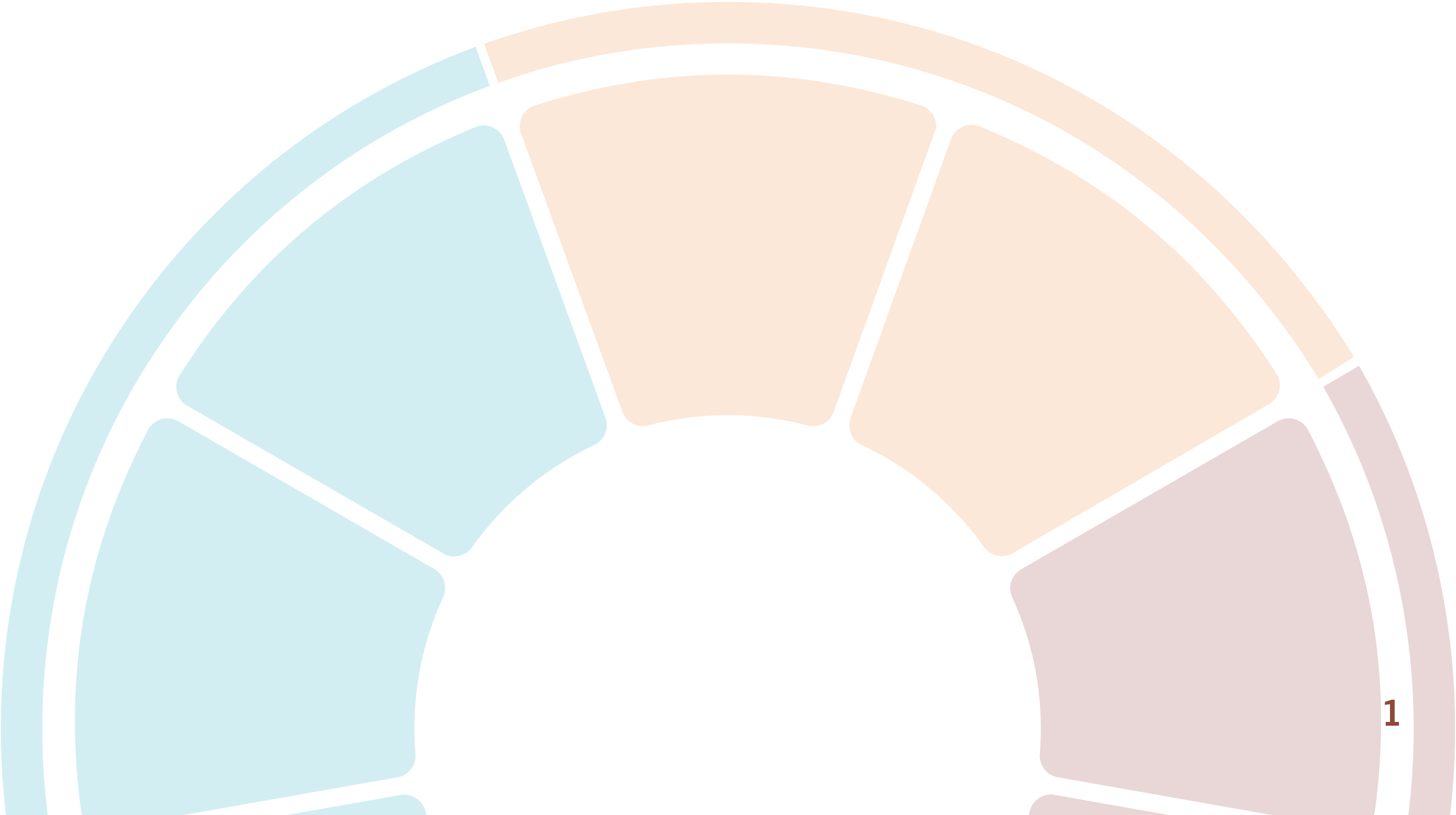
BC Centre for Palliative Care

Person- and Family-Centred Palliative Care Outcome Measures for BC

Informed by evidence, developed by consensus



About this Document

Establishing Person- and Family-Centred Palliative Care Outcome Measures for BC is an initiative led by the BC Centre for Palliative Care in collaboration with an advisory committee of regional and provincial health authorities and agencies. This initiative aimed to identify evidence-informed outcomes that reflect what matters most to people living with life-limiting illnesses and their families. Using a consensus-driven process, the initiative engaged an expert panel with representatives of people living with life-limiting illness, family members, healthcare professionals, palliative expert clinicians, researchers and community leaders. The recommended outcomes and measurement tools will help guide future efforts to assess and improve palliative care outcomes in BC.

How to Cite this Document

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For More Information

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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 also recognize Métis people and Métis Chartered Communities, as well as the Inuit and urban Indigenous peoples living across the province on various traditional territories.

Gratitude for Collaborators

The BC Centre for Palliative Care expresses its sincere gratitude and appreciation to everyone who contributed to the development of this document:

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Expert Panel

Sincere appreciation to the expert panel members who participated in the consensus process through surveys and focus groups. The following list includes those individuals who consented to be identified in this report.

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Background

One of the four priority areas for actions from Health Canada's Framework on Palliative Care in Canada (2018) is the development and promotion of standardized person- and family-reported outcomes and experience measures, as well as screening and assessment tools across all settings.

There is a need to understand how BC is measuring and reporting quality outcomes in the palliative patient population, as well as what quality of life measures are being used by health authorities or agencies in BC. There is currently no agreed standard in BC related to what measures should be used.

To address this gap, the BC Centre for Palliative Care, in collaboration with an advisory group of representatives of BC regional and provincial health authorities, launched an initiative in 2023 to develop consensus-driven, evidence-informed recommendations for measuring palliative care outcomes in BC for people with palliative needs. Specifically, the target population includes all those living with serious life-limiting illness for whom a palliative approach to their care would be beneficial and is not limited to those in the final months or days of their life.

The initiative builds on work being undertaken by Health Authorities and healthcare organizations in other jurisdictions, provincially and nationally. The goal is to help administrators and clinicians consistently measure person- and family-centred outcomes of palliative care in BC. Measuring person- and family-centred outcomes can help improve care quality and ensure that services truly align with the needs of those living with serious illness.

Phase One: Identifying priority outcomes

A consensus-building process using a Delphi method was undertaken with a selected panel to determine the person- and family-centred palliative care outcomes deemed essential to measure in BC. The population considered was people with serious illness across settings – excluding long-term care and pediatrics.

Approach

A thorough environmental scan was conducted to identify current white and grey literature describing person- and family-reported outcomes of palliative care and the tools available to assess these outcomes.

Informed by the literature, 30 person- and family-centred outcomes of palliative care were identified and organized into 10 domains. A three-round Delphi process was then used to build consensus among a multidisciplinary panel. Through this iterative approach, the panel prioritized the outcomes considered of highest priority - or 'essential' - to assess palliative care in BC.

Outcomes were considered to have met consensus as 'essential' if 75% of our panel rated the outcome as an essential priority to measure, 5 on a Likert scale, as shown in Box 1. Prior to rating the outcome's priority, panel members rated whether the outcome statement was clear and understandable. If the statement was not understandable, it was reworded and asked in the next survey. Specific palliative care-related terms used in the surveys were presented with definitions to ensure understanding among panel members throughout the process.

Box 1: Likert scale of priority used in all 3 consecutive surveys.

5	Essential priority: Completely necessary to measure to understand quality palliative care for people and their families
4	High priority: Very important to measure to understand quality palliative care for people and their families
3	Moderate priority: Important to measure to understand quality palliative care for people and their families
2	Somewhat a priority: Slightly important to measure to understand quality palliative care for people and their families
1	Low priority: Unnecessary to measure to understand quality palliative care for people and their families

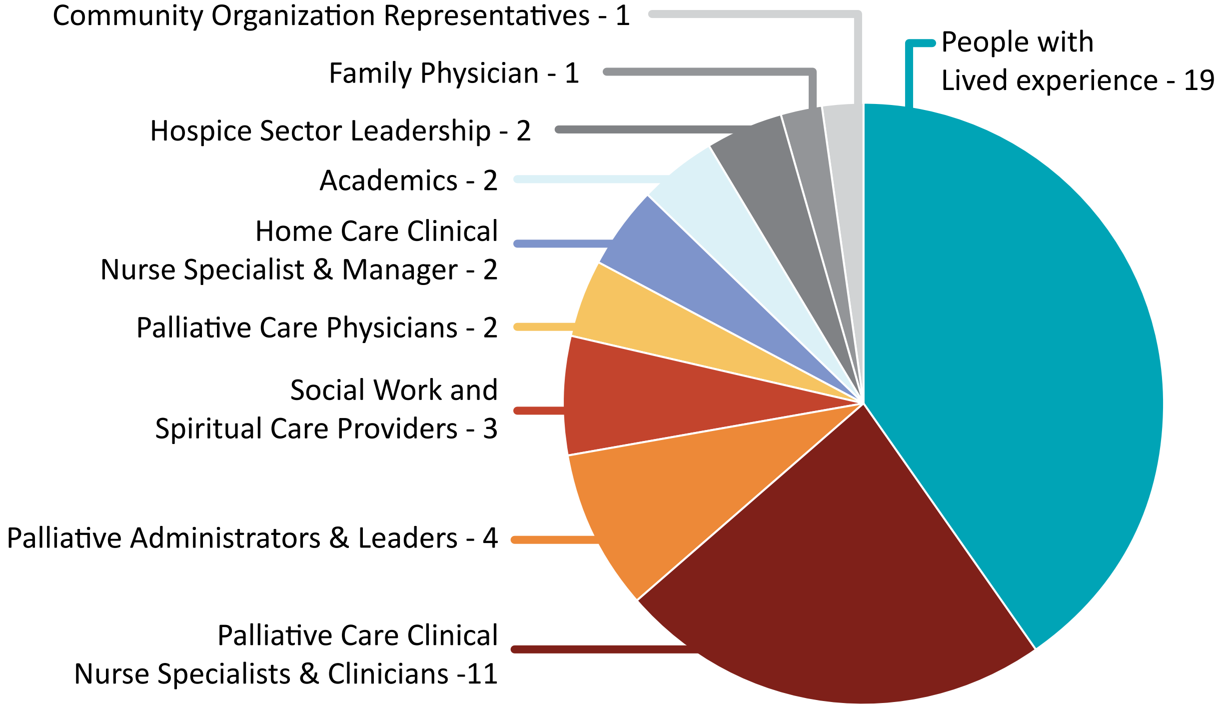
The panel consisted of people with a lived or living experience with a life-limiting illness or their families, as well as researchers, healthcare professionals and palliative care leaders and administrators from all BC health authorities, and key community partners.

Two focus groups with people with lived experience were held to inform the interpretation of the results of survey 1 and 2.

A fourth survey was conducted in which the expert panel rated the top three most important outcomes from the resulting list of ‘essential’ outcomes. In this round, clinicians and administrators who are members of the panel were also asked to indicate the level at which each outcome might be best suited to inform: the patient level to inform clinical assessment; the program level to support quality improvement; or the systems level to guide policy development and inform structures or processes. Consensus was defined as 75% or more of the panel selecting an outcome among their “top three” in terms of importance.

The quantitative and qualitative data collected through the surveys and focus groups were analyzed by the BCCPC’s research team and palliative care experts with guidance from Dr. Rick Sawatzky, Canada Research Chair in Equitable People-Centred Health Measurement.

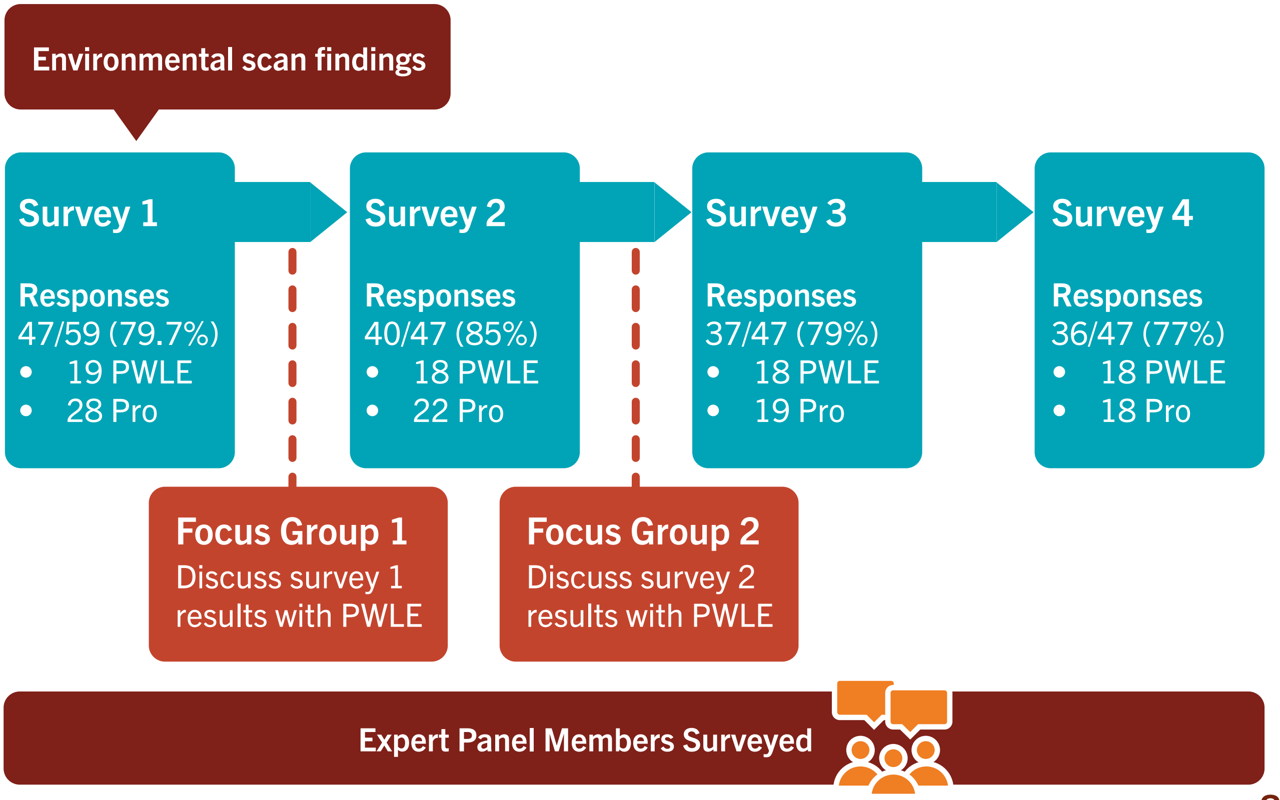
Figure 1: Membership of 47-person expert panel.



The panel had strong representation and participation from those with lived experience (40% of the panel). Participation of members from rural areas and Indigenous people with lived experience enriched the perspectives.

Figure 2: Overview of the Phase 1 process and expert panel response rates.

(PWLE - People with lived experience, Pro - Professionals)

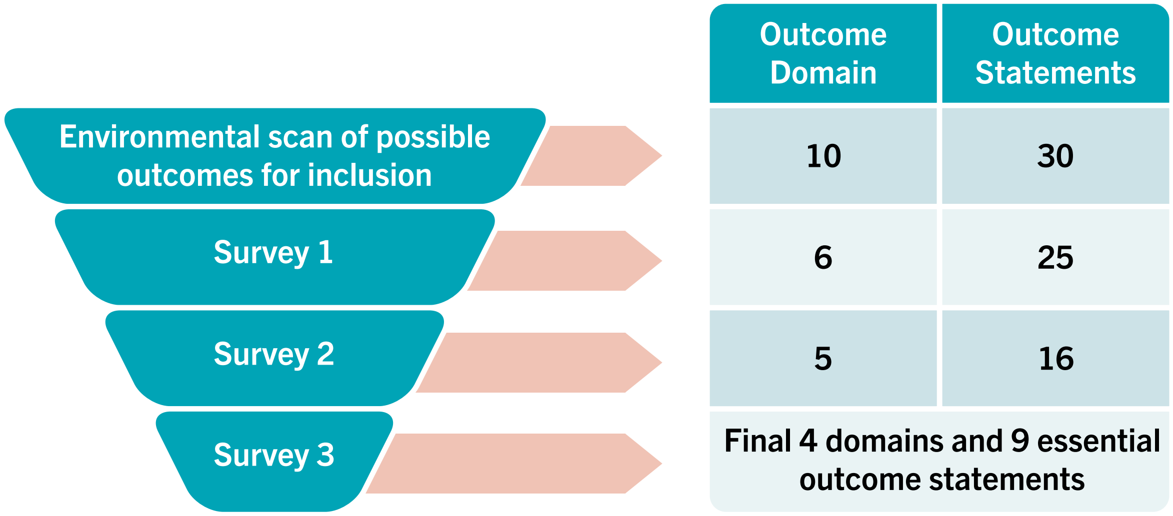


Phase One Results

Findings from phase one of the initiative answered the question:

> *What person and family-centred palliative care outcomes do people with lived experience, their families and health care providers in BC agree are the HIGHEST priority ('Essential') to measure in BC?*

Figure 3: The process of determining the essential outcome domains and statements.

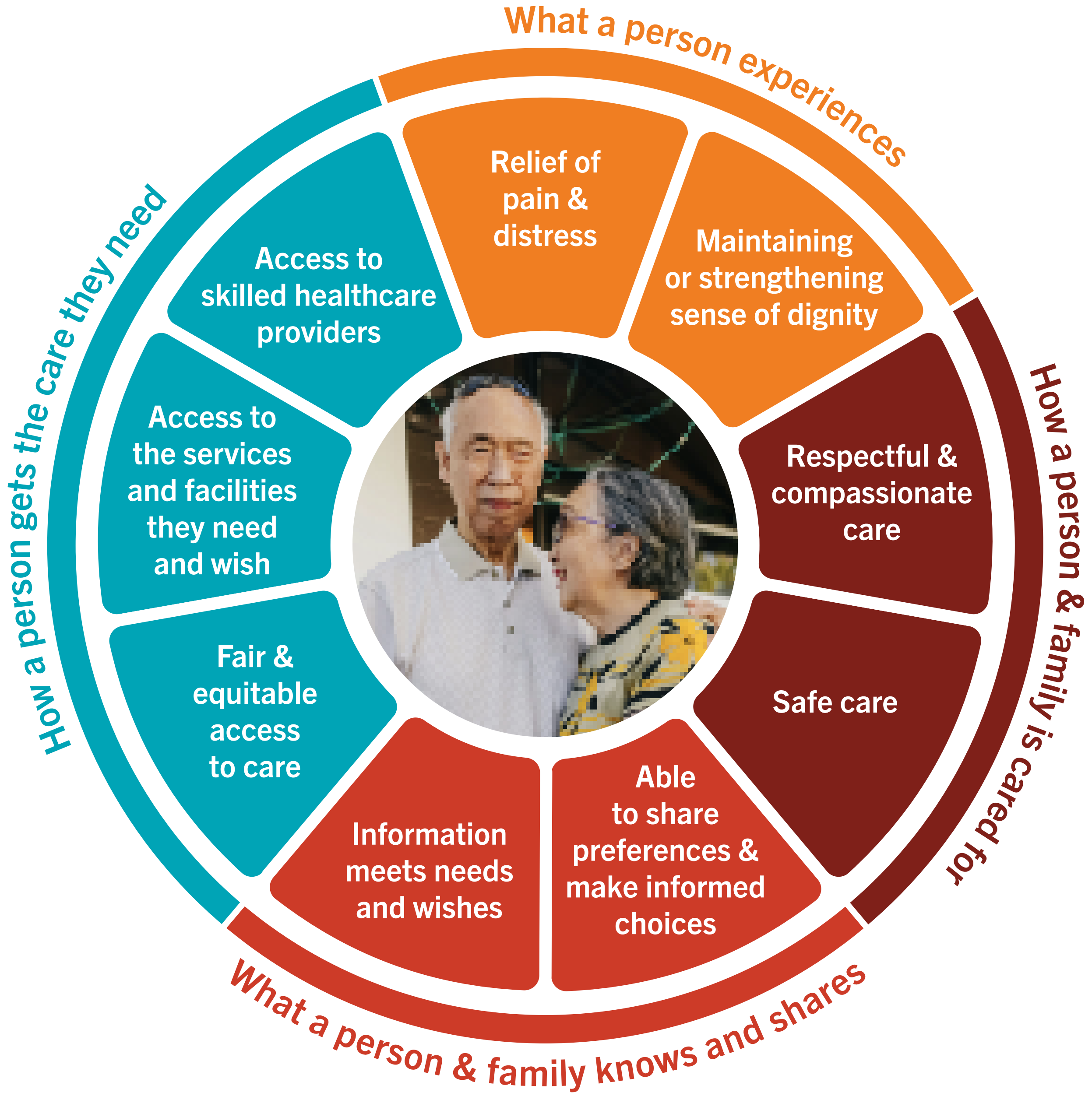


	Outcome Domain	Outcome Statements
Environmental scan of possible outcomes for inclusion	10	30
Survey 1	6	25
Survey 2	5	16
Survey 3	Final 4 domains and 9 essential outcome statements	

> **Exclusions:**
> **25** outcomes were rated as "**very important**" but only 9 reached 75% consensus as "**essential**"
> 5 additional outcomes reached 75% consensus as "**essential**" by person with lived experience but not by professionals

- Of the 30 proposed outcomes, many (25/30) were rated as important to measure – high and essential priorities.
- Through the survey process to narrow the outcomes to those most important, ultimately nine outcomes achieved 75% or greater consensus as 'Essential' to measure in BC, as rated by the expert panel members, including people and families with lived experience and professionals (See Figure 2 and Box 2). The outcomes are informed by literature and confirmed through iterative focus groups with panel members who have lived experience.
- Although there was agreement in the rating for many outcomes between professionals and people with lived experience, there were differences.
  - Five outcomes were rated as 'Essential' to measure by >75% of people with lived experience, but not by professionals and thus did not reach consensus for inclusion (Box. 3).
  - No outcomes were rated as 'Essential' to measure for professionals but not for people with lived experience.
- To review the list of all outcomes that did not reach consensus as an essential priority to include by either professionals or people with lived experience, see Appendix A.

Figure 4: Nine person- and family-centred palliative care outcomes meeting consensus as essential to measure in BC.



Box 2: List of person- and family-centred palliative care outcomes meeting consensus as 'essential' to measure in BC.

Outcome	Consensus Levels*
Well-Being:	
1. Relief of pain and distress - effective control of physical symptoms, distress or discomfort[1,2]	81%
2. Maintaining or strengthening a person's sense of dignity, including feeling seen, valued and respected[3]	87%
Appropriate Care:	
3. Respectful and compassionate care[2,4] – being treated with empathy and kindness in a healthcare setting. • The person feels that their values, beliefs, emotions, preferences, as well as cultural and spiritual practices are respected and honoured in all communications throughout their illness, dying, and for family following death.[5–9]	87%
4. Safe care – being cared for free from harm, hazards, or unacceptable risks • The person experiences safety in using prescribed medications.5 • The person perceives a sense of safety and security with care and in their environment.[5,10] • The person receives support for living with risk aligned with their wishes.[11]	87%
Information Needs, Preferences and Shared Decision Making:	
5. The extent to which the **information** given to the person and family by healthcare providers **meets their needs and wishes**.	77%
6. The person and family have opportunities to **share their preferences** with healthcare providers and have enough information to **make informed healthcare choices**.	77%
Access to Care:	
7. Fair and equitable access to care that meets the person's health and social situation and wishes – including medical, physical, emotional, spiritual, social and bereavement care.[1]	75%
8. Access to healthcare services and facilities to meet the person's specific needs and align with their wishes – such as inpatient hospice, inpatient hospital units, home care services, or specialized palliative care services.[9]	79%
9. Access to skilled healthcare providers, including palliative care specialists if needed[1,2] • The person feels that the providers are skilled in managing pain symptoms and psychosocial care.[8] • The person has timely access to specialized palliative care when needed, either directly from a specialized team or team member, or through consultation with their existing primary care team.[8]	82%

*Consensus levels: Percentage of respondents rating the outcome as 'essential' to assess in BC, with a consensus threshold of 75%.

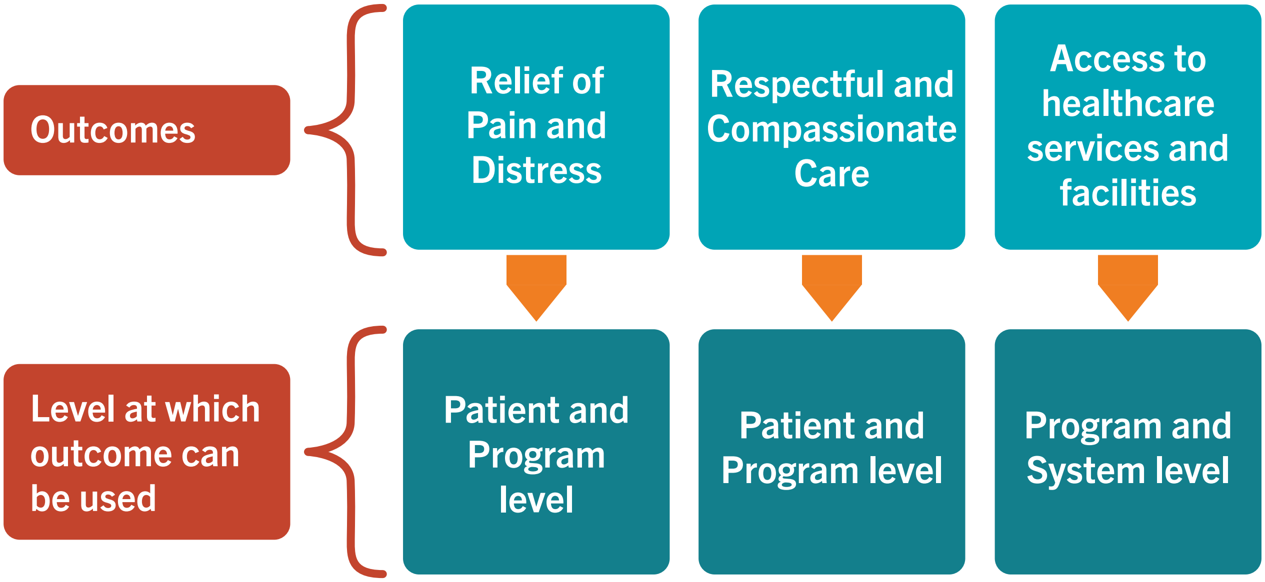
Box 3: Five outcomes rated as 'essential' to measure by people with lived experience but not professionals.

Outcome	Survey results
Shared decision making – person's preferences for treatment and place of care are shared with healthcare providers and decisions about care and treatment include the person and family, recognizing the person or their substitute decision maker is the decision-maker • The person is able to take their desired role in their healthcare decision-making • The person and family can express their opinions, wishes, preferences and concerns • The person and/or their substitute decision maker engage in decision-making for immediate and future care, including consideration of potential deterioration of clinical status or crisis • The person experiences ongoing conversations to address changes in wishes/experiences rather than a one-time discussion	Survey 3: 83% People with lived experience 63% Professionals
Timely access to care that is responsive to the needs of the person and their family	Survey 3: 80% People with lived experience 61% Professionals
The person experiences care related to illness and during changes in care teams and transitions in settings as organized, connected and supported. The person • does not have to repeat the same information to new healthcare providers. • receives coordinated care and support during transitions between home, hospice and hospital, particularly discharges home. • knows who is in charge of their care. • usually sees the same care providers over time	Survey 3: 78% People with lived experience 65% Professionals
The quality of communication that the person and family have with healthcare providers	Survey 1: 78% People with lived experience 69% Professionals
Access to care that is attentive and responsive to the needs of the person and their family	Survey 1: 79% People with lived experience 68% Professionals

Since the five outcomes in Box 3 did not achieve collective consensus by the expert panel as 'Essential' to measure in BC, they are not included in the next phase of the project, which focuses on 'Consensus-driven Essential' outcomes. However, these five outcomes remain high-priority outcomes and may still be valuable for administrators and providers to use in assessing their programs as needed.

Figure 5: The top three most important outcomes (Survey 4).

The outcomes that met consensus in the fourth survey as being the three most important outcomes to measure, and the levels at which each outcome would be best suited to inform.



Phase Two: Identifying tools for outcome measurement

Approach

In the first phase of the project, an expert panel of people with lived experience and healthcare professionals reached consensus on ***what*** person- and family-centred palliative care outcomes are considered an essential priority to measure in BC.

Phase 2 focused on ***how*** we can measure these essential outcomes. The aim was to identify and present validated, reliable tools for measuring the consensus-driven outcomes identified in Phase 1.

To achieve this, we conducted a literature review and environmental scan to identify measurement tools that address the consensus-derived 'essential' outcomes from phase 1 **and meet the following inclusion criteria:**

- demonstrated some evidence of psychometric validity
- recommended for use with people living with a variety of serious illnesses (i.e., cancer and non-cancer)
- developed for those with serious progressive illness rather than more broadly across chronic illness or healthcare generally
- designed for completion by person or family

We have excluded tools that are:

- specific to one care service or setting (e.g., tools that measure quality of care in the ICU)
- designed to measure multiple outcomes after the person's care is completed or following their death but measures less than 6 of the 8 consensus-derived priority outcomes to measure
- administered via an interview

A full list of excluded tools can be found in appendix B.

The selected measurement tools have been organized into two groups:

1. Tools that measure a single 'essential' outcome
2. Tools that measure multiple 'essential' outcomes. This group is further organized into:
   - Tools designed to measure multiple outcomes while the person is receiving palliative care
   - Tools designed to measure multiple outcomes after the person's care is completed or following their death

For each tool, we provide details on its length (number of questions), year of development, purpose, outcome measures, the care settings where it was validated, and links to published articles or the instrument, where available.

Phase Two Results: Tools for measuring a single outcome

This section presents tools that focus on each individual 'essential' outcome and are completed by the person receiving care and/or a family member during the care experience.

For tools that measure additional outcomes beyond the primary 'essential' outcome, we indicate the number of items in the tool related to the primary outcome, alongside the total number of items in the tool (noted in brackets).

Table 1: Measurement tools for "Relief of pain and distress" – Effective control of physical symptoms, distress or discomfort.[1,2]

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
Short Tools						
Receiving Desired Help for Pain (2015)	**Description:** Measures the degree to which people who receive palliative care receive the help they desire for pain.	Both person and family	3 (3)	Outpatient	Both	
The Edmonton Symptoms Assessment Scale (1991)	**Description:** Assesses 9 symptoms rated by severity.	Both person and family	9 (9)	Inpatient, Outpatient	Both	Survey, Alberta, Yukon, NL, Manitoba, BC, NS, PEI, Ontario
The Brief Pain Inventory - Short Form, (1991)	**Description:** Assesses the history, intensity, location, and quality of pain.	Person	9 (9)	Inpatient, Outpatient	Both	Alberta, Ontario
FACIT Pal-14 , (2013)	**Description:** Assesses health-related well-being among people receiving palliative care, applied to the past 7 days.	Person	6 (14)	Inpatient, Outpatient	Both	

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
Long Tools						
Short-Form McGill Pain Questionnaire 2 (SF-MPQ2), (2009)	**Description:** Assesses the quality and intensity of 23 types of pain and related symptoms, during the past week.	Person	24(24)	Outpatient	Both	
The Memorial Symptom Assessment Scale – Short Form (1994)	**Description:** Measures the average of the frequency, severity, and distress associated with 24 prevalent physical symptoms.	Both person and family	32 (32)	Inpatient, Outpatient	Both	
McGill Pain Questionnaire, (1975)	**Description:** Assesses quality and intensity of subjective pain containing three components: sensory intensity, cognitive evaluation of pain, and emotional impact of pain.	Person	78 (78)	Inpatient, Outpatient	Both	
The Rotterdam Symptom Checklist (1990)	**Description:** Outcome measure of symptom control (one dimension-severity/distress), which measures physical, psychological, and functional aspects of quality of life.	Both person and family	23 (39)	Various clinical and research settings	Both	

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
FACIT-Pal, (2009)	**Description:** Self-reported questionnaire used to assess quality of life in person's daily life in a palliative care setting, during the past 7 days.	Person	7 (39)	Inpatient, Outpatient	Both	
McGill Quality of Life Questionnaire-Revised, (2016)	**Description:** Multidimensional tool designed to measure physical well-being, physical symptoms, psychological symptoms, existential well-being and support, as well as overall quality of life, in the past 2 days.	Person	4 (17)	Inpatient, Outpatient	Both	
Comprehensive Problem and Symptom Screening (COMPASS) - combines ESAS and Canadian Problem Checklist, (2012)	**Description:** The COMPASS combines the Edmonton Symptoms Assessment Scale and Canadian Problem Checklist to comprehensively screen for distress during the past week, including psychosocial, practical, and physical concerns.	Person	17 (41)	Inpatient, Outpatient	Both	Yukon, NL

Table 2: Measurement tools for "Maintaining or strengthening a person's sense of dignity" – Feeling seen, valued and respected.[3]

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
Short Tools						
Feeling Heard and Understood (2016)	**Description:** Measure the degree to which people who receive palliative care feel heard and understood by those caring for them.	Both person and family	4 (4)	Inpatient, Outpatient	Both	
Long Tools						
Jacelon Attributed Dignity Scale (JADS) (2009)	**Description:** Measures self-perceived attributed dignity in community-dwelling older adults.	Both person and family	18 (18)	Senior centres	Both	
Inpatient Dignity Scale (IPDS) (2019)	**Description:** Measures a person's expectations and satisfaction with their dignity while receiving medical care.	Both person and family	18 (21)	Inpatient	Both	
The Patient Dignity Inventory (PDI) (2008)	**Description:** Measures a person's sense of dignity and related distress.	Both person and family	25 (25)	Inpatient, Outpatient, Critical Care	Both	Ontario

Table 3: Measurement tools for "Information Needs, Preferences and Shared Decision-Making."[2,4,12]

The extent to which the information given to the person and family by healthcare providers meets their needs and wishes. The person and family have opportunities to share their preferences with healthcare providers and enough information to make informed healthcare choices.

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
Short Tools						
Feeling Heard and Understood (2016)	**Description:** Measures the degree to which people who receive palliative care feel heard and understood by those caring for them.	Both person and family	4 (4)	Inpatient, Outpatient	Both	
Long Tools						
Comprehensive Problem and Symptom Screening (COMPASS) - combines ESAS and Canadian Problem Checklist, (2012)	**Description:** The COMPASS combines the Edmonton Symptoms Assessment Scale and Canadian Problem Checklist to comprehensively screen for distress, including psychosocial, informational, practical, and physical concerns.	Person	6 (41)	Inpatient, Outpatient	Both	Yukon, NL, Manitoba

Table 4: Measurement tools for "Respectful and compassionate care"[2,4] – Being treated with empathy and kindness in a healthcare setting.

The person feels that their values, beliefs, emotions, preferences, as well as cultural and spiritual practices are respected and honoured in all communications throughout the experience of illness, dying, and for family following death[5–8,FG]

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Population (non-cancer, cancer, or both)	Identified in Survey or used in a Province
Short Tools						
The Schwartz Center Compassionate Care Scale (SCCC) (2015)	**Description:** Assesses compassionate care in recently hospitalized people.	Both person and family	12 (12)	Inpatient	Both	
The Sinclair Compassion Questionnaire (SCQ) (2021)	**Description:** Evaluates compassion in the care received from a facility, as perceived by people receiving care.	Both person and family	15 (15)	Inpatient, Hospice, Long-term care, Community	Both	
Long Tools						
Quality of communication (2015)	**Description:** Assesses the foundational aspects of patient-clinician communication about end-of-life care.	Both person and family	19 (19)	Primary care	Both	

Outcomes for which no tools used during the care experience were found that measure only this outcome:

- **Fair and equitable access to care that meets the person's health and social situation and wishes** – including medical, physical, emotional, spiritual, social and bereavement care[1]
- **Access to healthcare services and facilities to meet the person's specific needs and align with their wishes**– such as inpatient hospice, inpatient hospital units, home care services, or specialized palliative care services.[FG]
- **Access to skilled healthcare providers, including palliative care specialists if needed**[1,2]
    - The person feels that the providers are skilled in managing pain symptoms and psychosocial care[8]
    - The person has timely access to specialized palliative care when needed, either directly from a specialized team or team member, or through consultation with their existing primary care team[8]
- **Access to safe care** – being cared for free from harm, hazards, or unacceptable risks
    - The person experiences safety in using prescribed medications[5]
    - The person perceives a sense of safety and security with care and in their environment[5,10]
    - The person receives support for living with risk aligned with their wishes[11]

Phase Two Results: Tools for measuring multiple outcomes

This section highlights tools designed to capture multiple outcomes aligned with person- and family-centred palliative care.

Table 5 includes tools that are meant to be completed by the person and/or family while the person is receiving care.

Table 6 includes tools that are meant to be completed by family members or caregivers after the person's care experience or death. We have presented only tools that cover 6 or more of the 9 outcomes that have met consensus as essential.

Table 5: Measurement tools used DURING the care experience that cover multiple outcomes.

Tool Name (Year)	Overview	Perspective	# Items in Tool	Outcomes represented (# items related to outcome)	Identified in Survey or used in Province
Short Tools					
Real Time Patient Experience Survey, (2017)	Electronic survey administered to people and families, assessing their care experience.	Both person & family	4	Information needs, preferences, and shared decision making (1)	BC (Fraser Health)
				Respectful and compassionate care (2)	
ConsiderRATE, (2021)	A measure of serious illness experience based on a review of what matters most to people who are seriously ill.	Both person & family	8	Relief of pain and distress (1)	
				Maintaining or strengthening dignity (1)	
				Information needs, preferences and shared decision making (3)	
				Respectful and compassionate care (1)	
Quality of End-of-Life Care (QOELC) Survey – Family, (2010)	Survey assessing clinician skills at providing end-of-life care for people and their families.	Family	10	Maintaining or strengthening dignity (2)	
				Information needs, preferences, and shared decision making (3)	
				Respectful and compassionate care (2)	
FAMCARE-Patient, (2009)	A written self-report scale sent to people with advanced cancer being seen in an outpatient palliative care setting - to assess patient satisfaction.	Person	13	Relief of pain and distress (4)	
				Information needs, preferences and shared decision making (5)	
				Access to skilled healthcare providers (4)	

Tool Name (Year)	Overview	Perspective	# Items in Tool	Outcomes represented (# items related to outcome)	Identified in Survey or used in Province
Integrated Palliative Care Outcome Scale (IPOS), (2019)	Captures the complex symptoms and concerns of those receiving palliative care, assess and monitor symptoms and concerns in advanced illness, determine the impact of healthcare interventions, and demonstrate quality of care.	Person	10	Relief of pain and distress (4) Maintaining or strengthening dignity (2) Information needs, preferences and shared decision making (1)	
Long Tools					
Canadian Health Care Evaluation Project (CANHELP) - Patient (2010)	Evaluates the satisfaction with care in the last month of life, for older people with life-threatening illnesses, and their family members.	Both person & family	38	Relief of pain and distress (4) Maintaining or strengthening dignity (2) Information needs, preferences, and shared decision making (11) Access to health care services (1) Access to skilled healthcare providers (1) Respectful and compassionate care (3)	BC (Island Health)
FAMCARE-2, (2010)	Measures satisfaction of family members with palliative care received by people and their family members.	Family/ Caregiver	20	Relief of pain and distress (1) Access to healthcare services (3) Access to skilled healthcare providers (4) Respectful and compassionate care (2)	Survey
Quality of Family Experience (QUAL-E Fam), (2014)	Measures quality of life at end of life from the perspective of family.	Family/ Caregiver	17	Relief of pain and distress (4) Information needs, preferences and shared decision-making (4)	
Quality of End-of-Life Care and Satisfaction with Treatment (QUEST), (2002)	Assesses satisfaction with care at the end of life.	Both person & family	28	Access to skilled healthcare providers (6) Respectful and compassionate care (6)	

Table 6: Measurement tools used AFTER the person's care experience or death that cover multiple outcomes.

Tool Name (Year)	Overview	# Items in Tool	Outcomes represented (# items related to outcome)	Identified in Survey or used in Province
CaregiverVoice Survey (CVS) [modified VOICES], (2012)	Investigates the experience of end-of-life care in the **last three months of life**, for people and their caregivers.	62	Relief of pain and distress (6)	Ontario
			Maintaining or strengthening dignity (6)	
			Information needs, preferences and shared decision making (8)	
			Fair and equitable access to care (8)	
			Access to health care services (8)	
			Access to skilled healthcare providers (4)	
			Respectful and compassionate care (7)	
Canadian Health Care Evaluation Project (CANHELP) - Bereavement/ Caregiver, (2010)	Evaluates the satisfaction with care in the **last month** of life, for older people with life-threatening illnesses, and their family members.	40	Relief of pain and distress (4)	BC (Island Health)
			Maintaining or strengthening dignity (2)	
			Information needs, preferences and shared decision making (11)	
			Access to health care services (1)	
			Access to skilled healthcare providers (1)	
			Respectful and compassionate care (3)	
Bereaved Family Survey (BFS) (2017)	Assesses families' perceptions of the quality of care received by veterans in the **last month of life** from inpatient veteran facilities.	20	Relief of pain and distress (5)	
			Information needs, preferences and shared decision making (1)	
			Fair and equitable access to care (2)	
			Access to health care services (1)	
			Access to skilled healthcare providers (1)	
			Respectful and compassionate care (2)	

Tool Name (Year)	Overview	# Items in Tool	Outcomes represented (# items related to outcome)	Identified in Survey or used in Province
Care of the Dying Evaluation (CODE) (2012)	A post-bereavement questionnaire focused on both the quality of a person's care and the level of family-to-family support provided in the **last days of life and the immediate post-bereavement period.**	42	Relief of pain and distress (4)	
			Maintaining or strengthening dignity (2)	
			Information needs, preferences and shared decision making (8)	
			Fair and equitable access to care (2)	
			Access to health care services (1)	
			Access to skilled healthcare providers (1)	
			Respectful and compassionate care (1)	
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey (2014)	Assesses the experiences of people who died while receiving hospice care, and the experiences of their primary informal caregivers.	47	Relief of pain and distress (4)	
			Maintaining or strengthening dignity (1)	
			Information needs, preferences and shared decision making (10)	
			Access to health care services (1)	
			Access to skilled healthcare providers (1)	
			Respectful and compassionate care (2)	

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Appendix

Appendix A

Outcomes that did not meet consensus as 'essential' by people with lived experience and professionals:

Outcome	Survey results
Feel supported emotionally, including: • The person feels their preferences are acknowledged and considered by healthcare providers. • The person feels supported by healthcare providers to express and process emotions such as grief, anger, anxiety, fear, confusion, and emptiness. • The person experiences kindness and empathy from the provider. *(from Outcome 4: Respectful and compassionate communication)*	Survey 3: 47% People with lived experience 58% Professionals
Family caregivers feel supported in their role as caregivers, including: • Family caregivers know the resources available and how to reach out for support as needed. • Family caregivers experience empathy related to caregiving from the provider. • Family caregivers feel prepared to care for their family member.	Survey 3: 61% People with lived experience 53% Professionals
The person and family understand the illness, its course, options for treatment and care, and medication use.	Survey 3: 67% People with lived experience 63% Professionals
Culturally safe care	Survey 3: 39% People with lived experience 63% Professionals
Maintains social relationships as wished, including: • The person feels socially connected (close to others). • The person feels support from others. • The person feels they are able to contribute and not be a burden to others.	Survey 2: 53% People with lived experience 29% Professionals
Feeling at peace, including being at peace with oneself, the illness journey, in relationships with loved ones and/or decisions about care.	Survey 2: 41% People with lived experience 21% Professionals
Personal perception of well-being	Survey 1: 74% People with lived experience 36% Professionals

Outcome	Survey results
Personal perception of quality of life	Survey 1: 67% People with lived experience 57% Professionals
Functional capacity – ability to perform daily activities like walking, dressing or cooking	Survey 1: 22% People with lived experience 14% for professionals
Clear-minded – being alert and oriented	Survey 1: 29% People with lived experience 19% Professionals
Social well-being - A person feels good in their relationships and connections with others.	Survey 1: 63% People with lived experience 32% Professionals
Maintaining meaning and identity – keeping a sense of purpose and of self despite changes in a person's physical condition	Survey 1: 47% People with lived experience 36% Professionals
Emotional well-being - The extent to which the emotional needs and wishes of the person and family are addressed.	Survey 1: 63% People with lived experience 69% Professionals
Empowerment – taking an active role in their healthcare, able to voice opinions, wishes and concerns	Survey 1: 63% People with lived experience 46% Professionals
Resilience – coping with feelings of loss such as anger, confusion, and emptiness	Survey 1: 42% People with lived experience 27% Professionals
Spiritual well-being - The extent to which the spiritual needs and wishes of the person and family are addressed.	Survey 1: 32% People with lived experience 31% Professionals
Feeling hope – maintaining a sense of security amidst uncertainty and a connection with the future	Survey 1: 21% People with lived experience 21% Professionals
Family well-being - The degree to which the family members' needs and wishes are met.	Survey 1: 53% People with lived experience 23% Professionals

Outcome	Survey results
Family coping – the ability of families to face and adapt to changing situations such as illness.	Survey 1: 32% People with lived experience 19% Professionals
Caregiver coping – dealing with the physical, emotional, and practical parts of providing care	Survey 1: 42% People with lived experience 54% Professionals
Family grief / bereavement – ways in which family members mourn and heal from the loss of the person who has died	Survey 1: 32% People with lived experience 20% Professionals
Family understanding – family understands the illness, its course, options for treatment and care, and medication use.	Survey 1: 68% People with lived experience 33% Professionals
Team-based care – those involved in providing care for the person and family work well together to ensure they receive optimal care.	Survey 1: 37% People with lived experience 46% Professionals

Appendix B

Tools that were excluded during phase two:

1. Sector-specific tools: questions targeted to one care setting or one patient population.

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (Items in tool)	Settings of validation	Populations (non-cancer, cancer, both)	Reason for exclusion	Identified in Survey or in Province
Dignity in Care Scale for Nurses (2019)	**Description:** Measures nurses' behaviours for maintaining a person's dignity in clinical care.	Staff	36 (36)	In person	Both	Specific to nursing and asks for staff perspective	Survey
Satisfaction with Care at the End of Life in Dementia (SWC-EOLD) (2019)	**Description:** Predominantly used in long-term care settings to evaluate carer satisfaction with end-of-life care provided to people living with dementia, measured in last 90 days of life.	Staff	10 (10)	Long-term care	Non-Cancer	Specific to long-term care and people living with dementia; asks for staff perspective	
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cancer Care Survey (1997)	**Description:** Assesses adults' experiences with cancer treatment - radiation oncology, medical oncology, and cancer surgery.	Person	53 (53)	Inpatient, outpatient	Cancer	Specific to people with cancer	
Family Satisfaction with Care in the Intensive Care Unit (FS-ICU) (2007)	**Description:** Measures family satisfaction with care in the intensive care unit.	Family	24 (24)	ICU	Both	Specific to ICU care setting	

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (Items in tool)	Settings of validation	Populations (non-cancer, cancer, both)	Reason for exclusion	Identified in Survey or in Province
Family Evaluation of Hospice Care (FEHC) (2005)	**Description:** Assesses family caregivers' perceived quality of care in the last month of a person's life.	Family	61(61)	Hospice	Both	Specific to hospice care setting	
Pain Assessment in Advanced Dementia (PAINAD) (2003)	**Description:** Observational pain tool that clinicians can use to assess pain in people living with dementia or other cognitive impairment.	Staff	5(5)	Inpatient, Outpatient	Both	Specific to people living with dementia or cognitive impairment; asks for staff perspective	Yukon, Alberta, BC (Northern Health), PEI
Edmonton Classification System for Cancer Pain (1989)	**Description:** Clinician-rated assessment evaluating pain classification in people with cancer: mechanism of pain, incident pain, psychological distress, addictive behavior, and cognitive function.	Staff	5(5)	Inpatient, Outpatient	Cancer	Specific to people living with cancer; asks for staff perspective	Alberta

2. Tools used **after** the person's care experience or death that cover multiple outcomes but didn't meet 75% of consensus-derived outcomes

Tool Name (Year)	Overview	# Items in tool	Outcomes not represented	Identified in Survey or in Province
Family Assessment of Treatment at the End-of-Life (FATE) Survey (2008)	**Description:** Assesses quality of end-of-life care, evaluating person's and family's perceptions of outcomes of care by asking how well the care provided met their needs.	32	Maintaining or strengthening dignity Access to health care services Safe care	
Quality of Dying and Death (QODD) (2002)	**Description:** Asks bereaved families to rate the quality of the dying experience for the decedent's last 7 days or if the person was unconscious or unresponsive during the last 7 days, over the last month before death.	31	Access to skilled healthcare providers Respectful and compassionate care Safe care	Survey

3. Tools excluded as administered by interview

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Populations (Non-cancer, cancer, both)	Reason for Exclusion	Identified in Survey or in Province
After death bereaved family member interview (hospital version) Part of the Toolkit of Instruments to Measure End of Life Care [TIME], (2001)	**Description:** Interview administered to bereaved family members of a person who died of a chronic progressive illness.	Family	42(42)	Inpatient, Outpatient	Both	Collect information via interview format – beyond measure used for indicators	Survey
Symptom Assessment O-V Acronym, (2000)	**Description:** Assesses comprehensive symptom assessment.	Person	8(8)	Inpatient, Outpatient	Both	Collect information via interview format – beyond measure used for indicators	BC (Fraser Health), Yukon

4. Instruments measuring outcomes that didn't meet our criteria for inclusion

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Populations (Non-cancer, cancer, both)	Reason for Exclusion	Identified in Survey or used Provincially
FICA Spiritual History Tool, (1996)	**Description:** Assess components of spirituality.	Person	11	Inpatient, Outpatient	Both	Outcome didn't meet consensus (spiritual well-being); interview format	Alberta, BC (Interior Health) Ontario
HOPE, (2001)	**Description:** Assesses the person's spiritual needs pertaining to medical care.	Person	4	Inpatient, Outpatient	Both	Outcome didn't meet consensus (spiritual well-being); interview format	Newfoundland & Labrador, Ontario
Bereavement Risk Assessment Scale, (2008)	**Description:** Psychosocial assessment for caregivers and their bereavement needs.	Staff/Family	40	Inpatient, Outpatient	Both	Outcome didn't meet consensus (family caregiver well-being)	BC
Adult Attitudes to Grief Scale, (2001)	**Description:** Assesses grief and vulnerability (need for support) by identifying grief reactions and coping responses of caregiver.	Family	18	Inpatient, Outpatient	Both	Outcome didn't meet consensus (family caregiver well-being)	BC
Quality of Life in Life Threatening Illness – Family Carer, (2006)	**Description:** Assesses what is important to carer's quality of life (QOL) across 7 domains.	Family	16	Inpatient, Outpatient	Both	Outcome didn't meet consensus (family caregiver well-being)	

Tool Name (Year)	Overview	Perspective	# Items in tool related to outcome (# Items in tool)	Settings of validation	Populations (Non-cancer, cancer, both)	Reason for Exclusion	Identified in Survey or used Provincially
Palliative Performance Scale 2 (PPSv2), (2001)	**Description:** Measures functional/ performance status in people receiving palliative care over time.	Staff	5	Inpatient, Outpatient	Both	Outcome didn't meet consensus (functions of daily activity)	Ontario, Nova Scotia, Newfoundland & Labrador, Manitoba, BC, Alberta, Yukon
Richmond Agitation Sedation Score -Palliative Version (RASS-PAL), (2014)	**Description:** Assesses person's level of sedation during Palliative Sedation Therapy.	Staff	1	Inpatient	Both	Specific to sedation therapy; asks for staff perspective	Alberta, BC (Interior Health)