction to advocate for LGBTQIA+, unhoused, newcomer, and other underserved populations. Together, these strategies form a cohesive and actionable approach to creating care systems that are truly inclusive, responsive, and just.

Organ Failure

The following ideas were submitted by participants who were not able to participate in the final learning exchange session.

What do we want to know or solve? (Breakout 1)

- **Inequities:** Why do people with non-malignant diseases—such as organ failure or hematologic conditions—receive less access to palliative care, often access it later, and are more likely to die in acute care settings, despite these illnesses accounting for a larger proportion of deaths?
- **Education**: There is a need to reframe and rebrand palliative care—particularly for patients with organ failure—through improved patient education and earlier integration. In addition, how can we ensure that medical education better prepares students to recognize the role of palliative care in managing non-malignant illnesses like organ failure?
    - How can we better understand the future implications for caregivers supporting someone with organ failure, especially as the person's capacity declines? How can we help navigate them through the healthcare system? Having a single point of contact to guide patients and caregivers through the stages of disease progression would help ensure timely access to resources and better preparation for what lies ahead.
- **Improve Goals of Care Planning in Long-Term Care:** How can we shift away from default DNR/M3 designations and instead support robust, individualized care planning to reduce emergency room visits and hospitalizations that could be avoided through earlier conversations?
- **Clarify the Continuum of Care:** How can we establish clearer processes for patients diagnosed with terminal organ failure to ensure coordinated care across stages of illness?
- **Clinical decision-making:** How do doctors determine if a treatment will benefit a patient more than its possible risks? It is important for doctors to read the patient's medical history before administering medication.
- **Improving support:** It's often unclear what resources or supports are needed until a crisis occurs. To improve planning, we need to gather insights from people with lived experience—not just to identify gaps, but to track meaningful improvements over time. How can we implement this together?

What could potentially be done right now, and by who? (Breakout 2)

- **Increase Funding for Outpatient Clinics:** Expand access to outpatient clinics focused on advance care planning and symptom management to prevent unnecessary hospitalizations and deaths among patients with organ failure.
- **Promote interdisciplinary research:** Encourage researchers to work cross-discipline as palliative care research is not funded to the same extent as research in other diseases (for example, organ failure).

Key Priority and Strategy for Action

A key priority for the organ failure population is improving coordinated, person-centered care that supports both patients and caregivers. This includes developing clear care pathways with a designated point of contact to guide families through disease progression, ensuring timely access to resources. Clinicians should be required to review patients' medical histories to support safer, more informed treatment decisions. Gathering insights from those with lived experience can help identify needs early and track improvements, while proactively supporting caregivers as they navigate complex care systems and shifting patient capacity.