Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

Effective Date: January, 2019
The recommendations contained in this guideline are a consensus of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams and are a synthesis of currently accepted approaches to management, derived from a review of relevant scientific literature. Clinicians applying these guidelines should, in consultation with the patient, use independent medical judgment in the context of individual clinical circumstances to direct care.

Participation of members of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams in the development of this guideline has been voluntary and the authors have not been remunerated for their contributions. There was no direct industry involvement in the development or dissemination of this guideline. CancerControl Alberta recognizes that although industry support of research, education and other areas is necessary in order to advance patient care, such support may lead to potential conflicts of interest. Some members of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams are involved in research funded by industry or have other such potential conflicts of interest. However the developers of this guideline are satisfied it was developed in an unbiased manner.
BACKGROUND

Currently, patients and families living with advanced cancer experience significant distress when the transition from cancer-directed therapies to ongoing palliative-focused care occurs abruptly.¹ Late or no palliative care use is associated with more aggressive and costly end-of-life care.² In Alberta, 60% of patients with metastatic gastrointestinal cancers had a late (within 2 months of death) or no palliative care referral.³,⁴ This was associated with aggressive care in 50% of those patients, as compared to 25% in those who received early palliative care. Choosing Wisely Canada⁵, the American Society of Clinical Oncology (ASCO)⁶-⁸, and other guidelines⁷,⁹-¹¹ recommend that palliative care should not be delayed or avoided in patients with metastatic cancer who are also pursuing disease-directed treatment. Additionally, Accreditation Canada¹² recommends there be “a process for initiating palliative and end of life care”. There is extensive evidence that integrating an early palliative approach with cancer care improves outcomes for patients with advanced cancer.¹³-²⁰ This approach has been described by Temel’s five elements of an early palliative approach to care¹⁴ and Boucher’s best supportive care checklist.²¹ Improved methods of tracking and addressing symptoms are associated with less emergency room usage and improved quality of life and survival.²² Refer to Evidence Table for a comprehensive review of the literature.

DEFINITIONS

To create clarity around the concepts in this guideline, the following definitions are provided:

How is advanced cancer defined?

Advanced cancer is defined as those with distant metastases, late-stage disease, cancer that is life limiting, and/or with prognosis of 6 to 24 months.⁶

Advanced colorectal cancer is generally not amenable to surgical resection of all sites of disease, and usually represents an incurable situation. As a small number of advanced colorectal cancer patients may achieve prolonged remission or cure, the potential for cure is not an exclusion for use of this guideline.

What is the palliative approach to care?

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten or postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life, and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.23

In brief the palliative approach to care includes whole person care, quality-of-life focus, and mortality acknowledgement.24

When is palliative care defined as “early”? 

**Early palliative care** starts close to the initial diagnosis of advanced cancer, specifically the “Integration of palliative care into standard oncology care: ASCO clinical practice guideline update” suggests within 8 weeks of diagnosis.6 Palliative care continues as an added layer of support throughout a disease trajectory, including concurrently with cancer modifying therapy (e.g. chemotherapy), or when patients choose to not have cancer modifying therapy, or when there are no cancer modifying options available. Palliative therapy options may include best supportive care, radiation, surgical or systemic therapy.

**Figure 1** shows how the early palliative care pathway is intended to be used in conjunction with the CancerControl Alberta Metastatic Colorectal Cancer Guideline and forms a continuum of care with other guidelines and pathways.

**Figure 1.** Integrated CancerControl Alberta colorectal care pathways.  
1) CancerControl Alberta guidelines for diagnosis and treatment of early stage colon cancer and early stage rectal cancer. 2) Metastatic colorectal cancer guideline. 3) Integrating an early palliative approach into advanced colorectal cancer care. 4) Acknowledging the prognostic uncertainty and the possibility that either disease progression to death or prolonged remission are potential outcomes when entering each of
the pathways. While there are no CancerControl Alberta guideline for this final box, there are Alberta Health Services (AHS) resources for both end of life care and prolonged remission/survival.

Who provides the palliative approach to care?

The Canadian Society of Palliative Care physicians identifies that a palliative approach “specifically acknowledges the capability of health care professionals who do not specialize in palliative care to attend to the needs of people who have advancing serious illnesses, regardless of the sector of care (home care, residential, hospital, etc.) and the stage the patient is at in the disease trajectory.”

In Alberta, the Palliative and End of Life Alberta Provincial Framework outlines three levels of palliative and end of life care (PEOLC) accessible to patients and families/caregivers† provincially.

**Primary Level**

ALL health care providers should have primary palliative care basic core competencies. This approach to care should be available in all care settings. Care is delivered by interdisciplinary primary care providers (e.g. oncology, family practice teams, urban integrated home care), which provide “clinical management and care co-ordination, including assessments, interventions, referrals and triage”. Providers manage psychosocial, physical and spiritual aspects of care along with communication (e.g. discussion of prognosis, Advance Care Planning, initial management of symptoms). Clinicians may utilize secondary and tertiary palliative care services through consultative processes to further support patients and their families.

**Secondary Level**

Secondary palliative care provides specialized palliative care consultation, advice, and services to primary providers, their patients and families. This includes care in various and specialized settings, such as the patient’s home, long term care, and hospice. Secondary palliative care providers (e.g. palliative care consultants) give advice and support in an interdisciplinary team setting. Not all patients with palliative care needs will require secondary level of care.

**Tertiary Level**

Tertiary palliative care is delivered by specialized interdisciplinary palliative care teams for complex cases, symptom management, or psychosocial concerns not responding to interventions. This level of care is supported by tertiary resources, for example, interventional procedures, diagnostics, in-patient palliative care units and frequent skilled assessments.

What is meant by integrated?

There are many definitions of integrated care. In this guideline, integrated care is understood as care that combines a palliative approach to care with disease-specific management, in a collaborative, coordinated and flexible manner dependent on a person’s and family/caregiver’s range of needs.

† Family/caregiver is defined in this guideline as inclusive of those the patient self-identifies as family (biological and family of choice) and any caregivers (outside of the health system including legally appointed and patient selected).
GOAL OF GUIDELINE

To improve the quality of life for people affected by advanced colorectal cancer by integrating an early palliative care approach into advanced cancer care.

GUIDELINE QUESTIONS

- What triggers should be used to indicate the need to apply an early integrated palliative approach to care?
- What are the essential components of an early palliative approach to care?
- How can these components be integrated into advanced colorectal cancer care?

DEVELOPMENT AND REVISION HISTORY

This guideline was reviewed and endorsed by the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams. Members of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams include: medical oncologists, radiation oncologists, palliative care consultants, surgical oncologists, family physicians, allied health professionals, nurse practitioners, registered nurses, and patient and family advisors. Evidence was selected and reviewed by a working group comprised of members from the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams and a Knowledge Management Specialist from the Guideline Resource Unit. A detailed description of the methodology followed during the guideline development process can be found in the Guideline Resource Unit Handbook.

This guideline was originally developed in October, 2018.

SEARCH STRATEGY

This guideline was developed to outline the integrated early palliative approach to care recommendations for patients with advanced colorectal cancer. It was informed by the results of randomized controlled trials (RCT) and systematic reviews up to 2018 (Evidence Table). It takes into consideration related information presented at local, national, and international meetings, as well as the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams’ interpretation of the data. This guideline was informed from the following clinical practice guidelines:

- Cancer Care Ontario, based on the Gold Standards Framework[^31]
- Accreditation Canada[^12]
- British Columbia clinical practice guidelines and protocols (BCGuidelines.ca[^32])

TARGET POPULATION

The recommendations outlined in this guideline apply to adults over the age of 18 years with advanced colorectal cancer. Different principles may apply to pediatric patients.
RECOMMENDATIONS AND DISCUSSION

This guideline has been summarized in the “Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care Pathway” (www.ahs.ca/GURU under “Gastrointestinal” heading then “Metastatic Colorectal Cancer: Early Palliative Approach” and select “Interactive Care Pathway”).

What are the essential components of an early palliative approach to care?

Several recent analyses of trials integrating oncology and palliative care point towards specific key elements of an early palliative care approach that support whole person care, quality-of-life focus, and mortality acknowledgement.6,14,21,33 In Alberta, these have been synthesized into four components (Figure 2).

Figure 2. Four essential components of an early palliative approach to care.
What is Illness Comprehension & Coping?

Illness comprehension is the extent to which the person understands and internalizes the scope of their illness including prognosis, treatment and care options. It is a complex psychological construct that is dynamic and is interrelated with illness adjustment and coping.34

What is Advance Care Planning?

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.35 ACP is not the same as Goals of Care Designation (GCD) determination. In Alberta, the ACP process is aimed at all adults and includes five elements that a person undertakes:

Think about: Thinking about their own values related to their health and well-being

Learn: Learning about their health or illness conditions, including prognosis and the kind of decisions they might be faced with in the future

Choose: Choosing an alternate decision maker (ADM) in the event they lose capacity for decision making

Communicate: Communicating with their ADM, other family or people close to them and with their health care provider about who their chosen ADM is and the kind of wishes and values they would like to guide their care in the event they lose capacity

Document: Documenting in a Personal Directive to legally appoint their agent (ADM) for personal decision making in the event they lose capacity. The Personal Directive also allows a person to document those wishes, beliefs and values that they want the agent to understand when making decisions about their personal matters.

What is Coordination of Care?

The definition is malleable based on perspective. The Agency for Healthcare Research and Quality uses the working definition: “Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care.”36,37 The five key elements comprising care coordination are: a) Numerous health care providers are involved; b) Providers are dependent upon each other to carry out separate activities in a patient's care; c) Each provider needs adequate knowledge about their own and others' roles, and available resources; d) Providers rely on exchange of information; and e) Integration of care activities has the goal of facilitating appropriate delivery of health care services.38 As complexity increases, the patient's ability to coordinate care themselves decreases and the need for participatory provider coordination increases.
Recommendations and Implementation Strategy

**STEP 1: SCREENING**

Clinicians caring for patients with advanced cancer should use the following opportunities to screen for those who may benefit from an early integrated approach to palliative care:

1. During assessment for symptom burden (physical and psychosocial)
2. With transition points in care or indication of advanced disease trajectory
3. When patient or family/caregiver asks for palliative or supportive care
4. Clinician judgement

All advanced colorectal cancer patients should be **screened** to identify those who may benefit from an early palliative approach to care on a systematic basis.\(^{39}\)

Opportunities for screening include:

1. **Symptom burden and patient concerns:**
   - Review symptom burden in combination with the Edmonton Symptom Assessment System Revised (ESAS-r) scores.\(^{40,41}\) A score $\geq 7/10$ on the ESAS-r is considered severe.\(^{39,42,43}\) ESAS-r data are available for Alberta patients from the “Putting Patients First” (PPF) form (Appendix 1).
   - Utilize the CancerControl Alberta Patient Reported Outcome (PRO) dashboards proactively. The PRO Clinic List dashboard shows the symptom burden of all patients booked into a clinic. It highlights which patients had high symptom burden on their last visit, for review in the current visit. The Clinic List has a direct link to each patient’s individual PRO trended dashboard where the clinician can view each patient’s symptom trajectory (PPF data from ESAS-r and Canadian Problem Checklist (CPC) responses) over the last 6 visits in more detail (Appendix 2). (This is an Alberta specific method in cancer centres entering PPF data into ARIA).

2. **Monitoring for transition points in care or indicators of advanced disease trajectory:**
   - Progression on current therapy;
   - When disease is recognized as incurable;
   - When on second-line systemic therapy\(^{44,45}\)
   - There are no further disease-modifying treatments available;
   - When unable to receive first-line systemic therapy, or patient declines further disease-modifying treatment;
   - There is a decrease in performance status or functional decline e.g. the patient is confined to bed or chair more than 50% of waking hours (ECOG $\geq 3$, Appendix 3);
   - When the clinician estimates the patient’s prognosis as 12 months or less. One way this can be achieved is by clinicians asking themselves the Surprise Question: “Would I
be surprised if the patient were to die in the next 12 months?” An answer of no indicates a higher likelihood of death within the next year;31,46,47

- When a patient with incurable cancer is discharged from the Cancer Centre for ongoing care in the community.

1.3. When patient or family/caregiver requests palliative care services or information

1.4. When clinician judgement determines the patient or family/caregiver would benefit from an early approach to palliative care:

- Patient and/or family/caregiver are having (or anticipating) difficulties with illness understanding, including naming the diagnosis, illness history, symptoms, causality and prognosis, ACP, mortality distress.48

Patients who screen positive for one or more of these screening methods meet criteria for use of an early integrated palliative approach to care.

Patients who screen negative should be rescreened regularly.

Step 2: IDENTIFY PATIENT NEEDS

Once patients have been screened, clinicians should identify unmet patient needs. This can be guided by the four essential components of an early palliative approach to care (Figure 2) and corresponding assessment tools (Table 1). Patient needs should be re-assessed at regular intervals.

Once screened and meeting criteria, routinely and systematically identify the patient’s unmet needs and functional status. This is a critical step to determine the most appropriate supportive care interventions and service type needed. Evidence points to the need to use an assessment tool systematically, in order to not miss suffering.22,49 Assessment tools allow identification of the specific issues of concern to the patient and family/caregiver. RCTs14,22,49,50 demonstrate that intentional monitoring and addressing of symptoms and problems as identified by patients is helpful in maintaining quality of life and possibly associated with increased survival. There is limited high grade evidence to guide which exact assessment tools to use.51 This guideline recommends the use of CancerControl Alberta’s standardized tools to assess patient needs (Table 1).52

The frequency of reassessment of need varied between the RCT studies, but all agree that “routine” monitoring is needed. Thus, this guideline recommends assessment of patient needs at most clinical encounters. Note that clinical encounters can be initiated by patients e.g. patient portal entered symptom scores or phone calls to clinics regarding worsening symptoms.
Table 1. Provincial assessment tools for each component of an early palliative approach to care.

<table>
<thead>
<tr>
<th>Component</th>
<th>Assessment Tool</th>
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<tbody>
<tr>
<td>Illness comprehension and coping</td>
<td>PPF: CPC and ESAS-r (anxiety and depression scales)</td>
</tr>
<tr>
<td></td>
<td>SICP</td>
</tr>
<tr>
<td>Symptoms and functional status</td>
<td>PPF: CPC and ESAS-r</td>
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<tr>
<td></td>
<td>ECOG</td>
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<tr>
<td></td>
<td>PPS</td>
</tr>
<tr>
<td>Advance care planning and patient’s preferred method of decision making</td>
<td>ACP/GCD Tracking Record</td>
</tr>
<tr>
<td></td>
<td>PPF: CPC</td>
</tr>
<tr>
<td></td>
<td>SICP</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>PPF: CPC</td>
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</table>

PPF= Putting Patients First, CPC= Canadian Problem Checklist, ESAS-r= Edmonton Symptom Assessment System-Revised, SICP= Serious Illness Care Program, ECOG= Eastern Cooperative Oncology Group, PPS= Palliative Performance Scale, ACP/GCD Tracking Record= Advance Care Planning/Goals of Care Designation

2.1. Putting Patients First (PPF)

The PPF tool includes the CPC and the ESAS-r and has been adopted as a provincial standard in Alberta.52 The CPC was developed by the Screening for Distress Working Group of the Canadian Partnership Against Cancer.53 The CPC is a comprehensive standardized tool for assessment that has been validated for screening for distress and encapsulates domains relevant to many of the early palliative care intervention studies.14 Assessment domains include: emotional, social/family/spiritual, practical, physical, mobility, nutritional, informational and the option to include open ended “other” concerns. The ESAS-r is an internationally validated tool to assess patient symptoms.40,41

2.2. Serious Illness Care Program (SICP)

Beyond the CPC, there are more in-depth methods to assess illness understanding and coping. One of these is the SICP54 (Appendix 6), which also elicits patient values as a part of ACP. See section 3.3 for more detail.

2.3. Eastern Cooperative Oncology Group (ECOG) and Palliative Performance Scale (PPS)

There are many ways to assess functional status and needs.55 The ECOG (Appendix 3) functional scale can indicate declining function that might be associated with increasing patient needs. The ECOG score might suggest both the level (e.g. ambulatory, home care, supportive living) and type of supports (e.g. mobility aids, hospital bed, toileting assistance) needed by the patient.56 The PPS57 is the standard tool used in palliative care to measure performance status using five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level (Appendix 4). Similar to ECOG, the PPS can indicate the need for additional support including hospice care.
2.4. Advance Care Planning/Goals of Care Designation Tracking Record (ACP/GCD Tracking Record)

Existing literature has several methods for assessing the degree to which a patient has engaged in prior ACP or their preferences related to decision-making. The PPF tool includes the question “Would you like information on Goals of Care or advance care planning (green sleeve)?”, “Understanding my illness and/or treatment”, “Talking with my health care team” and “Making treatment decisions”, which allow patients to indicate their self-perceived need for more information related to ACP. In Alberta, the ACP/GCD Tracking Record also provides prompts for clinicians, with five suggested questions to assess prior ACP activities and is the document in use provincially to record patient needs related to ACP (Appendix 5). The SICP also guides clinicians to elicit a patient’s informational needs related to their prognosis, “How much information about what is likely to come with your illness would you like from me?”

2.5. Coordination of Care

Patients with cancer often receive poorly coordinated care in multiple settings from many providers, and lack of coordination is associated with poor symptom control, medical errors, and higher costs. Improvement in cancer care coordination leads to better patient experience and higher quality of end of life care. Many factors impact patient complexity, including personal factors (e.g. social determinants of health), interactions with providers (e.g. no family physician), system complexities (e.g. rural location), societal influences, and changes over time. Care coordination needs tend to increase with complexity. It is important to assess care coordination needs (e.g. patient and family/caregiver factors, number of providers, complexity of treatment plan), however, there is limited evidence to recommend one assessment tool over another. Practical concerns identified on the PPF may indicate higher needs around care coordination e.g. financial concerns, difficulty getting to and from appointments and language barrier.

**Step 3: PRIMARY PROVIDER MANAGEMENT OF UNMET NEEDS**

Primary palliative care management of unmet patient needs is strongly recommended using the four essential components of an early palliative approach to care as a guide:

1. Illness comprehension and coping
2. Management of symptoms by providers and patients’ self-management
3. Advance care planning and patient’s preferred method of decision making
4. Coordination of care

Primary providers should initiate management of unmet needs. Defining which care provider is primarily responsible and whether they refer to additional care providers for support and interventions can be dependent on both the referring clinicians’ own competencies in managing the issue and on the locally available consultation services.
3.1. Illness comprehension and coping

Evidence has shown that addressing a patient’s understanding of their illness, how they are coping and how those close to them are coping, is associated with improved patient outcomes.\textsuperscript{13,33,48,54,61,62} In addition to consulting secondary palliative care providers, Table 2 shows some other methods that can be used to support patients and family/caregivers.

Table 2. Potential methods to address illness comprehension and coping.

<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
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<tbody>
<tr>
<td>Specialist provided</td>
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<tr>
<td>Spiritual care</td>
<td>Existential and faith based supports</td>
</tr>
<tr>
<td>Art therapy, music therapy</td>
<td>Facilitated creative art therapies</td>
</tr>
<tr>
<td>Psychosocial counselling</td>
<td>Including: psychotherapy, Cognitive Behavioral Therapy, family therapy, individual and group therapy, CALM (Managing Cancer and Living Meaningfully)</td>
</tr>
<tr>
<td>Provided by family physicians, oncologists and nurses (with training)</td>
<td></td>
</tr>
<tr>
<td>Vital talk\textsuperscript{63}</td>
<td>Strategies and clinician resources for responding to difficult conversations</td>
</tr>
<tr>
<td>SICP\textsuperscript{54}</td>
<td>Program of resources, education workshop and systems change processes to increase meaningful conversations between people living with serious illness and their clinicians about their values and priorities</td>
</tr>
<tr>
<td>Dignity conserving therapy (including life review)\textsuperscript{64,65}</td>
<td>Question guides and approaches e.g. asking “what do I need to know about you as a person to give you the best care possible”</td>
</tr>
</tbody>
</table>

Patient preference, available time and clinician skills may be factors in the extent to which exploring patient illness understanding and coping occurs during clinical encounter, and clinician judgment is required about whether and when to refer for additional formal coping supports. This guideline encourages primary providers to explore and identify techniques to use in their practice.

3.2. Management of symptoms by providers and patients

3.2.1. Providers

Management of symptoms is a cornerstone of palliative care.\textsuperscript{23} Symptoms may be managed pharmacologically (e.g. steroids, opioids), non-pharmacologically (e.g. behavior modification, meditation), and/or by physical interventions (e.g. stents, palliative surgery, radiation).

Treatment of advanced colorectal cancer symptoms should be based on patient preferences, wishes, and goals for care. Symptoms that are complex may require palliative care consultation and collaboration with other care teams (see referrals section 3.4.2). Clinical practice guidelines are available for some symptoms at www.ahs.ca/GURU. Symptom management tip sheets are available on GURU’s website (www.ahs.ca/GURU) under “Palliative & Supportive Care” for the following symptoms:
- Anxiety
- Constipation
- Decreased appetite and cachexia
- Delirium
- Depression
- Diarrhea
- Dyspnea
- Fatigue
- Malignant bowel obstruction
- Nausea and vomiting
- Oral care
- Sleep disturbance
- Pain
- Tenesmus (a feeling, sometimes painful, of constantly needing to pass stool despite an empty rectum)

3.2.2. Patient self-management strategies

Patient self-management strategies, including upfront information shared by providers, can enhance symptom management, ability to cope and quality of life. Providers should encourage use of the following resources:

- Telephone triage or nurse navigator available for cancer patients within each Alberta cancer centre. Each cancer centre has its own “Emergency Contact” cards, which are available on the internal AHS website for each cancer site through patient education on Insite under “Treatment (Systemic Treatment, Radiation, and Surgery)” then under “Systemic Treatment” (https://insite.ahs.ca/cca/Page13453.aspx)
- Healthlink (811) for health questions, or Inform Alberta (211) for questions about services available within the community.
- Patients on Palliative Home Care can call for support 24/7. Local numbers can be obtained through the patient’s home care coordinator.
- Patient information on palliative care in Alberta: https://myhealth.alberta.ca/palliative-care/resources
- CancerControl Alberta Patient Education Resources:
  - Patient education guides for patient and family exist for: Systemic Treatment, Radiation Treatment and Immunotherapy. These “Living Your Best” guides cover a variety of topics (cancer treatments, symptoms, living your best while on treatment) and self-help strategies. Providers should review these books and their content with patients on a regular basis. PDF copies are available at https://insite.ahs.ca/cca/Page13453.aspx.
  - “Sources of Help” booklets have been developed provincially, which cover community, government and local business supports and services: https://www.ahs.ca/cancer/Page9613.aspx
    - Patients also value support groups, see “Sources of Help” or contact your local cancer centre for support group listings.
Some patients/families might use the AHS CancerControl Alberta My Care Conversations Cancer Consult Recording App with the aim of improving their recall of key conversations and enhancing their self-management and ease of decision-making. More information is at www.ahs.ca and search “My Care Conversations Cancer Consult Recording App” or visit: https://www.ahs.ca/cancer/Page16144.aspx.

3.3. ACP and patient’s preferred method of decision making

By preparing patients and those who may have to make in-the-moment decisions on their behalf, ACP is associated with a number of benefits. Choosing Wisely Canada recommends “don’t delay advance care planning conversations”. AHS procedure on ACP and GCD states, “all adults who have capacity should be given the opportunity to participate in ACP as a part of routine care, started early in a longitudinal relationship with a health care provider and revisited when the health or wishes of an adult changes”. Encourage patients to have conversations about ACP throughout cancer treatment. Clinicians, within their scope of practice, can be instrumental in:

- Encouraging reflection on and expression of personal values, beliefs and preferences related to personal goals, health care and their preferred method of decision making (e.g. shared decision making, supported decision making with family/caregiver, self-determined, physician-directed);
- Sharing prognostic information, tailored to the patient’s readiness and preferences around illness understanding;
- Supporting the patient in selecting an appropriate ADM;
- Encouraging the patient to communicate with their ADM, family/caregivers, other health care team members about their values, beliefs and preferences and who they have selected as ADM;
- Encouraging the patient to create a Personal Directive;
- Documenting ACP conversations on the ACP/GCD Tracking Record.

Resources:
- Patient and health care provider resources are available at www.conversationsmatter.ca.

The SICP was developed in cancer outpatient clinical context to provide a systematic approach to increasing meaningful conversations between seriously ill people and their clinicians about their values and priorities. It has been adapted to use in family physician clinics and other settings and is in an early phase of adoption within AHS. This is a helpful bridging process between ACP and GCD determination, as shown in Figure 3.

3.3.1. Goals of Care Designations

In Alberta, “Goals of Care Designations (GCD) are medical orders that describe the general and sometimes specific focus of a patient’s desired care approach, harmonized with what is medically appropriate to provide. They also create awareness of a person’s care choices in relation to the care sector they are living in or being cared for. They ideally arise from fully informed conversations between patients (or their alternate decision-maker) and health care providers”. The use of GCD is described in an AHS level 1 provincial policy and procedure. GCD should be determined when clinically indicated and should be reviewed at the request of the patient or ADM, after transfers, or if there is a significant change in the patient’s condition or circumstances.
GCD are a useful component of an early palliative approach to care because they are a mechanism that “helps make our system more patient-centred, improves continuity of care, supports care quality and safety for patients, reduces unwanted transfers and procedures, reduces decisional burden and moral distress for families and caregivers, and helps prevent inappropriate consumption of resources.”

Per AHS, “once a Goals of Care Designation conversation has been held, and if clinically indicated, a Goals of Care Designation order shall be created and documented in the Advance Care Planning/Goals of Care Designation Tracking Record.” By documenting in a common place, follow up can be shared between the care team. The Green Sleeve is a plastic pocket used in Alberta as the specific resource to contain and transfer ACP documentation (e.g. GCD order, Advance Care Planning/Goals of Care Designation Tracking Record, Personal Directive copies, Guardianship Orders).

Figure 3. Conceptual model of where SICP fits within AHS’s model of ACP and GCD determination.

3.4. Coordination of care

Coordination of care is usually the responsibility of all health care providers. The important coordination activities are: a) Establish accountability or negotiate responsibility, b) Communicate, c) Facilitate transitions, d) Create a proactive plan of care, e) Support self-management goals, f) Link to community resources, g) Align resources with patient and population needs and h) Monitor, follow up, and respond to change. In certain zones this coordination might be achieved through a patient navigator and/or home care case manager. These coordinators are particularly valued by rural zone patients.

3.4.1. Advanced cancer resources

To assist health care providers in coordination activities, compilations of advanced cancer resources are available. These tips are being made in collaboration with local palliative programs as “Local Tips for Providers”:

- Calgary (www.ahs.ca/GURU > Guidelines > Gastrointestinal > Metastatic Colorectal Cancer: Early Palliative Approach > “Local Tips For Providers”):
  
  - Include information on caregiver support and community based resources, and these provincially funded programs:
    - Alberta Aids to Daily Living (AADL)
    - Financial benefits
- Palliative Coverage Program (also known as “Palliative Blue Cross” or “Palliative Drug Coverage”)
- Palliative Oxygen

- Edmonton ([www.palliative.org](http://www.palliative.org)): 
  Edmonton currently has tips on accessing palliative care resources and management of symptoms.

- General information about palliative care search “palliative care” on AHS internal website (Insite) or visit [https://www.ahs.ca/info/Page14559.aspx](https://www.ahs.ca/info/Page14559.aspx)

### 3.4.2. Referral Based Services for Advanced Cancer Care

Lack of provider role clarity and variation in service availability, along with variation in patient need (i.e. functional and ambulatory status), can make it challenging to identify when and which specialist palliative care or other supportive care services are needed. Relevant supportive services that may assist in fulfilling an early palliative approach to care include: integrated home care, EMS Assess Treat and Refer Program (EMS-ATR), community paramedic program, psychosocial oncology, and rehabilitation oncology. See “Referral Based Services for Advanced Cancer Care” document for provider types available, their description and referral criteria. Note that the Alberta Referral Directory (ARD) is the centralized location for referral information. More resources for improving referrals and access to services can be found at “Access Improvement” on Insite ([https://www.ahs.ca/info/Page13719.aspx](https://www.ahs.ca/info/Page13719.aspx)).

**Specialist Palliative Care Services** provide secondary or tertiary advice or care when needs of the patient are complex and beyond the scope of the primary provider care team. The palliative consultant can also support the primary care team in providing a primary palliative approach to care. Quality indicators suggest that palliative-focused home care nursing support is an important element in improving quality of care and reducing inappropriate use of resources. When providers are making referrals to palliative care services, clarification should be provided to the patient explaining that palliative care is an added layer of support that can be used alongside cancer treatments. Patient friendly palliative care descriptions are available in CancerControl Alberta patient education guides, see section 3.2.2.

Some examples of when referral to specialist palliative care would be appropriate are:
- severe symptoms (≥ 7 ESAS-r). Note clinician judgement is required as patients with severe psychosocial-related symptoms (e.g. depression and anxiety) might instead need a referral to psychosocial oncology providers;
- palliative care unit or hospice referral;
- assisting with conflict resolution or health care decision making; or
- clarification of goals of treatment or management plan.

### 3.4.3. Communication and Documentation

Standardized communication increases consistency, minimizes duplication and improves teamwork while promoting patient safety. All providers involved in the patient’s care should send updates to other providers when there are changes in the patient’s condition, needs, or status. Important elements include patient’s cancer illness understanding, prognosis, and details of ACP and GCD (Green Sleeve). *Effective communication* reduces the need for patients and families to repeat information. Patients and families
need information to prepare for and improve care transitions; this may include written information or instructions, action plans, goals, signs or symptoms of declining health status, and contact information for the team. Family physicians also want to be kept informed and involved.

The following communication tools should be used to enable standardized communication:

i) Transition letters: At transition points in care, communication between the Cancer Centre and family physician should be emphasized by use of transition letters. Transition letters for advanced colorectal cancer exist for:
   - Shared Care: This letter outlines collaborative care where primary palliative care and symptom management can be shared between providers. It indicates cancer modifying care to be managed by medical oncology and non-cancer related care to be managed by family physician. This letter is initiated when second-line therapy is ordered or patient is determined to have advanced disease. The patient version of “Shared Care” letter should be given to patient during clinic visit.
   - No Further Systemic Therapy: This letter is for transition points in care when either: patient decides to stop disease-modifying treatment, patient is too unwell for any further cancer modifying treatment, or there are no further cancer modifying treatments available. It outlines shifting of care to the community and to ensure community supports are in place. The letter is initiated and sent to the family physician.

ii) Green Sleeve: The Green Sleeve is a plastic pocket used in Alberta as the specific resource to contain and transfer ACP documentation (e.g. GCD order, ACP/GCD Tracking Record, Personal Directive copies, Guardianship Orders).

Step 4: EXPLORING END OF LIFE TOPICS

Clinicians are recommended to support patients who are exploring end of life topics. The following topics may be addressed depending on individual patient needs:

1. End of Life Planning
2. Estate and Funeral Planning
3. Hospice Access
4. Medical Assistance in Dying (MAID)
5. Grief and Bereavement

At any point after a cancer diagnosis and often as cancer progresses, patients and their families/caregivers may have questions, worries or preferences about dying, death or preparation for after death. Clinicians are a valued source of information or guidance about end of life topics and can help ensure that key activities, like preparing a will or guardianship issues for dependents, have been addressed. Topics that people may want to inquire about include:

- How to recognize when death is near and what dying may look like, including modes of death e.g. “natural death”, palliative sedation for intractable symptom issues in final hours or days, death during resuscitation or medical management in hospital, or Medical Assistance in Dying;
- How to proactively anticipate and manage changing needs (e.g. if a patient is likely to lose the ability to take oral medication or become bed bound);
• Possible care locations before death (home, care facility, hospice, hospital).

Managing existential distress, death anxiety and changes in personal role or close relationships may involve the supports outlined in section 3.1; other topics in end of life care are listed below.

4.1. End of life planning

• Review ACP discussions and patient preferences for care at end of life.
• Determine the most appropriate GCD that reflects the person’s values and clinical context.
• Revisit caregiver supports.
• Ensure patient is on Alberta Health [Palliative Coverage Program](https://www.health.alberta.ca/services-and-programs/palliative-care/Palliative-Care-Program) (also known as “Palliative Blue Cross” or “Palliative Drug Coverage”).
• Discuss possible and preferred location(s) of care towards end of life e.g. home, hospice, hospital, or other facility.
  o Develop a plan for expected death in the community if patient would like to remain at home:
    • [AHS expected death in the home guideline](https://extranet.ahsnet.ca/teams/policydocuments/1/clp-patient-death-home-setting-hcs-213-01.pdf)

4.2. Estate and Funeral Planning

Remind patient and their family/caregivers to begin this planning early on. For example, a will and financial enduring power of attorney are part of estate planning. Assist them to connect to the appropriate resources to fulfill this planning, such as social work or their lawyer.

4.3. Hospice Access

• Hospice care is a specialized service available in certain locations that provides 24/7 facility-based palliative care to those who are approaching end of life and whose needs cannot be met at home/other location.
• There are [highly specific criteria](https://www.health.alberta.ca/services-and-programs/palliative-care/Palliative-Care-Program) for referral to hospice and access is determined by secondary palliative care clinicians. See the “[Referral Based Services for Advanced Cancer Care](https://www.health.alberta.ca/services-and-programs/palliative-care/Palliative-Care-Program)” document and/or talk to your local palliative care clinician about whether hospice may be appropriate for a specific patient and family/caregiver.

4.4. Medical Assistance in Dying (MAID)

AHS has developed the Medical Assistance in Dying Policy to guide medical assistance in dying services. This policy is posted on the [AHS Medical Assistance in Dying](https://www.health.alberta.ca/services-and-programs/palliative-care/Palliative-Care-Program) website and available from the Care Coordination Service upon request. A [physician FAQ](https://www.health.alberta.ca/services-and-programs/palliative-care/Palliative-Care-Program) sheet is available.
4.5. Grief and Bereavement

Ask patients about their emotional supports and let patients and caregivers know that grief and bereavement resources are available both before and after death. Most services are accessed by self-referral and clinicians can help by providing the access information. See “Referral Based Services for Advanced Cancer Care” document for grief and bereavement resources.
GLOSSARY OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AADL</td>
<td>Alberta Aids to Daily Living</td>
</tr>
<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td>ADM</td>
<td>Alternate Decision Maker</td>
</tr>
<tr>
<td>AHS</td>
<td>Alberta Health Services</td>
</tr>
<tr>
<td>ARD</td>
<td>Alberta Referral Directory</td>
</tr>
<tr>
<td>ARIA</td>
<td>Electronic medical record used in some CancerControl Alberta sites</td>
</tr>
<tr>
<td>CALM</td>
<td>Managing Cancer and Living Meaningfully</td>
</tr>
<tr>
<td>CPC</td>
<td>Canadian Problem Checklist</td>
</tr>
<tr>
<td>ECOG</td>
<td>Eastern Cooperative Oncology Group</td>
</tr>
<tr>
<td>EMS-ATR</td>
<td>EMS- Assess, Treat and Refer Program</td>
</tr>
<tr>
<td>ESAS-r</td>
<td>Edmonton Symptom Assessment System Revised</td>
</tr>
<tr>
<td>GCD</td>
<td>Goals of Care Designation</td>
</tr>
<tr>
<td>GURU</td>
<td>Guideline Utilization Resource Unit</td>
</tr>
<tr>
<td>MAID</td>
<td>Medical Assistance in Dying</td>
</tr>
<tr>
<td>PD</td>
<td>Personal Directive</td>
</tr>
<tr>
<td>PEOLC</td>
<td>Palliative and End of Life Care</td>
</tr>
<tr>
<td>PPF</td>
<td>Putting Patients First</td>
</tr>
<tr>
<td>PPS</td>
<td>Palliative Performance Scale</td>
</tr>
<tr>
<td>PRO</td>
<td>Patient Reported Outcome</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
</tr>
<tr>
<td>SICP</td>
<td>Serious Illness Care Program</td>
</tr>
</tbody>
</table>

DISSEMINATION

- Present the guideline at local and provincial tumour team meetings and weekly rounds.
- Post the guideline on the Alberta Health Services website.
- Send an electronic notification of the new guideline to all members of CancerControl Alberta.

MAINTENANCE

A formal review of the guideline will be conducted at the Annual Provincial Meeting in 2022. If critical new evidence is brought forward before that time, the guideline working group members will revise and update the document accordingly.
REFERENCES


(70) Alberta Health Services. Provincial clinical knowledge topic: advance care planning and goals of care designations, all ages, all locations. 2018 Sep 13.


APPENDIX 1: PUTTING PATIENTS FIRST FORM

APPENDIX 2: PRO DASHBOARD

APPENDIX 3: EASTERN COOPERATIVE ONCOLOGY GROUP

APPENDIX 4: PALLIATIVE PERFORMANCE SCALE

APPENDIX 5: ADVANCE CARE PLANNING/GOALS OF CARE DESIGNATION TRACKING RECORD

APPENDIX 6: SERIOUS ILLNESS CARE PROGRAM (SICP) CONVERSATION GUIDE

EVIDENCE TABLE
APPENDIX 1: PUTTING PATIENTS FIRST PAGE 1 (ESAS-R)

Talking About What Matters To You
Putting Patients First

Your answers will help us understand how you have felt since your last visit, and how you feel today. Knowing this will help us care for you. If you cannot or do not wish to fill out this form for any reason please let us know.

Note: Please make sure to fill out both sides of the form

A member of your healthcare team will go over the form with you and talk to you about what concerns you the most today. If we are not able to talk about all of your concerns today, we will decide the next steps together.

<table>
<thead>
<tr>
<th>Date (yyyy-Mon-dd)</th>
<th>Completed by:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Patient □ Family □ Assisted by family/health professional</td>
</tr>
</tbody>
</table>

Please answer the yes/no questions:

1. Have you been to Emergency and/or been admitted to hospital since your last visit? □ Yes □ No
2. Have your medications changed since your last visit? (e.g. stopped, started, dose change) □ Yes □ No
3. Have you had a fall since your last visit? □ Yes □ No
4. Would you like information on Goals of Care or advance care planning (green sleeve)? □ Yes □ No
5. Are you receiving home care services? □ Yes □ No
6. Have you used tobacco in the past year? □ Yes □ No In the past 30 days? □ Yes □ No

Please circle the number that best describes how you feel NOW

0 means you do not have that symptom, 10 means it is at its worst

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0 1 2 3 4 5 6 7 8 9 10</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td></td>
<td>Worst possible pain</td>
</tr>
<tr>
<td>No tiredness (Lack of energy)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible tiredness</td>
</tr>
<tr>
<td>No drowsiness (Feeling sleepy)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible drowsiness</td>
</tr>
<tr>
<td>No nausea</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td>No lack of appetite</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible lack of appetite</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible shortness of breath</td>
</tr>
<tr>
<td>No depression (Feeling sad)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible depression</td>
</tr>
<tr>
<td>No anxiety (Feeling nervous)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible anxiety</td>
</tr>
<tr>
<td>Best well-being (How you feel)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible wellbeing</td>
</tr>
<tr>
<td>No Other problem</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible _____________________</td>
</tr>
</tbody>
</table>

Continue on back side ➔
### APPENDIX 1: PUTTING PATIENTS FIRST PAGE 2 (CPC)

**What concerns have you had since your last visit? Check any boxes that have concerned you.**

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Physical</th>
<th>Nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fears/Worries</td>
<td>Fever/Chills</td>
<td>Weight gain (amount)</td>
</tr>
<tr>
<td>Sadness</td>
<td>Bleeding/Brusing</td>
<td>Weight loss (amount)</td>
</tr>
<tr>
<td>Frustration/Anger</td>
<td>Cough</td>
<td>Special diet</td>
</tr>
<tr>
<td>Changes in appearance</td>
<td>Headaches</td>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>Intimacy/Sexuality</td>
<td>Concentration/Memory</td>
<td>Mouth sores</td>
</tr>
<tr>
<td></td>
<td>Vision or hearing changes</td>
<td>Taste changes</td>
</tr>
<tr>
<td></td>
<td>Numbness/Tingling</td>
<td>Heartburn/Indigestion</td>
</tr>
<tr>
<td></td>
<td>Sensitivity to cold</td>
<td>Vomiting</td>
</tr>
<tr>
<td></td>
<td>Changes to skin/hair</td>
<td>Diarrhea</td>
</tr>
<tr>
<td></td>
<td>Bladder problems</td>
<td>Constipation</td>
</tr>
<tr>
<td></td>
<td>Lymphedema/Swelling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range of motion</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Speech difficulties</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sleep</td>
<td></td>
</tr>
</tbody>
</table>

**Mobility**

- Dizziness
- Walking/Mobility
- Trouble with daily activities (e.g., bathing, dressing)

**Other Concerns:**

Thank you for filling out this form. The rest of the form will be completed by your healthcare professional.

---

**To be filled out by a healthcare professional only - Screening Intervention Documentation**

<table>
<thead>
<tr>
<th>Review of Form:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Patient declined to fill out form □ Language barrier □ Other</td>
</tr>
<tr>
<td>Form reviewed through conversation with patient</td>
</tr>
<tr>
<td>If form not reviewed why: □ Patient declined discussion □ Other:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is patient at falls risk?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Priority Concern Identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

Specify ONE priority concern (either ESAS or CPC):

- **ESAS:** □ Pain □ Drowsiness □ Appetite □ Depression □ Well-being □ Tiredness □ Nausea □ Shortness of breath □ Anxiety □ Other
- **CPC:** □ Emotional □ Practical □ Mobility □ Social/Family/Spiritual
  □ Nutrition □ Physical □ Informational □ Other

Specific area indicated under the CPC domain:

**Actions taken:**

- □ Provided information/Education □ Offered Tobacco Cessation Advice □ Prescription provided
- □ Provided emotional support □ Referral suggested but patient declined □ No further action required

**Referrals:**

- □ Social Work □ Palliative Care □ Fatigue □ Tobacco Clinic □ Dyspnea/Respiratory
- □ Psychology □ Nutrition □ Home Care □ OT/Physio/Speech □ CO Navigation
- □ Spiritual Care □ Pharmacy □ Pain Clinic □ Other

Further details on action taken:

- □ See progress notes/nursing documentation for further information

**Reviewed By:** (Name of Health Care Professional)  **Signature:** (of Health Care Professional)  **Date:** (yyyy-Mon-dd)
APPENDIX 2: PRO DASHBOARD (INDIVIDUAL DASHBOARD)

INDIVIDUAL SYMPTOM TRACKING REPORT (OR INDIVIDUAL TRENDED DASHBOARD)

This report can be generated for any patient in CancerControl Alberta (CCA) who has completed a Putting Patients First (PPF) form and the staff have entered it as part of the clinical documentation. It is intended to support both the patient and the provider team to visualize the patient’s symptom burden over time and to highlight areas of high symptom burden. It also links clinical response and referrals made to each clinical visit/PRO report.

It pulls all info from ARIA (our EMR) entered by clinicians regarding all previous visits. Patients get a “patient friendly” simplified version when they check in for their visit as a reference for when they fill in today’s “Symptom Tracking Report” (which we refer to as the Putting Patient’s first form).
APPENDIX 2: PRO DASHBOARD (CLINIC LIST)

<table>
<thead>
<tr>
<th>Clinic Date</th>
<th>Visit Time</th>
<th>Event</th>
<th>Visit Provider</th>
<th>ACR #</th>
<th>Patient</th>
<th>Comments</th>
<th>Date Entry</th>
<th>Symptom Complexity</th>
<th>Request for Goals of Care (PPF)</th>
<th>Goals of Care on File in ARIA</th>
<th>Weight Change(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sep 11, 2018</td>
<td>06:00 to 06:10</td>
<td>Other-CC</td>
<td></td>
<td>ac7</td>
<td>m F</td>
<td>Non-Attending - CC; check status re: PI approved for Densitometry?</td>
<td>2018-Sep-04</td>
<td>L</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a26</td>
<td>m N</td>
<td>Non-Attending - CC; check PSA and order CT and bone scan PSA/Testes done Sep 7; PSA = 0.5 (compared to last PSA done Aug 8 = 0.9); Testes &lt; 0.2</td>
<td>2018-Aug-23</td>
<td>M</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1011</td>
<td>m G</td>
<td>Non-Attending - CC; BW; Due to cycle, 1 month Gem tomorrow; BW done</td>
<td>2018-Sep-04</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1011</td>
<td>m G</td>
<td>Non-Attending - CC; BW; Due to cycle, 1 month Gem tomorrow; BW done</td>
<td>2018-Sep-04</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
</tbody>
</table>

CLINIC LIST REPORT

This report can be generated for any clinic in CancerControl Alberta (CCA) based on location, date and provider, and is intended to support clinic preparation or team huddle prior to the start of clinic.

It pulls all info from ARIA (our EMR) about the clinic including notes entered by clinicians regarding a patient’s next visit, as well as the symptom burden the patient reported on their last PRO symptom screen (Putting Patients First form), along with when that screen was filled out, and other relevant info re: goals of care, and % weight change in the last 3 months.

Clinicians can easily click on the patient name or ACR# to link to each individual’s Trended PRO Dashboard.
APPENDIX 3: EASTERN COOPERATIVE ONCOLOGY GROUP (ECOG)

ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
</tr>
</tbody>
</table>

### APPENDIX 4: PALLIATIVE PERFORMANCE SCALE (PPS)

#### Palliative Performance Scale (PPSv2) version 2

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with effort</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>50%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>40%</td>
<td>Reduced</td>
<td>Unable hobby/house work Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a best fit for the patient which is then assigned as the PPS% score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   **Example 1:** A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious would be scored at PPS 50%.

   **Example 2:** A patient who has become paraplegic and quadriplegic reducing total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including transferring. The patient may have normal intake and full conscious level.

   **Example 3:** However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not total care.

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward' precedence is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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*Copyright © 2001 Victoria Hospice Society*
Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall "best fit" using all five columns.

1. Ambulation
   - "mainly sit and rest" or "mainly in bed" and "totally bed bound" are clearly similar. The subtle differences are related to terms in the self-care column. For example, "totally bed bound" at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between "sit" and "bed" is proportionate to the amount of time the patient is able to sit up vs. need to lie down.

2. Reduced ambulation" is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work, occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

3. Activity & Extent of disease
   - "Some," "significant," and "extensive" disease refer to physical and investigative evidence which shows degrees of progression. For example, in breast cancer, a local recurrence would imply "some" disease, one or two metastases in the lung or bone would imply "significant" disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcaemia or other major complications would be "extensive" disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, "some" may mean the shift from HIV to AIDS, "significant" implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. "Extensive" refers to one or more serious complications with or without continuation of active antivirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

4. Self-Care
   - "Occasional assistance" means that most of the time patients are able to transfer out of bed, wash, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

   "Considerable assistance" means that regularly every day the patient needs help, usually by one person, in doing some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

   "Mainly assistance" is a further extension of "considerable." Using the above example, the patient now needs help getting up but also needs assistance in brushing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

   "Total care" means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

5. Intake
   - Changes in intake are quite obvious with "normal intake," referring to the person's usual eating habits while healthy. "Reduced" means any reduction from that and is highly variable according to the unique individual circumstances. "Minimal" refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

6. Conscious Level
   - "Full consciousness" implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. "Confusion" is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. "Drowsiness" implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. "Coma" in this context is the absence of response to verbal or physical stimuli, some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.
APPENDIX 5: ADVANCE CARE PLANNING/GOALS OF CARE DESIGNATION TRACKING RECORD

Advance Care Planning/Goals of Care Designation Tracking Record

- **Purpose:** to document the content of Advance Care Planning (ACP)/Goals of Care Designation (GCD) conversations and/or decisions.

  - **Benefits:**
    - Assists healthcare providers in being aware of previous conversations and to understand the reasons underlying the current GCD order.
    - Gives clues about where to pick up the conversation if decisions need to be reviewed or confirmed.
    - The ACP GCD Tracking Record is a continuous record that goes in the Green Sleeve. Documenting on both Tracking Record and progress note may be necessary to ensure transfer of critical information.
    - The original form is kept in the patient’s Green Sleeve. When the patient moves to a new care setting, including home, a copy remains with the sending facility.

<table>
<thead>
<tr>
<th>Date (yyyy-mm-dd)</th>
<th>Site/Attendees</th>
<th>Conversation Summary Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Required Documentation</td>
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<tr>
<td></td>
<td></td>
<td>Any member of the healthcare team can record conversations on this form.</td>
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<tr>
<td></td>
<td></td>
<td>Include who was involved in today’s discussions (e.g., patient, family, healthcare provider) (include name and relationship/discipline)</td>
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<td></td>
<td></td>
<td>Summarize conversation and/or key decisions from today’s discussion</td>
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<td>It helps to document responses to the following speaking prompts.</td>
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<td>- Have you completed a Personal Directive?</td>
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<td>- Have you selected an alternative decision maker? If so do they know your wishes?</td>
</tr>
<tr>
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<td></td>
<td>- What is your understanding now of where you are with your illness?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- If your health situation worsens what are your important goals?</td>
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<tr>
<td></td>
<td></td>
<td>- Do you know if you have a Green Sleeve?</td>
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<tr>
<td></td>
<td></td>
<td>- Do you know if you have a Goals of Care Designation (GCD) order?</td>
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</tbody>
</table>

Learn more: www.convosmatter.ca
### Advance Care Planning/Goals of Care Designation Tracking Record

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<thead>
<tr>
<th>Date (yyyy-Mon-dd)</th>
<th>Site/Attendees</th>
<th>Conversation Summary Notes</th>
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<td>Any member of the healthcare team can record conversations on this form.</td>
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<td></td>
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<tr>
<td></td>
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<td>- Do you know if you have a Goals of Care Designation (GCD) order?</td>
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</tbody>
</table>

Learn more - www.conversationsmatter.ca

103153/Rev2019-05

Page 1 of 1 (Side B)
APPENDIX 6: SERIOUS ILLNESS CARE PROGRAM (SICP) CONVERSATION GUIDE

Serious Illness Conversation Guide

<table>
<thead>
<tr>
<th>CONVERSATION FLOW</th>
<th>PATIENT-TESTED LANGUAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Set up the conversation</td>
<td>“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?”</td>
</tr>
<tr>
<td>• Introduce purpose</td>
<td></td>
</tr>
<tr>
<td>• Prepare for future decisions</td>
<td></td>
</tr>
<tr>
<td>• Ask permission</td>
<td></td>
</tr>
<tr>
<td>2. Assess understanding and preferences</td>
<td>“What is your understanding now of where you are with your illness?”</td>
</tr>
<tr>
<td>“How much information about what is likely to be ahead with your illness would you like from me?”</td>
<td></td>
</tr>
<tr>
<td>3. Share prognosis</td>
<td>“I want to share with you my understanding of where things are with your illness...”</td>
</tr>
<tr>
<td>• Share prognosis</td>
<td></td>
</tr>
<tr>
<td>• Frame as a “wish...worry”, “hope...worry” statement</td>
<td></td>
</tr>
<tr>
<td>• Allow silence, explore emotion</td>
<td></td>
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<tr>
<td></td>
<td>“Uncertain: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.” OR “Time: “I wish we were not in this situation, but I am worried that time may be as short as ________ (express as a range, e.g. days to weeks, weeks to months, months to a year).” OR “Function: “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”</td>
</tr>
<tr>
<td>4. Explore key topics</td>
<td>“What are your most important goals if your health situation worsens?”</td>
</tr>
<tr>
<td>• Goals</td>
<td></td>
</tr>
<tr>
<td>• Fears and worries</td>
<td></td>
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<tr>
<td>• Sources of strength</td>
<td></td>
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<tr>
<td>• Critical abilities</td>
<td></td>
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<tr>
<td>• Tradeoffs</td>
<td></td>
</tr>
<tr>
<td>• Family</td>
<td></td>
</tr>
<tr>
<td>5. Close the conversation</td>
<td>“I’ve heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ______. This will help us make sure that your treatment plans reflect what’s important to you.”</td>
</tr>
<tr>
<td>• Summarize</td>
<td></td>
</tr>
<tr>
<td>• Make a recommendation</td>
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<tr>
<td>• Check in with patient</td>
<td></td>
</tr>
<tr>
<td>• Affirm commitment</td>
<td></td>
</tr>
<tr>
<td>6. Document your conversation</td>
<td></td>
</tr>
<tr>
<td>7. Communicate with key clinicians</td>
<td></td>
</tr>
</tbody>
</table>
EVIDENCE TABLE
Early Palliative Care and Metastatic Colorectal Cancer Literature Search Report

August 15th 2018

P- Metastatic colorectal cancer patients (subsequently expanded to include lung and pancreatic cancers)
I- Early palliative care
C- Late or traditional palliative intervention
O- Survival

Pubmed Search Strategy:
“colorectal carcinoma” OR “colorectal neoplasms” OR “lung carcinoma” “small cell lung carcinoma” OR “lung neoplasms” OR “pancreatic carcinoma” OR “pancreatic neoplasms” MeSH
OR
“colorectal carcinoma” OR “colorectal carcinomas” OR “colorectal cancer” OR “colorectal neoplasm” OR “colorectal neoplasms” OR “colorectal tumour” OR “colorectal tumours” OR “colorectal tumor” OR “colorectal tumors” Ti/ab.
AND
“palliative care” OR “palliative medicine” OR “palliative therapy” OR “palliative treatment” OR “palliative treatments” OR “terminal care” OR “hospice care” MeSH
OR
“palliative care” OR “palliative medicine” OR “palliative therapy” OR “palliative treatment” OR “palliative treatments” OR “terminal care” OR “hospice care” OR “early palliative care” OR “early palliative medicine” OR “early palliative therapy” OR “early palliative treatment” OR “early palliative treatments” OR “early terminal care” OR “early hospice care” Ti/ab.

Limit: 5 years, humans, English language

Results: 74 articles identified, 18 articles that provided evidence for the impact of early vs. late or no palliative care were selected, plus 19 additional references identified through peer review
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Citation</th>
<th>Type of Study</th>
<th>Methods</th>
<th>Patients &amp; Interventions</th>
<th>Results/Recommendations</th>
</tr>
</thead>
</table>
| Ahluwalia, 2018 | J Pain Symptom Manage 2018; 56: 831-870 | Systematic review | Review to synthesize the best current evidence for PC interventions across eight domains that structure the National Consensus Project clinical practice guidelines | N/A | • 139 systematic reviews met inclusion criteria  
• Reviews addressed the structure and process of care; physical, psychological, social, spiritual, religious, existential, and cultural aspects; care of the patient nearing EOL; and ethical and legal aspects  
• There was low-quality evidence on the impact of early/integrated PC (i.e. PC provided early in the trajectory of an illness and/or integrated with standard treatment) on most patient outcomes including QoL, physical symptoms, re-hospitalization, patient satisfaction with care, and ACP, mainly due to individual study limitations and inconsistent findings  
• There was very low-quality evidence for early/integrated PC on patient psychological health and mortality and family psychological health, satisfaction with care, and ACP  
• A substantial body of evidence exists to support clinical practice guidelines for quality PC, but the quality of evidence is limited |
| Bagciyan, 2018 | Palliat Med 2018; 32: 59-68 | Qualitative analysis | Review of outpatient charts with advanced cancer (lung, GI, GU, breast, other) to determine what components of PC are important for early palliative intervention | N=70 early PC  
N=72 delayed PC | • Outpatient PC consultations for newly diagnosed patients with advanced cancer addressed patient needs in the following areas:  
  o marital status (81.7%)  
  o spirituality/emotional well being (80.3%)  
  o caregiver/family support (79.6%)  
  o symptoms-mood (81.7%)  
  o pain (73.9%)  
  o cognitive status (68.3%)  
  o general treatment recommendations-counseling (39.4%)  
  o maintaining current medications (34.5%)  
  o initiating new medication (23.9%)  
  o symptom specific treatment recommendations-pain (22.5%) |
<table>
<thead>
<tr>
<th>Author, Year</th>
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<th>Methods</th>
<th>Patients &amp; Interventions</th>
<th>Results/Recommendations</th>
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<tbody>
<tr>
<td>Boucher, 2018</td>
<td>J Palliat Med 2018; 21: 1074-77</td>
<td>Survey</td>
<td>Clinicians treating patients with advanced cancers at 4 centres completed a checklist of BSC at eligible patient encounters</td>
<td>N=15 clinicians N=9 advanced care practitioners</td>
<td>• 40% noted improved impact using BSC for &quot;overall impact on your delivery of supportive/PC&quot;  • 46% noted improved impact using BSC for &quot;overall impact on your documentation of supportive/PC&quot;  • 33% noted increased impact of BSC on &quot;frequency of comprehensive symptom assessment&quot;  • None noted decreased frequency or worsening impact on any measure with use of BSC  • 73% agreed/strongly agreed that checklists could be easily integrated, 73% saw value in integration, and 80% found it easy to use</td>
</tr>
<tr>
<td>Collins, 2018</td>
<td>J Pain Symptom Manage 2018; 56: 185-94</td>
<td>Population cohort study</td>
<td>Patients identified through hospital registration data; statistics collected to identify EOL quality indicators</td>
<td>N=14,759 NSCLC N=2,932 SCLC N=9,445 prostate N=19,564 breast cancer</td>
<td>• 80% of patients died in hospital  • 83% had suboptimal EOL care  • 59% received a palliative approach to care a median of 27 days before death</td>
</tr>
<tr>
<td>Hoerger, 2018</td>
<td>Ann Behav Med 2018 [Epub]</td>
<td>Systematic review and meta-analysis</td>
<td>Systematic review and meta-analysis of randomized controlled trials</td>
<td>N/A</td>
<td>• 9 studies included  • In the 3 high-quality studies with long-term survival data (n = 646), patients randomized to outpatient specialty PC had a 14% absolute increase in 1 year survival relative to controls (56% vs. 42%, p &lt; .001). The survival</td>
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<tr>
<td>Author, Year</td>
<td>Citation</td>
<td>Type of Study</td>
<td>Methods</td>
<td>Patients &amp; Interventions</td>
<td>Results/Recommendations</td>
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<tr>
<td>ahead of print]</td>
<td>comparing outpatient specialty PC with usual care in adults with advanced cancer</td>
<td>advantage was also observed at 6, 9, 15, and 18 months, and median survival was 4.56 months longer (14.55 vs. 9.99 months).</td>
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<tr>
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<td>In the 5 high-quality studies with QoL data (n = 1,398), outpatient specialty PC improved QoL relative to controls (g = .18, p &lt; .001), including for physical and psychological measures</td>
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</tr>
<tr>
<td>Hoerger, 2018</td>
<td>J Clin Oncol 2018; 36: 1096-1102</td>
<td>Secondary analysis of randomized controlled trial</td>
<td>Patients with lung or non-colorectal GI cancer were randomly assigned to receive early PC + standard care</td>
<td>N=171 early PC + standard care</td>
<td>• Analysis of 2921 PC visits mostly addressing coping (64.2%) and symptom management (74.5%) • Patients who had higher proportion of visits that addressed coping experience improved QoL (p=0.02) and depression symptoms (p=0.002) • Patients who had a higher proportion of visits addressing treatment decisions were less likely to initiate chemotherapy (p=0.02) or be hospitalized (p=0.005) in the 60 days before death • Patients who had higher proportion of visits addressing ACP were more likely to use hospice (p=0.03)</td>
</tr>
<tr>
<td>Hui, 2018</td>
<td>CA Cancer J Clin 2018; 68: 356-76</td>
<td>State-of-the-science review</td>
<td>Review directed at the practicing oncology clinician; discusses 1) the contemporary literature examining the impact of PC on care outcomes, 2) conceptual frameworks on interdisciplinary, timely, and targeted PC,</td>
<td>N/A</td>
<td>Impact of PC on care outcomes: • Most RCTs demonstrate that PC combined with oncologic care improves QoL and symptom control • Clinical trials involving interdisciplinary PC teams, vs. nurse-led PC, appear to be more likely to be associated with positive findings • 3 recent meta-analyses concluded that PC was associated with improved QoL; however, the effect size was small, maybe related to heterogeneity in trial design • A meta-analysis examining the timing of PC referral supported greater benefits on QoL with earlier referral • PC can improve health care value by reducing costly investigations, interventions, and hospitalizations at the end of life, especially those with questionable benefits</td>
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</table>

Conceptual frameworks to define key elements of PC delivery:
<table>
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<tr>
<th>Author, Year</th>
<th>Citation</th>
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<th>Patients &amp; Interventions</th>
<th>Results/Recommendations</th>
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</thead>
</table>
|              |          |               | and 3) strengths and weaknesses of innovative care models | • The interconnectedness of symptoms and supportive care needs necessitates a comprehensive interdisciplinary team to provide multidimensional care  
• Although interdisciplinary PC teams are ideal, single-disciplinary PC may have a role in the provision of primary PC, particularly in resource-limited settings  
• PC is most effective as a preventive measure when it is introduced early in the disease trajectory (e.g. for patient education, proper symptom management, longitudinal counseling and spiritual care, enhancing illness understanding, ACP)  
• Timely PC is associated with improved QoL and EOL care  
• Because of scarce health care resources, it is impossible for all patients to be seen by PC from the time of diagnosis; similar to cancer targeted therapy, a more personalized approach to refer patients with higher current or anticipated supportive care needs may result in better outcomes  
• Oncologists have an important role in providing primary PC, which includes basic symptom assessment and treatment, communication, decision making, and referral to specialist PC  
Innovative models of care delivery:  
• There is strong evidence to support stand-alone PC clinics (ideally staffed with an interdisciplinary team in larger centers) to improve patient outcomes; these clinics represent the current standard of care against which other outpatient models should be measured  
• Embedded clinics may be more suitable in smaller centers with limited PC resources  
• Further research is needed to assess the impact of nurse-led PC and how this care model interfaces with specialist PC teams |
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<tr>
<th>Author, Year</th>
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</tr>
</thead>
</table>
| Lee, 2018   | Am J Hosp Palliat Care 2018; 35: 166-72 | Retrospective review | Retrospective medical record review of patients with metastatic colorectal cancer who died between 2011 and 2014, comparing use of outpatient PC | N=50 patients used outpatient PC N=82 patients did not use outpatient PC | • RCTs have found that oncology teams delivering PC alone resulted in poorer QoL outcomes vs. concurrent care with a specialist PC team; however, it is important that all oncologists are trained in providing a basic level of PC  
• Automatic referral to PC may allow for more personalized care; it requires routine screening, standardized referral criteria, and established PC team  
• An international consensus study identified 9 needs-based criteria and 2 time-based criteria for referral to outpatient PC for patients with advanced cancer  
• 32% of patients who received outpatient PC were admitted to hospice vs. 17% of patients who did not receive PC (p=0.047)  
• Mean inpatient days within 30 days of death was shorter for PC group (4.02 vs 7.77 days, p=0.032)  
• No difference in proportions of patients who received chemotherapy and visited ED within 30 days from death |
| Vanbutsele, 2018 | Lancet Oncol 2018; 19: 394-404 | Randomized controlled trial | Patients with advanced cancer (GI, GU, lung, breast, head and neck, melanoma) were assigned to either early and systematic integration of PC or standard oncological care | N=94 standard care alone N=92 PC + standard care | • Overall QoL score at 12 weeks by EORCT QLQ C30 scale=59.39 standard group vs 61.98 PC group (p=0.03)  
• Overall QoL score by MQOL single item scale=5.94 standard group vs. 7.05 PC group (p=0.0006) |
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<th>Type of Study</th>
<th>Methods</th>
<th>Patients &amp; Interventions</th>
<th>Results/Recommendations</th>
</tr>
</thead>
</table>
| Bakitas, 2017 | J Oncol Practice 2017; 13: 557-67 | Review        | Review of multiple RCTs for common practical elements, methods and techniques that oncologists can use to deliver parts of concurrent interdisciplinary PC | N/A                      | • The authors recommend standardized assessment of patient-reported outcomes, including the evaluation of symptoms with such tools as the Edmonton or Memorial Symptom Assessment Scales, spirituality with the FICA Spiritual History Tool or similar questions, and psychosocial distress with the Distress Thermometer  
• All patients should be assessed for how they prefer to receive information, their current understanding of their situation, and if they have considered some ACP  
• Approximately 1 hour of additional time with the patient is required each month  
• If the oncologist does not have established ties with spiritual care and social work, he or she should establish these relationships for counseling as required  
• Caregivers should be asked about coping and support needs  
• Oncologists can adapt PC techniques to achieve results that are similar to those in the RCTs of PC plus usual care compared with usual care alone |
| Ferrell, 2017 | J Clin Oncol 2017; 35: 96-112     | Guideline update | Expert panel review of RCTs, systematic reviews, and meta-analyses | N/A                      | • N=9 RCTs, 1 quasi-experimental trial, 5 secondary analyses included in the guideline update  
• Inpatients and outpatients with advanced cancer should receive dedicated PC services early in their disease course concurrent with active treatment; family and friend caregivers of patients with early or advanced cancer should also be referred to PC services |
| Gorin, 2017   | Ann Behav Med 2017; 51: 532-46    | Systematic review and meta-analysis | Literature search to address cancer care coordination | N/A                      | • N=52 studies included in the review, and N=11/52 studies included in the meta-analysis  
• Cancer care coordination approaches led to improvements in 81% of outcomes, including screening, measures of patient experience with care, and quality of EOL care |
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<thead>
<tr>
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</tr>
</thead>
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| Groenvold, 2017 | Palliat Med 2017; 31: 814–24 | Randomized controlled trial | Multicentre trial comparing early PC + standard care to standard care alone for patients with advanced cancer (lung, GI, breast, other) | N=145 PC + standard care N=152 standard care alone | • Early PC showed no effect on change in primary need  
• Analysis of secondary outcomes including survival also showed no difference with the exception of nausea/vomiting |
| Haun, 2017 | Cochrane Database Syst Rev 2017; 6: CD011129 | Systematic review | Review of RCTs and cluster-RCTs on professional PC services that provided or coordinated comprehensive care for adults at early advanced stages of cancer | N/A | • Included 7 RCTs and cluster-RCTs that together recruited 1614 participants  
• Compared with usual/standard cancer care alone, early PC significantly improved health-related QoL at a small effect size (SMD 0.27, 95% CI 0.15 to 0.38; participants analyzed at post treatment = 1028; evidence of low certainty)  
• No differences in survival or depressive symptoms  
• 7 studies that analyzed 1054 participants post treatment suggest a small effect for significantly lower symptom intensity in early PC compared with the control condition (SMD -0.23, 95% CI -0.35 to -0.10; evidence of low certainty)  
• Current results should be interpreted with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods |
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| Temel, 2017  | J Clin Oncol 2017; 35: 834-41    | Randomized controlled trial | Patients with newly diagnosed incurable lung or non-colorectal GI cancer randomized to receive early integrated PC + oncology care or usual care | N=175 early integrated PC and oncology care N=175 usual care | - Intervention patients (vs. usual care) reported greater improvement in QoL from baseline to week 24 (1.59 vs. 23.40; P=.010) but not week 12 (0.39 vs. 21.13; p=.339)  
- Intervention patients also reported lower depression at week 24, controlling for baseline scores (adjusted mean difference, -1.17; 95% CI, -2.33 to -0.01; p=.048)  
- Intervention effects varied by cancer type, such that intervention patients with lung cancer reported improvements in QoL and depression at 12 and 24 weeks, whereas usual care patients with lung cancer reported deterioration; patients with GI cancers in both study groups reported improvements in QoL and mood by week 12  
- Intervention patients versus usual care patients were more likely to discuss their wishes with their oncologist if they were dying (30.2% vs. 14.5%; p=.004). |
| Whitney, 2017| J Clin Oncol 2017; 35: 3610-17   | Retrospective review   | Review of cancer registry data to calculate hospitalization rates in the year after diagnosis among patients with advanced breast, NSCLC, colorectal, or pancreatic cancer | N=25,032                | - 71% of patients with advanced colorectal cancer were hospitalized, 16% had 3 or more hospitalizations, and 64% of hospitalizations originated in the ED  
- Re-hospitalization rates were significantly lower after discharge from a hospital with an outpatient PC program (IRR=0.90, 95% CI 0.83-0.97) and were higher after discharge from a for-profit hospital (IRR=1.33, 95% CI 1.14- 1.56) |
| Basch, 2016  | J Clin Oncol 2016; 34: 557-65    | Randomized controlled trial | Patients with metastatic breast, GU, gynecologic, or lung cancers were | N=441 PRO group N=325 usual care group | - HRQoL improved in PRO group vs. usual care group (34% vs. 18%) and worsened among fewer (38% vs. 53%)  
- Overall mean HRQoL declined by less in PRO group vs. usual care group (1.4 vs. 7.1 point drop, p<0.001) |
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| Kavalieratos, 2016 | JAMA 2016; 316: 2104-14 | Systematic review and meta-analysis | Review of trials of PC interventions in adults with a life limiting disease | N/A | • Review included 12,731 patients and 2,479 caregivers  
• PC interventions associated with improvements in patient QoL and symptom burden  
• Findings for caregiver outcomes inconsistent |
| Maltoni, 2016 | Eur J Cancer 2016; 65: 61-8 | Randomized controlled trial | Comparison of standard care + on-demand early PC vs. standard care + systematic early PC for patients with metastatic or locally advanced inoperable pancreatic cancer | N=100 standard care + on-demand early PC  
N=107 standard care + systematic early PC | • QoL scores at 12 weeks=84.4 systematic PC vs. 78.1 on-demand PC (p=0.022)  
• Hepatic cancer subscale scores=52.0 systematic PC vs. 48.2 on-demand PC (p=0.008)  
• No OS difference between treatment arms |
| Seow, 2016 | J Pain Symptom Manage 2016; 51: 204-12 | Retrospective cohort study | Examined rates of home care nursing in the last 6 months of life vs. standard nursing care in the last month of life, and rates of ED | N=54,576 | • 85% of cases had an ED visit and 68% received EOL home care nursing  
• Patients receiving EOL nursing at any week had a significantly reduced ED rate in subsequent week of 31% (RR=0.69, 95% CI 0.68-0.71) compared with standard nursing  
• Receiving EOL nursing and standard nursing in the last month of life at rate of more than 5 hrs/week was associated with a decreased ED rate of 41% (RR=0.59, |
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| Bakitas, 2015 | J Clin Oncol 2015; 33: 1438-45 | Randomized controlled trial | Comparison of early vs. delayed PC intervention among patients with advanced cancer (lung, GI, GU, breast, other) | N=103 early PC N=104 delayed PC | • PROs (QoL, symptom impact, mood) not statistically significant after enrolment or before death  
• Resource use in early and delayed PC groups:  
  o Hospital days (RR=0.73; 95% CI 0.41-1.27, p=0.26)  
  o ICU days (RR=0.68; 95% CI 0.23-2.02, p=0.49)  
  o ED visits (RR=0.73; 95% CI 0.45-1.19, p=0.21)  
  o Chemotherapy in last 14 days (RR=1.57; 95% CI 0.37-6.7, p=0.26)  
• 1 year survival=63% in early PC vs. 48% delayed PC (p=0.038)  
• Rate of home deaths=54% early PC vs. 47% delayed PC (p=0.6) |
| Cheung, 2015 | Cancer 2015; 15; 121: 3307-15 | Retrospective study | Review of population data to identify cancer decedents (lung, GI, breast, prostate, other) who received or did not receive aggressive EOL care and to compare costs of cancer care | N=83,158 no aggressive care N=24,095 any aggressive care | • Mean per patient cost over final month=$18,131 aggressive care group vs. $12,678 non-aggressive care group (p<0.0001)  
• For patients receiving EOL care in the highest cost quintile, early and repeated PC consultation was associated with reduced costs  
• Chemotherapy in the last 2 weeks of life predictive of increased costs (median increase $536; p<0.0001) whereas access to PC predictive of lower costs (median decrease $418; p<0.001) |
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| Dionne-Odom, 2015 | J Clin Oncol 2015; 33: 1446-52 | Randomized controlled trial | Caregivers of patients with advanced cancer (lung, GI, GU, breast, other) were randomly assigned right after randomization (early group) or 3 months after randomization (delayed group) to receive 3 weekly phone coaching sessions, monthly follow-up, and a bereavement call | N=61 caregivers in early group N=61 caregivers in delayed group | • There were no differences in QoL or burden between groups  
• In decedents’ caregivers, a terminal decline analysis indicated between-group differences favoring the early group for depression and stress burden but not for QoL, objective burden, or demand burden  
• Early-group caregivers had lower depression scores at 3 months and lower depression and stress burden in the terminal decline analysis  
• Palliative care for caregivers should be initiated as early as possible to maximize benefits |
| Ferrell 2015 | J Pain Symptom Manage 2015; 50: 758-67 | Prospective quasi-experimental study | Patients with NSCLC were sequentially enrolled into a control group or a concurrent interdisciplinary PC intervention group | N=219 patients in control group N=272 patients in intervention group | • 491 patients were included in the primary analysis  
• Patients who received the intervention had significantly better scores for QoL (109.1 vs. 101.4; p<0.001), symptoms (25.8 vs. 23.9; p<0.001), spiritual well-being (38.1 vs. 36.2; p=0.001), and lower psychological distress (2.2 vs. 3.3; p<0.001) at 12 weeks, after controlling for baseline scores, compared to patients in the usual care group  
• Patients in the intervention group also had significantly higher numbers of completed advance care directives (44% vs. 9%; p<0.001), and overall supportive care referrals (61% vs. 28%; p<0.001) |
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<td>Hudson, 2015</td>
<td>Psycho-Oncol 2015; 24: 19-24</td>
<td>Randomized controlled trial</td>
<td>Caregivers of patients with advanced cancer receiving home-based PC were randomized to standard care, or a psycho-educational intervention delivered through 1 home visit and 3 phone calls, or 2 home visits and 2 phone calls</td>
<td>N=57 in 1-visit group N=93 in 2-visit group N=148 in control group</td>
<td>• There was significantly less worsening in distress between baseline and 8 weeks post-death in the 1-visit intervention group than in the control group; however, no significant difference was found between the 2-visit intervention and the control group</td>
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<td>Sun 2015</td>
<td>Cancer 2015; 121: 3737–45</td>
<td>Two-group, prospective sequential, quasi-experimental design</td>
<td>Family caregivers of patients diagnosed with NSCLC were accrued to a usual care group or intervention group; Caregivers in the intervention group were presented at interdisciplinary care meetings, and received 4</td>
<td>N=157 family caregivers in the usual care group N=197 family caregivers in the intervention group</td>
<td>• Caregivers who received the interdisciplinary PC intervention had significantly better scores for social well-being (5.84 vs. 6.86; p&lt;.001) and lower psychological distress (4.61 vs. 4.20; p=.010) at 12 weeks compared to caregivers in the usual care group • Caregivers in the intervention group had significantly less caregiver burden compared to caregivers in the usual care group (p=.008)</td>
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• 95% of studies were observational, and 81% originated from the United States  
• 49% of studies were performed in hospitals and 32% in nursing homes  
• Do-not-resuscitate orders (39%) and written advance directives (34%) were most often studied  
• ACP was often found to decrease life-sustaining treatment, increase use of hospice and PC and prevent hospitalization |
| Seow, 2014 | BMJ 2014; 348: g3496 | Pooled analysis of retrospective cohort study | Comparison of specialist PC vs. standard care | N=3109 patients (~80% with cancer) received specialist PC  
N=3109 patients received standard care | • Hospitalization rate=31.2% specialized PC group vs. 39.3% standard care group (p<0.001)  
• Rate of ED visits in last 2 weeks of life=28.9% specialized PC group vs. 34.5% standard care group (p<0.001)  
• Fewer deaths in hospital for patients in specialist PC group vs. standard care group (N=503 vs. 887; p<0.001); pooled RR of dying in hospital=0.46 (95% CI 0.4-0.52) |
| Uitdehaag, 2014 | J Pain Symptom Manage 2014; 47: 518-30 | Randomized controlled trial | Patients with incurable primary or recurrent esophageal, pancreatic, or hepatobiliary cancer were randomized to nurse-led follow-up at home or | N=36 evaluable patients (i.e. completed at least one follow-up survey) in the nurse-led group  
N=30 evaluation patients in the | • Patients in the nurse-led follow-up group were significantly more satisfied with the visits, whereas QoL and health care consumption within the first 4 months were comparable between the two groups  
• Nurse-led follow-up was less expensive than conventional medical follow-up; however, the total costs for the first 4 months of follow-up in this study were higher in the nurse-led follow-up group because of a higher frequency of visits  
• The results suggest that conventional medical follow-up is interchangeable with nurse-led follow-up |
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| Zimmermann, 2014    | Lancet 2014; 383: 1721–30          | Cluster randomized controlled trial | Comparison of early PC consultation + follow-up vs. standard care for patients with advanced lung, GI, GU, breast or gynecological cancers | N=228 early PC N=233 standard care | • At 3 months, there was a non-significant difference in change score for FACIT-Sp between early PC vs. standard care groups (3.56 points; 95% CI -0.27-7.40, p=0.07), a significant difference in QUAL-E (2.25 points; 95% CI 0.01-4.49, p=0.05) and FAMCARE-P16 (3.79 points; 95% CI 1.74-5.85, p=0.0003)  
• At 3 months, no difference in change score for ESAS (-1.70 points; 95% CI -5.26-1.87, p=0.33) or CARES-MIS (-0.66 points; 95% CI -2.25 -0·94, p=0·40) between early PC vs. standard care groups  
• At 4 months, there were significant differences in change scores for all outcomes except CARES-MIS                                                                 |
| Greer, 2013         | CA Cancer J Clin 2013; 63: 349-63   | Review                             | Review of literature on early integration of PC                          | N/A                       | • Many treatments for cancer but not enough focus on side effects of progressing disease  
• Introducing PC at time of diagnosis of advanced cancer leads to meaningful improvement in experience of patients and caregivers  
• Recommendations: discuss mechanisms by which early PC benefits patients and families, guide the dissemination and application of this model in outpatient settings, and inform health care policy regarding the delivery of high quality cost effective and comprehensive cancer care |
<p>| McNamara, 2013      | J Palliat Med 2013; 16: 774-79      | Retrospective cross sectional study | Review of death registry data for cancer patients                        | N=746                     | • In final 90 days before death, 31.3% who had early access to PC and 52% of those who did not have access visited an ED (OR=2.86; 95% CI 1.91- 4.30) |
| Dyar, 2012          | J Palliat Med 2012; 15: 890-95      | Randomized controlled trial        | Patients with metastatic cancer (breast, N=12 in intervention group)     |                            | • The study closed early due to published data demonstrating the benefits of early PC interventions in |</p>
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| Smith, 2012  | J Clin Oncol 2012; 30: 880-87 | ASCO provisional clinical opinion statement | Addresses the integration of PC services into standard oncology practice at a time a person is diagnosed with metastatic or advanced cancer | N/A | • Statement based on results of 7 RCTs  
• Patients should be offered concurrent PC and standard oncologic care at initial diagnosis  
• While survival benefit from early PC has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that PC combined with standard care or as the main focus leads to better patient and caregiver outcomes, including improvement in symptoms, QoL, patient satisfaction, and reduced caregiver burden  
• Earlier PC leads to more appropriate referral to and use of hospice and reduces the use of futile intensive care  
• No trials have demonstrated harm to patients or caregivers or excessive costs from early PC |
| Gonsalves, 2011 | J Palliat Med 2011; | Retrospective chart review | Assessment of last 100 patients in 2002 and | N=100 patients no | • In the last 30 days of life, compared to 2002, patients in 2008 had a higher incidence of: chemotherapy |

lung, prostate, other) were randomized to standard care or an advanced registered nurse practitioner-directed intervention that included discussions of the benefits of hospice, discussions on living wills and advanced directives. N=14 in control group

the management of metastatic cancer patients and patients wanting the intervention  
• Statistically significant improvements from baseline were noted in the emotional and mental QoL assessments (as determined by the FACT-G and LASA questionnaires) in the intervention group that were not seen in the control group  
• Patients found it useful to have the living will and Five Wishes documents offered as part of the intervention
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N=74 standard care | • Patients assigned to early PC had a better QoL vs. patients assigned to standard care (mean FACT-L score=98.0 vs. 91.5, p=0.03)  
• Fewer patients with depressive symptoms in PC group vs. standard care group (16% vs. 38%, p=0.01)  
• Although fewer patients received aggressive EOL care in the early PC group vs. the standard care group (33% vs. 54%, p=0.05), the median survival was longer (11.6 months early PC group vs. 8.9 months standard care group, p=0.02) |
| Bakitas, 2009 | JAMA 2009; 302: 741-49 | Randomized controlled trial | Multicomponent, psycho-educational intervention conducted by advanced practice nurses for patients with advanced cancer (GI, GU, lung, breast) | N=161 weekly sessions x 4 + monthly follow-up  
N=161 usual care | • Compared with patients receiving usual care, patients receiving nurse-led, PC intervention had higher scores for QoL (p=0.02) and mood (p=0.02), but did not have improvements in symptom intensity scores  
• Intensity of services (days in the hospital/ICU or ED visits) did not differ between the two groups |

**Abbreviations:** ACP, advance care planning; BSC, best supportive care; CI, confidence interval; ED, Emergency Department; EMR, electronic medical record; EOL, end of life; ESAS, Edmonton Symptom Assessment Scale; GI, gastrointestinal; GU, genitourinary; HRQoL, health related quality of life; ICU, intensive care unit; IRR, incident rate ratio; NSCLC, non-small cell lung cancer; OR, odds ratio; OS, overall survival; PC, palliative care; PRO, patient reported outcome; QoL, quality of life; RCT, randomized controlled trial; RR, relative risk; SCLC, small-cell lung cancer.