

The Washington Rural Palliative Care Initiative Handbook

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Please see acknowledgments on page 187 for additional funders and in-kind contributions.

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Welcome

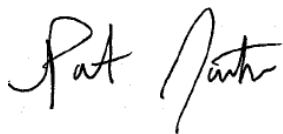
When rural community members are living with serious illness, leaving the community to travel for care in a distant city can be stressful, if not tragic, leaving familiar places and supportive people at a time of vulnerability and need. That distant care may miss the point and try to “fix” an illness that will inevitably progress rather than staying focused on quality of life as defined by the patient. Clinical teams that only know curative care and hospice, can struggle with feelings of helplessness as they witness suffering, and do not have the skills or confidence to offer palliative care.

Covid-19 has stretched every health system to the brink, with workforce and capacity challenges while caring for communities locked in divisive political struggles that lead clinical teams to face difficult patient behaviors. Recovery will be a gradual process. We recognize that workforce challenges may continue to cause you to take this work at a slow pace. It is your work, with your goals, and your pace.

In this exciting initiative, rural health teams and other members of the community work to improve the approach to serious illness, improve coordination across local care settings, and educate the community so that patients and those who love them understand the value palliative care can bring.

There is truly no place like home, and when seriously ill rural community members find out it is possible to stay home with the support of palliative care, there is often a sense of tremendous relief.

There are wonderful gifts as well as challenges along the path, and we are so pleased that your community has decided to join us.

A handwritten signature in black ink that reads "Pat Justis". The signature is written in a cursive, flowing style.

Pat Justis
Leader, WA Rural Palliative Care Initiative

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WA State Department of Health
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Initiative Overview

Welcome to the Learning Action Network (LAN)

What is a LAN?

One writer calls a LAN a “philosophy of action, of collaborative mutual striving for useful and informed action in the world.” Another writer says, “Learning and Action Networks (LANs), ... are groups of like-minded community members working together towards a common goal to achieve better care.”

The Washington Rural Palliative Care Initiative uses the LAN structure. Our emphasis is on peer-to-peer mentoring and support. It can be lonely and daunting to bring on a new service or to spread new skills and seek cultural changes. Working with others on a similar journey can make the experience less stressful and help you stay better informed.

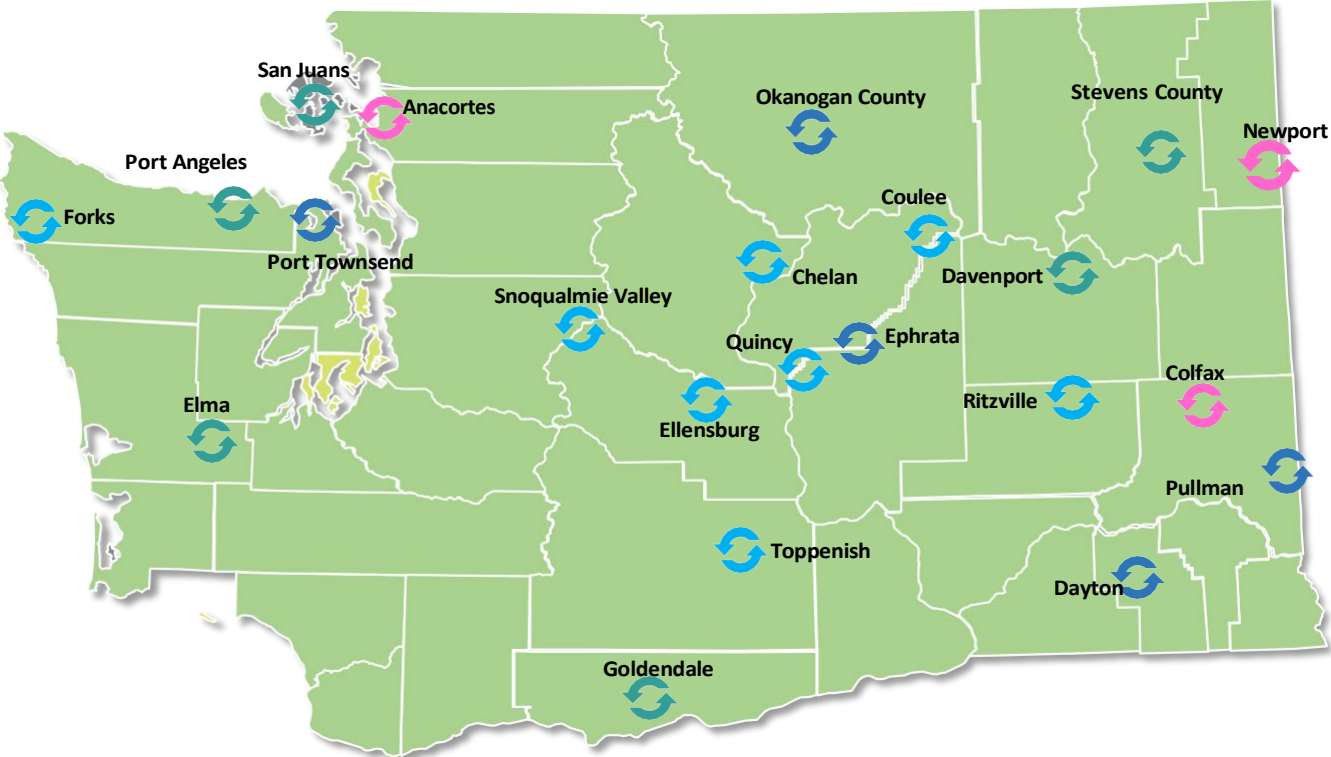
LANs are a close cousin to the Breakthrough [Collaboratives](#) but generally do not make the same time demands. However, they do share an allegiance to learning in a community, measuring improvement, transparency within the group about both successes and mistakes, and perhaps most importantly, the guiding idea that “**everyone teaches, and everybody learns.**” Although specific subject matter experts may be brought to the group, it is the teams’ deep knowledge of their own organization and community that brings depth and meaning for other participants.





Washington Rural Palliative Care Initiative Guiding Principles

1. Rural healthcare organizations and communities set their own goals and pace.
2. Any progress is a success.
3. The initiative is intended to be supportive but not prescriptive.
4. Everyone teaches and everyone learns.

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Washington Rural Palliative Care Initiative



Cohort 1  Cohort 2  Cohort 3 
Paused teams 

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Washington Rural Palliative Care Initiative Definitions

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones, and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness and make timely, informed decisions about care.¹

Serious Illness is a condition that “negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress... [and] carries a high risk of mortality.”² Traditional life-prolonging or curative care often does not meet a person’s range of needs as illness progresses. Fragmented care delivery and frequent transitions between care settings, unmet physical and psychological symptoms, and responsibilities put on family members and other caregivers create undue stress and burden.³ Further, many people who would prefer to remain at home experience high-intensity care often in a hospital setting.^{4,5}

WRPCI Goals

- Assist rural health systems and communities to integrate palliative care in multiple settings, to better serve patients with serious illness in rural communities.
- Decrease transfers to far away urban tertiary services.
- Move upstream to serve patients with serious illness earlier in their experience of illness.
- Develop funding models for sustainable services



¹ Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care

² Kelley AS. Defining "serious illness". J Palliat Med. 2014 Sep; 17(9):985.

³ Institute of Medicine. 2015. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. September 2014. Washington, DC: The National Academies Press.

⁴ Jenq G, Tinetti ME. Changes in end-of-life care over the past decade: more not better. JAMA. 2013 Feb 6; 309(5):489-90.

⁵ (Paragraph with definition of serious illness and key points from Bree Collaborative Palliative Care Recommendations, 2019)

Serious Illness in Washington

- “Find it and fix it” is one way used to describe the underlying premise of healthcare focused on acute illness and injury. Chronic conditions call for a different approach, and particularly those serious illnesses that have a large effect on quality of life. While serious illness can hit at any age, older adults are at highest risk. About 80 percent of older adults have at least one chronic disease, and 77 percent have at least two.⁶
- Data from 2021 show Washington’s age 65 and older population is 16.68 percent of the overall population statewide, while the 30 rural counties have an average of 26.85 percent of the population aged 65 and older. Five rural counties have over 30 percent aged 65 and older and another six rural counties have greater than 25 percent. Nine other rural counties have populations aged 65 and older above 20 percent. There are only three rural counties below the state average.
- “Patients with chronic illness in their last two years of life account for about 32 percent of total Medicare spending, with much of it going toward physician and hospital fees (Medicare Part A and Part B) associated with repeated hospitalizations.”⁷
- The evidence shows that palliative care not only improves symptom control, quality of life, and satisfaction, it also decreases total cost of care with less use of emergency departments and hospital beds.
- When offered a complete range of choices and fully informed, patients and their families often choose less invasive forms of care.
- When skilled care for serious illness is offered, rural residents can remain in their communities, with those they love, instead of being transferred to urban hospitals⁸

“People living with serious illness make up the 5% of patients driving over half of all health care spending. They are disproportionate users of 911 calls, recurring emergency department (ED) visits, hospitalizations, and skilled nursing facility admissions. Yet despite high utilization of crisis care and high spending, this population often receives low value, even distressing, service from our health care system.”

CAPC

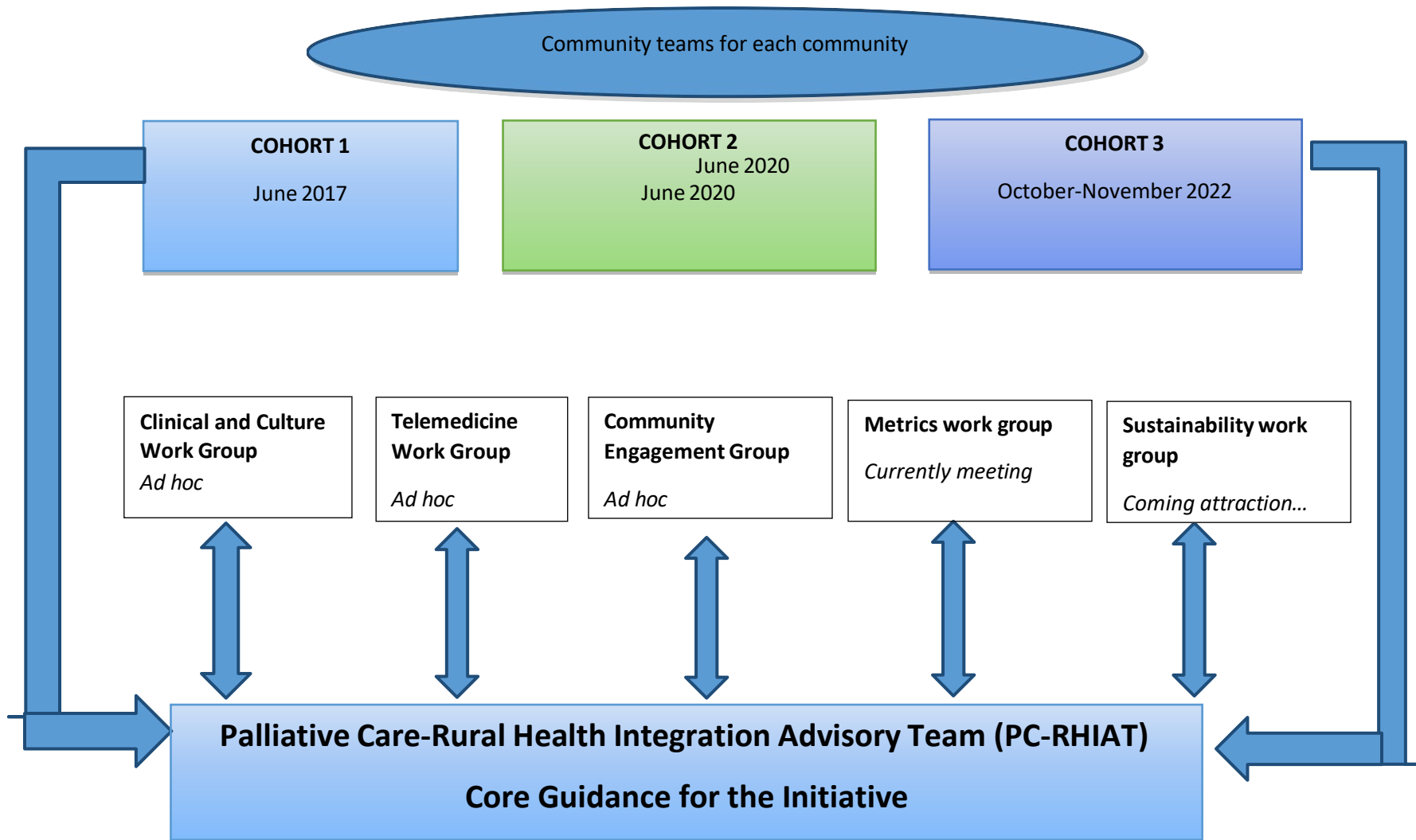
⁶ Dartmouth Atlas, <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1> accessed 3/6/201

⁷ Ibid

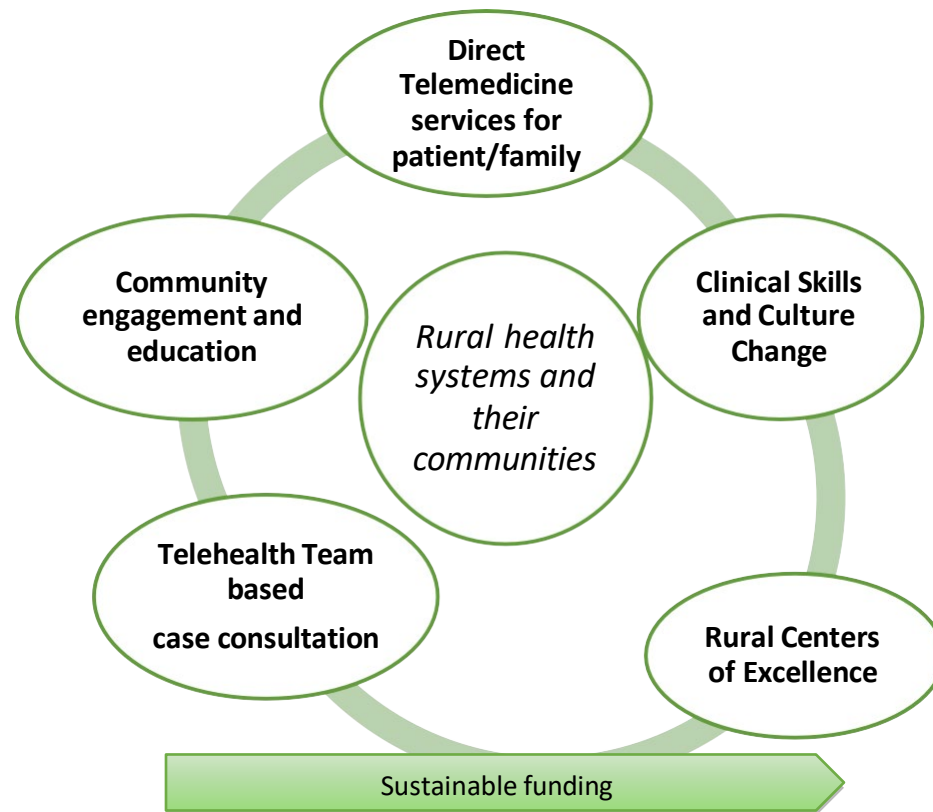
⁸ <https://www.capc.org/documents/download/214/>

⁸ O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2009 Jul; 8(3):CD001431.

WRPCI Structure Diagram



WRPCI Model



Washington Rural Palliative Care Initiative Portal



- The WA Portal was designed to bring clinical, public health, and community-based organizations together in a collaborative workspace.
- Washington Rural Palliative Care Initiative's (WRPCI) public pages serve anyone interested in rural palliative care.
- The team spaces are password-protected spaces for confidential discussions and posting of unfinished drafts, measures, tailored resources, and sensitive topics.
- The WRPCI Portal holds an ever-growing set of resources on palliative care in one place and is easily accessed.

Visit

<https://waportal.org/partners/home/washington-rural-palliative-care-initiative>

Please email Mandy Latchaw for assistance with the WA Portal:

Mandy.latchaw@doh.wa.gov

We encourage all team leads to join the **Palliative Care Cohort Leader Team** and for all team members to join the **Palliative Care Cohort Team**.

The teams appear on "My Portal" on the portal site above.

Descriptions of events

Activity Name	Frequency	Description
<p>Telehealth case consults</p> <p>No meeting in August</p>	<p>Once per month</p> <p>2nd Tuesday 12:00 - 1:00</p>	<p>All cohort sites are welcome. Those who are willing, rotate to present clinical cases for an interdisciplinary discussion using a HIPAA compliant telehealth connection. Education drawn from cases.</p> <p>Nursing Coordinator, Deb Watson, assists with case selection and preparation as needed.</p>
<p>PC-RHIAT meetings</p> <p>Palliative Care-Rural Health Integration Advisory Team</p>	<p>Quarterly 1st Wed 1:00 - 2:00</p>	<p>The advisory team for the WA Rural Palliative Care Initiative guides the planning process, provides input on key decisions, and offers expertise to help achieve the desired results. Cohort leads are asked to come and team members are always welcome.</p>
<p>Cohort Roundtables</p>	<p>3 times per year 12:00-1:00</p>	<p>A discussion among Cohort site participants about the challenges, surprises, and pleasures of developing a new palliative care service. Focused on operational issues and sustainability.</p>
<p>Serious Illness Conversation Skills Education</p>	<p>TBD 4th Tue likely</p>	<p>To be scheduled based on an assessment of each site's goals and needs.</p>
<p>Mentoring calls via Zoom</p>	<p>Every 6-8 weeks or by arrangement</p> <p>30 or 60 minutes</p>	<p>One or more members of the cohort team have an opportunity to discuss their development path, explore needed resources, discuss frustrations and successes, and explore next steps with Pat Justis at DOH and peer mentors. <i>Strongly Suggested for Cohort 3 teams</i> or with Cohort 1 & 2 teams who face challenges or need to refuel.</p>
<p>Physician to Medical Staff conversations or education</p>	<p>By request</p>	<p>By arrangement, DOH will pay Medical Director Gregg VandeKieft, MD for his time to talk/present to medical staff groups or individuals.</p> <p>Gregg VandeKieft, MD is an experienced board-certified palliative care and family medicine physician.</p>

Optional events for new teams

Activity Name	Frequency	Description
Community meeting 1: Asset and gap analysis	One time	A community team completes the Asset and Gap Analysis tool using dialogue to develop shared perceptions. Facilitated by the team lead(s) Planning assistance offered.
Community meeting 2: Action plan development	One time	Meeting 2, facilitated by the DOH team, offers brief level setting palliative care education, and a process to develop the action plan, using the Asset and Gap Analysis to focus.
Community meeting 3: Action plan review and reset	One time	Optional six-, nine- or 12-month review of the Action Plan to note progress and update the plan for the next time period.

Please see page X for more information on community meetings.

A Word about Telehealth Case Consults

Telehealth case consults serve two primary purposes. First, they are a forum to generate and gather ideas and suggestions for the care of the specific patient presented. Second, these sessions model interdisciplinary teamwork and provide exposure to the perspectives and language of specialty palliative care clinicians. The case consults offer a rich education experience.

Although patient names are not used, to make sure the highest standard of patient confidentiality is met, all participants and observers are asked to complete a confidentiality agreement. The Nursing Coordinator for WRPCI arranges for the signature and retention of the confidentiality agreements.

The teams engaged in WRPCI take turns presenting cases using a standard template. **(See page 76)** All engaged teams are welcome to attend and observe. At approximately 45 minutes into the one-hour session, all teams are invited to participate in the dialogue with questions or comments.

Format to sessions

- Introductions of facilitator, leader, and panel members
- The cohort “waves” to welcome all teams with one or more members present
- Introduction of the presenting team
- Presentation of the case
- Dialogue between panel and presenting team
- Open dialogue for all attendees

To mitigate the stress of work that often sits very close to human suffering, there are some practices to adopt for your team early on and consistently moving forward.

- Seek consultation with your peers. Mental health clinicians are taught to use consultation to avoid boundary issues, create fresh perspective, and avoid inflicting their own biases or emotional work on clients. This practice is highly relevant to palliative care delivery.
- Hold Interdisciplinary Team (IDT) meetings regularly to use the expertise of each discipline in synergy for the best care, but also to help the team members stay healthy and well supported. -
- Recognize that you are not there to “fix” people and are unlikely to influence lifelong patterns.
- Be clear about the limits of your influence.
- Work on your own implicit biases.
- Understand that some patients will not act in their own best interest. Let go of your agenda and help them explore what they want and need.
- Take vacations regularly, small, and large



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First Steps

Rural Palliative Care: Community Team Development

Building

Evolving

Thriving

Palliative Care Leadership

A small group of inspired individuals spreads knowledge, gains support, and removes barriers

Impact that palliative care services can have is shared with patients, families, and providers; leadership understands and supports palliative care development

Leadership provides motivation and resources for further palliative care development; empowers staff to build strong processes and consistent services

Clinical Team – Palliative Care Skills

Palliative care skills are limited outside of hospice providers interdisciplinary team (IDT) discussions are inconsistent and/or limited

Increased awareness and palliative care skill building across broader sections of the health care workforce; IDT discussions are more regular and structured

Skills and knowledge are fully integrated across the team; formal and regular IDT meetings; linkages are strong for additional expertise and support as needed

Advance Care Planning Processes

A variety of processes and formats among providers and settings; sharing across settings is limited

Alignment of processes and formats among providers and settings; plan for sharing across settings of care in place

Aligned process, format, and communication channels across settings and into the community; patient wishes are documented, accessible, and followed

Care Coordination and Collaboration with Community Services and Supports

Limited and may be highly dependent on individual awareness of resources and/or patient engagement

Services and access points are understood and available; identification of needs and gaps completed at a community level; care plans shared intermittently

Processes for referrals and services are integrated across settings; integrated care plans are readily accessible, in use, and updated as appropriate; service development expands for areas identified as gaps

Community Awareness of Palliative Care

Limited and may be highly dependent on individual providers, patients, and families

Common language about palliative care utilized among community partners; palliative care services are visible and becoming understood in the community

Community understands, supports, and requests palliative care services and resources

Availability of Formal Palliative Care Services

Focused services with limited patients, conditions, and providers involved

Services available to specific subsets of patient populations and/or settings of care

Services broadly accessible and available to a wide variety of patient populations and settings of care

Washington Rural Palliative Care Initiative

Getting Started: A Map to Key Steps



Step 1	Step 2	Step 3	Step 4
<p>Educate senior leaders and front-line leaders. Include the billing and coding leader about the definitions of palliative care and serious illness, and how palliative care will benefit those you serve. Consider leaders of non-clinical departments</p> <p>Suggested tools Video- <i>Offering Palliative Care in Rural Communities</i> (5 min 29 sec) https://youtu.be/0-9HQyfDQUk</p> <p>Center for the Advancement of Palliative Care https://www.capc.org/documents/download/214/</p>	<p>The team who shapes the development path may or may not deliver the services later. The best team members:</p> <ul style="list-style-type: none"> ✓ Have an interest or passion ✓ Have either the flexibility or support to take a bit of time for this work ✓ Represent more than one discipline ✓ May have had an experience with a loved one's serious illness <p>Sponsors are leaders who care about the work and agree to help remove barriers and carry the message of the work's value</p>	<p>Invites will come from Patricia.justis@doh.wa.gov You may forward those invites to anyone you wish.</p>	<p>Please see diagram on the following page to make a decision about whether to hold a community meeting or not.</p>
<p>Objective: all members of the leadership team can describe what palliative care is, and how it can benefit your patients</p>	<p>Objective: -2-5 people are willing to help shape the work.</p>	<p>Objective: Integrate activities into calendars.</p>	<p>Objective: Your team and leadership are aligned on the plan.</p>

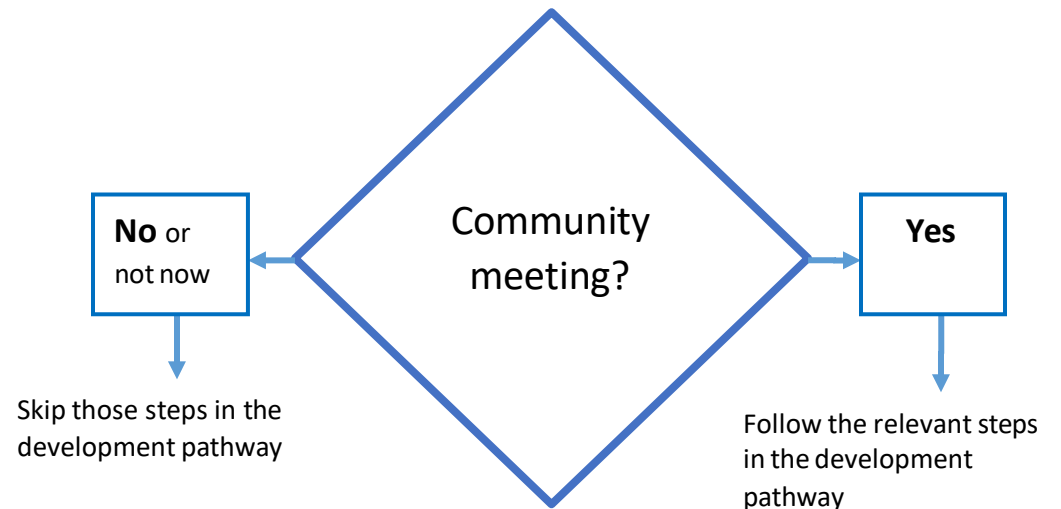
Decision

Pros of community meetings

- Identify assets and build on them with a coalition.
- Build support for non-medical services and interventions while building investment for changes in the healthcare organization.
- Uncover supports you did not anticipate.
- Build community awareness so that patients and families, current and future, will understand the benefits of PC.
- People from outside your healthcare organization can offer insightful perspectives.
- Target priority gaps after a thoughtful assessment.
- DOH will provide templates and materials and facilitate one of the two meetings.
- Teams who have held these meetings have had a valuable experience.

Cons of community meetings

- Takes time and effort to organize.
- There may be fear that below-the-waterline tensions may enter the meeting.

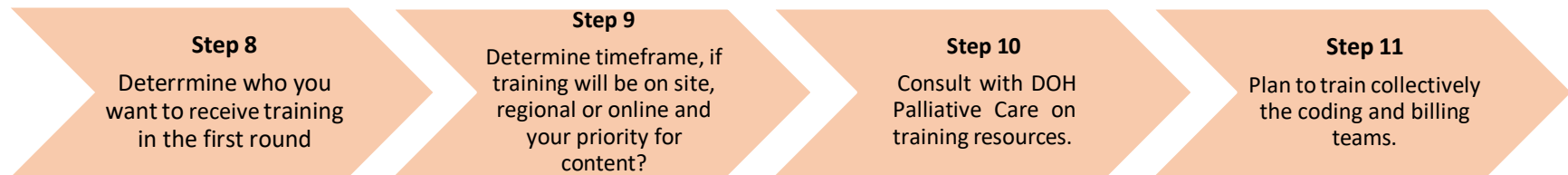


Community Meeting Steps



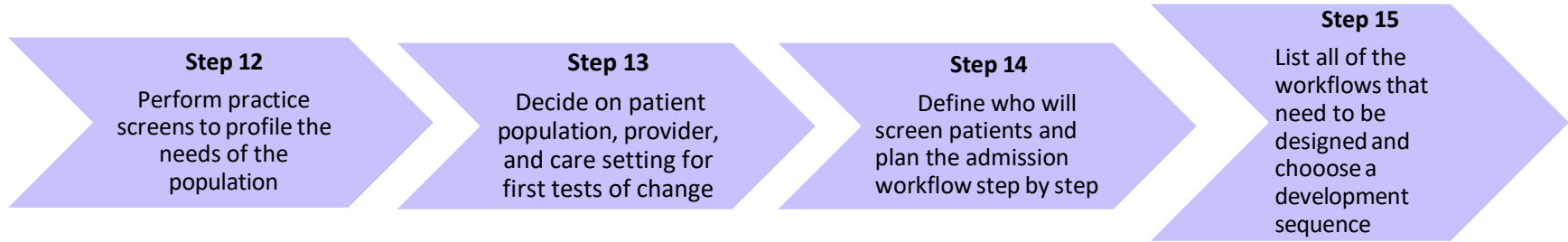
Step 5	Step 6	Step 7
<p>A list of types of organizations to consider inviting to your two community meetings is on page 30. You also have:</p> <ul style="list-style-type: none"> • sample invites on page 31 • sample agenda (facilitator version) for Community Meeting 1 on page 33 • sample participant agenda for Community Meeting 1 on page 36 	<p>The Asset and Gap Analysis tool is on page 38. You may request an electronic fillable version.</p> <p>This is a consensus process, and the dialogue is as important as the completed tool. Please avoid having any individuals complete it on their own.</p> <p>We strongly suggest sending out a single invite that asks participants to attend a series of two meetings and list both dates and times.</p>	<p>DOH comes to your community facilitate meeting #2. The sample agenda is on page 37. The action plan is on page 47.</p> <p>You may decide during this second meeting if you want to continue PC community team meetings. This has worked very well for some communities</p>
<p>Objective: Identify the list of who to invite to the community meeting</p>	<p>Objective: Conduct Meeting #1 to complete the Asset and Gap analysis as a community team.</p>	<p>Objective: Conduct meeting #2 and complete an action plan. Decide on your strategy for the community team moving forward.</p>

Training



Step 8	Step 9	Step 10	Step 11
<p>We suggest a basic and brief training for leaders, and then the first members of the team that will deliver the service. Alternatively, if you do not plan to develop a service, this might mean a widespread training to build serious illness communication skills.</p> <p>There is no wrong option. This is a discussion for your team to have and communicate to us.</p>	<p>Negotiate logistics with DOH team after you have a proposed set of training ideas</p>	<p>DOH has funding to pay for training. You may also access training online through a CAPC membership or other reputable sources of training. Please see the Portal for links to other options.</p> <p>https://waportal.org/partners/washington-rural-palliative-care-initiative/tools/training</p>	<p>Coders and billers need to understand the program goals and what differences in documentation might be needed.</p> <p>Consider a training with providers, coders, and billers together. See CAPC site: https://www.capc.org/toolkits/optimizing-billing-practices/</p> <p>Two billing courses on this pathway https://www.capc.org/training/learning-pathways/communication-skills-conversations-about-serious-illness/</p>
<p>Objective: Select an audience that aligns with your goals.</p>	<p>Objective: Determine the site, length, and content for your first round of training.</p>	<p>Objective: Determine how to pay for training and schedule the offering for a target audience.</p>	<p>Objective: Educate team members who are frequently overlooked so that they have the information to do their job in alignment with program goals.</p>

Assess and Design workflows



Step 12	Step 13	Step 14	Step 15
<p>Mock screenings do not require patient interviews. We suggest you screen at least 20 patients as potential PC candidates, and sample from several settings. Please use the standard tool (link below) used at all sites.</p> <p>Bring the data to your planning team and make meaning from the result by identifying what kinds of patients screened in or out, what kinds of symptoms were dominant, and predict what services would be helpful</p>	<p>Start small with one setting, one provider, and a few patients. Though you may aspire to integrate PC across multiple settings, decide where to start. Some “try-storm” (test an idea about improving a process by trying it)where they see just one patient to see what they discover.</p> <p>Though we like to see openness to all diagnoses that fit the serious illness definition, it is an option to start with a single diagnostic group.</p>	<p>Identify the first and last step in the admission to service flow. In the test setting:</p> <ul style="list-style-type: none"> • Who will decide if a patient is screened? • Who will complete the screening and discuss it with the provider? • What tools do you need to discuss the services and obtain patient consent? • What referral sources will you rely on for this setting? 	<p>Possible workflows to consider:</p> <ul style="list-style-type: none"> • Identification of patients for screening who, where and then what • Admit process • Clinical team scheduling and visiting • Care intensity titration • Response to referral sources, internal and external • Discharges and transfers to hospice • Coding and billing • Invitations for patient and family philanthropy <p>See Page 50 for workflow ideas</p>
<p>Objective: Assess patient needs to assist in planning. https://waportal.org/sites/default/files/documents/NewRevised-WRPCI.pdf</p>	<p>Objective: Determine where you will start and which provider’s patients will first test the process.</p>	<p>Objective: Design the admission workflow. Put one action in each step, saying who will do what.</p>	<p>Objective: List the possible, decide on the sequence of development and will be needed to participate in each workflow.</p>

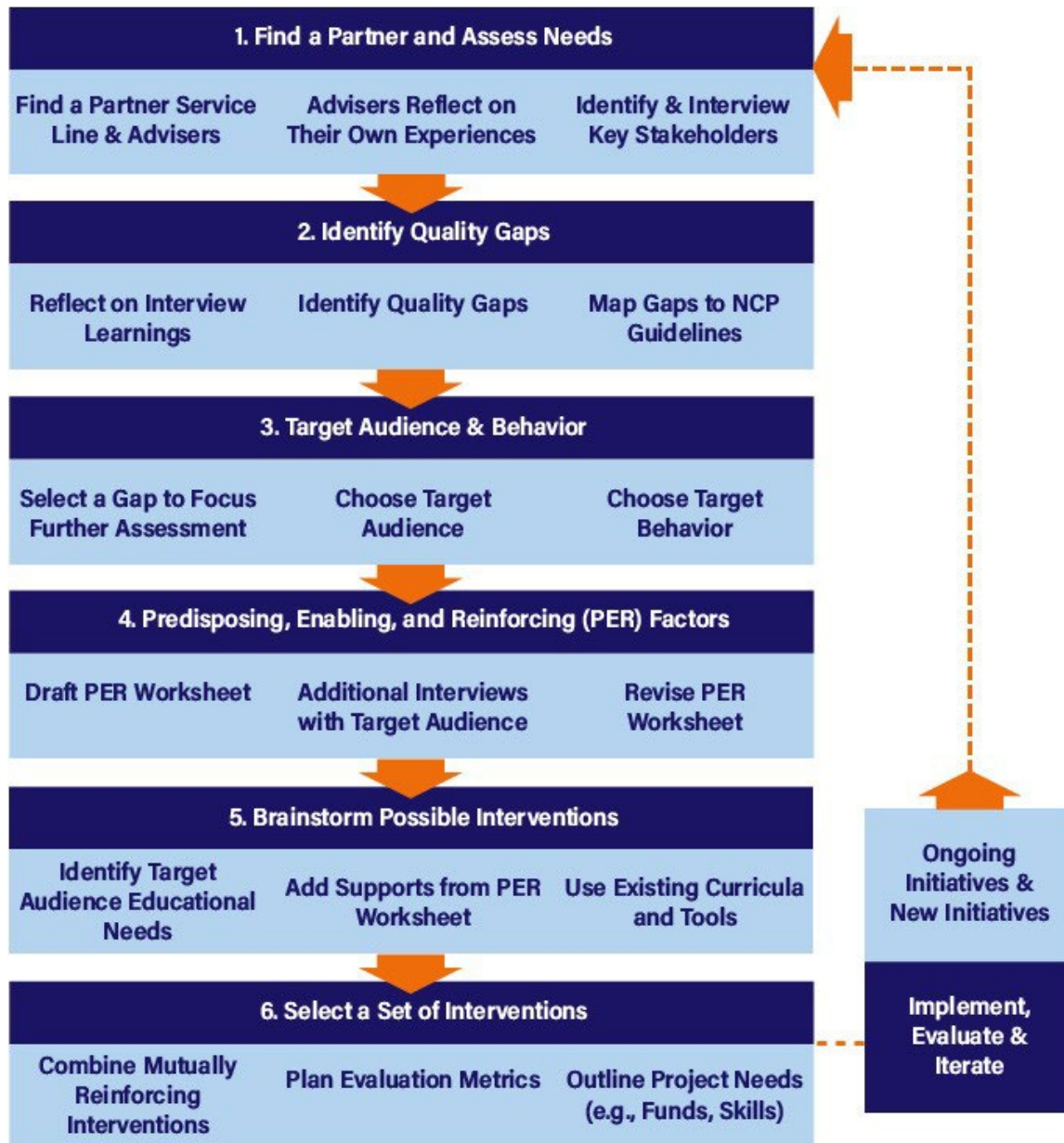
Continue Program Design



Step 16	Step 17	Step 18	Step 19
<p>You can shamelessly borrow documents to customize for your team from other teams and talk to palliative care programs outside the initiative.</p> <p>Develop a registry to track patients.</p> <p>Identify what electronic health record changes or new templates would optimize your clinical work and QI measures.</p>	<p>Members of WRPCI have agreed to aggregate a set of measures and metrics workgroup. See page 65 for the list of measures, data dictionary and sample data collection spreadsheet.</p>	<p>Decide upon your:</p> <ul style="list-style-type: none"> • Overall goal, • Audiences with whom you want to communicate • The objectives for each audience • What strategies you will employ, with target dates and budget. 	<p>In the best-case scenario community members have had advance care planning conversations, have selected a health care proxy, and understand what PC is and is not.</p>
<p>Objective: Identify needed documents, gather, or create and maximize EHR integration.</p>	<p>Objective: Join those who are collecting measures when ready; seeing patients, data agreement signed, and workflow designed</p>	<p>Objective: Thoughtfully select communication strategies.</p>	<p>Objective: Decide on at least one community education strategy.</p>

Another Development Model: Optional

The [California Health Care Foundation](#) has a wide body of resources and information related to palliative care. They use the diagram below entitled “Needs Assessment Process Map.”



You may find this model helpful or want to combine steps from our developmental path with steps from this path. Please see the next page for more in depth information about Step 4.

Predisposing, Enabling and Reinforcing (PER) Factors

The California Health Care Foundation outlines tools to identify key audiences and what you want them to know, believe, and value in the stages of Precontemplation and Contemplation. This falls under **Predisposing**.

Enabling covers the stages of Preparation and Action, in which you identify what skills the audience needs, what they need access to, and what barriers they need removed.

The **Reinforcing** part of “PER” is related to the stage of maintenance of behaviors, identifying what the audience needs related to reminders, positive reinforcement, negative reinforcement, and social supports.

The following pages provide you with a PER worksheet with embedded questions and a blank worksheet blank. Some small modifications have been made to move this from a hospital-focused worksheet to one that suits our multiple settings initiative.

(All language on the form attributed to California Health Care Foundation)

Read more about the PER worksheet: Marietta A. Langlois and Jeffrey S. Hallam, “[Integrating Multiple Health Behavior Theories into Program Planning: The PER Worksheet](#),” *Health Promotion Practice* 11, no. 2 (Mar. 2010): 282–8.

More resources from the California Health Foundation

[Home on the Range: Plans and Providers Team Up to Bring Palliative Care to Rural Californians](#)

[Serious Illness and End of Life Care](#)

[Implementation of Palliative Care Capabilities Across Services and Settings: Key Ingredients and Resources for a Successful Implementation](#)

[Generalist Palliative Care Implementation Project and Evaluation Plan Template](#)

[Standardizing Home-Based Palliative Care: Necessary, Doable, and Fruitful](#)

Worksheet with Prompts: Predisposing, Enabling, & Reinforcing (PER) Factors Planning Worksheet

Instructions: Use the questions below to guide your drafting of the blank PER worksheet on the following page.

ORGANIZATION AND TEAM LEAD(S)	<i>List your organization and team lead(s)</i>		
PARTNER SVC LINE / ORG	<i>List your partner service line or organization</i>		
AUDIENCE TO TARGET	<i>What is the main group of people whose behavior you want to change?</i>		
BEHAVIOR TO TARGET	<i>What specific behavior do you want the target audience to perform?</i>		
OTHER KEY INDIVIDUALS	<i>Which other individuals influence the audience to perform the desired behavior?</i>		
PREDISPOSING: Stages of Precontemplation & Contemplation	ENABLING: Stages of Preparation & Action	REINFORCING: Stages of Maintenance of Behavior	
KNOW <i>What does target audience need to know in order to perform target behavior?</i>	BE ABLE TO (skills) <i>What does target audience need to be able to do in order to perform target behavior?</i>	REMINDED <i>How could the target audience be reminded to perform the target behavior?</i>	
BELIEVE / VALUE <i>What beliefs and values will encourage the target audience to perform target behavior?</i>	ACCESS TO <i>What does target audience need to have access to, in order to perform the target behavior?</i>	POSITIVE REINFORCEMENT <i>What positive reinforcements / rewards will the target audience receive if they perform the target behavior?</i>	
INTENTION <i>What intentions will the target audience need to have in order to perform target behavior?</i>	BARRIERS REMOVED <i>What are the barriers that would need to be removed in order for the target audience to perform the target behavior?</i>	NEGATIVE REINFORCEMENT <i>What negative reinforcements /outcomes will the target audience receive if they perform the target behavior?</i>	
		SOCIAL SUPPORT <i>What social supports will reinforce or reward the target audience for performing the target behavior?</i>	

Blank Worksheet: Predisposing, Enabling, & Reinforcing (PER) Factors Planning Worksheet

Draft responses to each of the items below using the prompts on the previous page. Note: bullets are for your convenience, you don't have to have 4 items in each box! Do try to think of 1-2 items for each box.

ORGANIZATION AND TEAM LEAD(s)		
PARTNER SVC LINE / ORG		
AUDIENCE TO TARGET		
BEHAVIOR TO TARGET		
OTHER KEY INDIVIDUALS		
<i>PREDISPOSING:</i> Stages of Precontemplation & Contemplation	<i>ENABLING:</i> Stages of Preparation & Action	<i>REINFORCING:</i> Stages of Maintenance of Behavior
KNOW • • • •	BE ABLE TO (skills) • • • • •	REMINDED • • • • •
BELIEVE / VALUE • • • •	ACCESS TO • • • •	POSITIVE REINFORCEMENT • • • •
INTENTION • • • •	BARRIERS REMOVED • • • •	NEGATIVE REINFORCEMENT • • •
		SOCIAL SUPPORT • • •



Community Meetings

COMMUNITY MEETINGS: WHO TO INVITE

Meeting #1: Complete an Asset and Gap Analysis. The community facilitates this meeting at least two weeks prior to the action plan meeting described below,

Meeting #2: Develop an Action Plan. DOH facilitates this meeting.

Rural Coalitions or other existing groups can be considered but need to be specifically chartered for these meetings and purpose.

Potential participants in a community meeting about rural palliative care for serious illness

- **Hospitals** – Including discharge planners, physicians/providers, hospital leaders, nursing, care coordinators, pharmacists, chaplains if on staff, CNAs, ED staff, and others
- **RHC Managers** (hospital owned)
- **RHC Managers** Independent Rural Health Clinics
- Federally Qualified Health Centers or Community Health Centers
- **Skilled nursing facilities for rehab and long-term care**
- **Home health/hospice agencies**
- **EMS agencies**
- **Community pharmacies**
- Private nursing and home care agencies
- Health Home Care Managers
- **Area Council on Aging and their case managers**
- Parish nurses and cross-denominational chaplains
- Senior centers and senior services
- Community Action Councils
- **Retired licensed healthcare professionals**⁹
- **Assisted Living directors**
- **Senior Housing**
- **Adult Family Home operators**
- Primary care providers
- **Behavioral health providers**
- **Human services organizations**
- City / county government
- Civic leaders and service clubs
- **Oncology clinics, if local**
- Accountable Communities of Health representatives
- Housing Authority
- Patient and family perspectives
- Community college health professions faculty
- Community transportation
- Community banks

Those potential participants in **bold** are considered essential.

We have only bolded what we consider to be the vital few among the important many. You are also free to alter this list and create your own “essential” list.

If you hope to offer some non-medical supports, we strongly suggest service clubs, community volunteer groups and parishes.

⁹ See sustainability section for more information on volunteers

Sample invite

This template is for community-lead organizations to invite community partners and organizations to participate in their Community Palliative Care Team Meetings.

Date:

Re: Washington Rural Palliative Care Initiative

Dear (Hospital CEO; DON; Home Health Agency Director; Hospice Director; Nursing Home Director; or leader of other community organizations):

<Name of Lead Community Organization> has the opportunity to participate in the Washington Rural Palliative Care Initiative, to strengthen palliative care programs in this community. We are reaching out to you as a valued community partner to invite you to participate with us in this project by being a part of our Community Palliative Care Team.

Palliative care is an approach to managing serious illness that centers on quality of life. Palliative care customizes treatment to meet the needs of each individual, seeking to relieve pain, anxiety, shortness of breath, fatigue, nausea, loss of appetite, and other symptoms. Practitioners of palliative care help patients and their families understand treatment options, facilitate effective communication among health care professionals, patients, and family members. Emotional and spiritual support for the patient and family are hallmarks of palliative care.

Palliative care differs from hospice in that it is appropriate at any point in a serious illness and can be provided at the same time as curative treatment. It may be offered in a variety of settings: hospitals, clinics, long-term care facilities, or people's homes. For more information on palliative care, go to www.getpalliativecare.org

Washington State Office of Rural Health, at Washington State Department of Health, facilitates the Learning Action Network (LAN) called Washington Rural Palliative Care Initiative to offer training, tools and support while fostering peer-to-peer conversations. Communities dialogue with other peer communities to spread effective practices and mutually overcome challenges.

<Name of Lead Community Organization> is excited to be participating in this project for rural communities in our state. We hope your organization will consider helping us advance palliative care in our community. Our initial Community Palliative Care Team meeting will be on <date, time, location>. In that first meeting we will discuss the strengths/assets and gaps/challenges related to palliative care in our community.

In our second meeting, the Action Planning Workshop on <date, time, location> a facilitator will help us work together to assure we build a common understanding of palliative care and develop our community action plan

You are encouraged to bring appropriate administrative and clinical leadership representation from your organization to the meeting.

To confirm your participation, please respond to <name, email> by <date>

Thank you for your commitment to improved patient care. We look forward to partnering with you on this exciting, patient-centered initiative. In the meantime, please contact <name, email> if you have questions about the project.

Sincerely,

<Signature>

<Signature>

<Name/credentials>

<Name/credentials>

Senior Leader

Palliative Care Team Lead

Sample Agenda for Meeting 1 with guidance (Sample participant agenda follows)

Washington Rural Palliative Care Initiative Initial (Meeting #1) Community Meeting Agenda

We have not ascribed agenda times and will leave that to each community. Janelle from Stratis suggests two hours total. We do suggest that you keep the emphasis on the Asset and Gap Analysis and proportion time carefully to see that you have the bulk of your time for that discussion.

Prior to the meeting, share a link to the National Quality Forum National Framework and Preferred Practices for Palliative and Hospice Care Quality.

https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

1. **Team Member introductions**

- Could include name, organization, role, what they hope to get out of participation in the project
- Be sure to highlight any team members that have recently joined if you've added additional organizations/people to your team.

2. **Project Overview:** Our team and community are invited to participate in the WA Rural Palliative Care Initiative to develop or strengthen palliative care services in our communities. The goal of this process will be to first assess our assets and our gaps in care for community members with serious illness, then develop an action plan. Washington Department of Health (DOH) State Office of Rural Health (SORH) is supporting the program in a public-private partnership.

3. **Review/Discuss definition of Palliative Care vs. Hospice to help ensure team has a shared understanding:**

Serious Illness is a condition that “negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress... [and] carries a high risk of mortality.”¹⁰ Traditional life-prolonging or curative care often does not meet a person’s range of needs as illness progresses. Fragmented care delivery and frequent transitions between care settings, unmet physical and psychological symptoms, and responsibilities put on family members and other caregivers create

¹⁰ Kelley AS. Defining "serious illness". J Palliat Med. 2014 Sep; 17(9):985.

undue stress and burden.²¹¹ Further, many people who would prefer to remain at home experience high-intensity care often in a hospital setting.¹²

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment-whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care. ¹³

Hospice care is a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears. Hospice care further addresses the bereavement needs of the family following the death of the patient.¹⁴

Key Point:

Every community will decide how to best work in collaboration with existing home health and hospice services, this initiative is meant to be supportive and increase hospice referrals rather than compete in any way.

4. Review and begin completion of the Asset and Gap Analysis. If not feasible to complete the Asset and Gap Analysis as a group, be sure to discuss and gather input on the following:

- What are the greatest palliative-care related needs in our community?
- What aspects of palliative-care support are already in place?
- What aspects of palliative care would you prioritize as most important for our team to focus on?

¹¹ Institute of Medicine. 2015. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. September 2014. Washington, DC: The National Academies Press.

¹² Jenq G, Tinetti ME. Changes in end-of-life care over the past decade: more not better. JAMA. 2013 Feb 6; 309(5):489-90.

¹³ Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care.

¹⁴ National Quality Forum. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality A Consensus Report*. 2006.

Next Steps:

- Are there specific palliative care related areas we'd like Washington State to focus on during the in-person discussion (resources, topics, models for improvement, etc.)?
- Team Operations:
 - What method works best for ongoing team communication (e-mail, calls)?
 - What roles do we need to have in place to operate as a team? What organizations/people can take on those roles (i.e., organizer, facilitator, note taker, timekeeper, etc.)?
 - Can we set a standing meeting time? Perhaps once per month?
 - Expectations for participation?
- What communication do we need to send out to our organizations/community regarding this initiative? Who will do that?

Review the time and place for meeting #2, action planning

Washington Rural Palliative Care Initiative

<Name of Palliative Care Community>
Community Meeting #1
Asset and Gap Analysis Planning Session

Sample participant agenda

2 hours

Meeting objectives

- Build a common understanding of serious illness and palliative care.
- Assess the current state in the community for serious illness care, the assets, and gaps.

Time	Topic
20 min	Agenda Overview and Team Member Introductions
10 min	Overview of WA Rural Palliative Care Initiative
10 min	Definitions of Palliative Care and Serious Illness
70 min	Asset and Gap Analysis
10 min	Summary of Next Steps

Washington Rural Palliative Care Initiative

Sample agenda

<Name of Palliative Care Community>

Community Meeting #2

Action Planning Session

Date XX, 2023

AGENDA

Objectives: Develop an initial goal and action plan for palliative care in your community

Time	Topic
30 minutes	Welcome and Introductions
60 minutes	Palliative Care and Community Capacity Building
45 minutes	Lunch
75 minutes	Case Studies - Clarify community focus area(s)
30 minutes	Model for Improvement and Action Plan Basics
15 minutes	Break
90 minutes	Community Action Plan Development <ul style="list-style-type: none">• Goals and aim• Measures• Work plan (timeline, responsibilities...)
15 minutes	Wrap-up Identify additional resources needed Next steps for team and initiative

Washington Rural Palliative Care Initiative

Asset and Gap Analysis (2023 Revision)

Each Community Team participating in the WA Rural Palliative Care Initiative is asked to complete this Asset and Gap Analysis to identify the resources, needs, and opportunities in your community to develop, implement, and sustain successful palliative care services.

Please work with your Community Team to discuss and gather the below information, and return completed form by **DATE 2023**

Send completed forms to: Pat Justis

Email : patricia.justis@doh.wa.gov

Feel free to contact Pat Justis at patricia.justis@doh.wa.gov or 360-338-2875 with any questions.

Name of Community

Team Leader

Definitions

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones, and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.¹⁵

Hospice care is a service that provides palliative care for patients who have a limited life expectancy and require comprehensive support during a terminal illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears. Hospice patients are usually not eligible for curative treatments after accepting Hospice care. The Hospice team also addresses the bereavement needs of the family following the death of the patient. *

Serious illness is a condition that “negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress... [and] carries a high risk of mortality.”¹⁶ Traditional life-prolonging or curative care often does not meet a person’s range of needs as illness progresses. Fragmented care delivery and frequent transitions between care settings, unmet physical and psychological symptoms, and responsibilities put on family members and other caregivers create undue stress and burden.²¹⁷ Further, many people who would prefer to remain at home experience high-intensity care often in a hospital setting.¹⁸¹⁹

**

¹⁵ Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care by Washington Rural Palliative Care Initiative Advisory Team. **National Quality Forum*. A National Framework and Preferred Practices for Palliative and Hospice Care Quality A Consensus Report. 2006

¹⁶ Kelley AS. Defining "serious illness". *J Palliat Med*. 2014 Sep; 17(9):985.

¹⁷ Institute of Medicine. 2015. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. September 2014. Washington, DC: The National Academies Press.

¹⁸ Jenq G, Tinetti ME. Changes in end-of-life care over the past decade: more not better. *JAMA*. 2013 Feb 6; 309(5):489-90.

¹⁹ definition of serious illness and key points from Bree Collaborative Palliative Care Recommendations, 2019

Services and Processes

The following questions help to assess the current level of services in your community.

1. Indicate which services are currently available in your community and if they are provided directly by an organization represented on your Community Team.

Services	Currently available in our community?		Provided by an organization on our Community Team?	
	Yes	No	Yes	No
Adult/geriatric nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bereavement care (apart from hospice)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case management for chronic disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community health workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care (supportive care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home health services (medical care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospice care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain management consultation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parish nursing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pastoral care/chaplaincy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care for family caregivers apart from hospice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups, such as caregiver support groups or grief support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals on Wheels or another meal support service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

2. Which of the following do you believe provide opportunities for improving care for the patients you serve? Rate each opportunity on a scale from 0 to 4, with 4 being the highest.

Opportunities for improving care	Rate level of opportunity to improve care				
	None	Moderate	High		
Advance directives assistance	0	1	2	3	4
Alternatives to hospital admission at end of life	0	1	2	3	4
Chronic disease case management	0	1	2	3	4
Comprehensive care plan for those requiring comfort care	0	1	2	3	4
Home visits as part of care coordination (not part of home health services or home care)	0	1	2	3	4
Pain management consultation	0	1	2	3	4
Providing education to families/caregivers about caring for people with advanced illness	0	1	2	3	4
Providing education to staff about caring for people with advanced illness	0	1	2	3	4
Psychosocial support for patient/family	0	1	2	3	4
Referrals to hospice, home health services, home care, or other placements	0	1	2	3	4
Spiritual care	0	1	2	3	4
Symptom management consultation	0	1	2	3	4
Transitioning the plan of care between hospital, nursing home, home care, etc.	0	1	2	3	4
Other (please specify):	0	1	2	3	4

A Place to Begin

3. In which of these specific health care settings do you want to focus your initial palliative care efforts?

- Yes No Clinic
- Yes No Home Health
- Yes No Hospice
- Yes No Hospital Specific department? _____
- Yes No Nursing Home
- Other (please specify):
-

This section focuses on the background and experience of health care professionals in your community related to palliative care.

4. Do any physicians, nurses, nursing assistants, or other clinicians on your **Community Team** organizations have **certification** in palliative care/hospice?

Yes No

5. Do any physicians, nurses, nursing assistants, or other clinicians on your **Community Team** organizations have **training** in palliative care/hospice?

Yes No

If yes, indicate the number of staff for each certification /training on the next page.

Profession	Palliative care/hospice board certification (physicians & nursing)	EPEC trained (Education in Palliative and End of Life Care) – for physicians	ELNEC trained (End of Life Nursing Education Consortium)	Other palliative care/hospice training or education e.g., PCLC (Palliative Care Leadership Center) or clinical training
Chaplain				
Nurse				
Nursing assistant				
Nurse practitioner				
Pharmacist				
Physician				
Physician’s assistant				
Social Worker				
Other (Please specify):				

6. In general, what is your perception of the knowledge of palliative care among health care professionals in your community? Rate each on a scale from 0 to 4, with 4 being the highest.

Professional	Rate perceived level of knowledge				
	None	Moderate	High		
Administration	0	1	2	3	4
Chaplain	0	1	2	3	4
Medical (MD, PA, NP)	0	1	2	3	4
Nursing	0	1	2	3	4
Pharmacy	0	1	2	3	4
Social work	0	1	2	3	4
Other clinical (PT, OT, SLP, etc.)	0	1	2	3	4

Education in Palliative Care

This section focuses on the training and preparation of health care professionals in your community related to palliative care.

7. Do the organizations on your Community Team provide educational opportunities or resources related to palliative care to professional staff?

Yes No Unsure

If yes, list the staff positions that are provided with these educational opportunities.

8. Do the organizations on your Community Team provide educational opportunities or resources related to palliative care to the community?

Yes No Unsure

If yes, who provides this education?

9. Indicate the clinical education needs of your Community Team related to palliative care by rating each area on a scale from 0 to 4, with 4 being the highest.

Educational need areas	Rate need for Community Team				
	None		Moderate		High
Advanced care planning	0	1	2	3	4
Ethical dilemmas in palliative care	0	1	2	3	4
Grief counseling	0	1	2	3	4
Health insurance literacy (e.g., understanding coverage and costs to help patients and families with decision making)	0	1	2	3	4
Interdisciplinary teamwork (e.g., care coordination)	0	1	2	3	4
Involving patients/families in care decisions	0	1	2	3	4
Pain assessment and management	0	1	2	3	4
Providing emotional support to patients/families	0	1	2	3	4
Strategies to inform patient/family of	0	1	2	3	4

Educational need areas	Rate need for Community Team				
	None	Moderate			High
diagnosis/prognosis					
Symptom management (Other than pain management)	0	1	2	3	4
Understanding cultural beliefs/values	0	1	2	3	4
Understanding family dynamics/ support systems	0	1	2	3	4
Understanding local community resources	0	1	2	3	4
Understanding philosophy of palliative care	0	1	2	3	4
Understanding spiritual needs of patients/families	0	1	2	3	4
Other (please specify):	0	1	2	3	4

Which of the following support systems are in place for health care professionals in your community to help them personally deal with caring for people with advanced illness?

- Yes No Debriefing sessions
- Yes No Discussion groups within disciplines
- Yes No Interdisciplinary discussion groups/forums
- Yes No Staff support groups
- Yes No Time off for staff
- Other (please specify): _____
- Not aware of any support systems

Barriers to Palliative Care

This section examines your perception of potential barriers to palliative care, the degree of impact these barriers may pose in developing a palliative care program, and the factors that drive decisions within your community related to palliative care.

9. Indicate which of the following barriers to providing palliative care may affect your community. Rate each on a scale from 0 to 4, with 4 being the highest.

Potential barrier	Rate ability to affect your community				
	None		Moderate		High
Community awareness of palliative care	0	1	2	3	4
Human resources to provide services	0	1	2	3	4
Lack of clinician knowledge and experience about palliative care	0	1	2	3	4
Coordination of care between providers/ settings	0	1	2	3	4
Medical staff commitment/buy-in to palliative care	0	1	2	3	4
Reimbursement	0	1	2	3	4
Other (please specify):	0	1	2	3	4

Comments:

10. Please list the most important things you want to accomplish with this project.

Thank you for your time and participation.

Action Plan

(Use SMART* criteria):	Process Steps	Responsible Person	Date/Timeline	Measurement

(Use SMART* criteria):	Process Steps	Responsible Person	Date/Timeline	Measurement

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Developing Workflows

What's a workflow?

A workflow is a graphic representation of the steps in a process. Each step has an action and should identify who will perform the action using job titles rather than employee names.

A step may have a document attached and might also include who the step is performed for, typically patients and their families but sometimes internal customers.

A cluster of workflows is a system. It is very difficult to plan or improve quality at the system level, so it is preferable to focus on the workflows

Workflows to design for a new PC service

- Screening
- Admitting
- Response to referral sources
- Daily clinical care
- After hours coverage and triage of emergencies
- Measure documentation and uploads
- QI projects
- Discharges
- Coding and billing
- Education for key audiences

Second stage

- Philanthropic giving or other sustainable strategies
- Public education

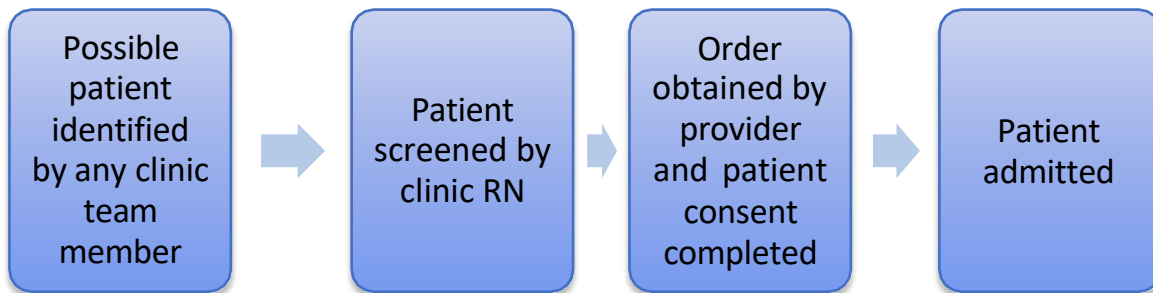
Tips on workflow mapping (aka process flow aka process map aka flow diagram)

- **Decide on the first and last step.** You can segment the process to make it easier to detail. Boundaries make for a smoother start to define the process.
- **Use high level workflows first,** then decide where you need to detail. A high-level workflow has 5-7 steps and no decisions. A detailed workflow can be very useful but is also quite time consuming so detail selectively, where it's needed.
- **You may want to use a matrix or swim lane diagram** (also called cross-functional) to clearly show who is responsible for each step and examine the best practice for hand offs.

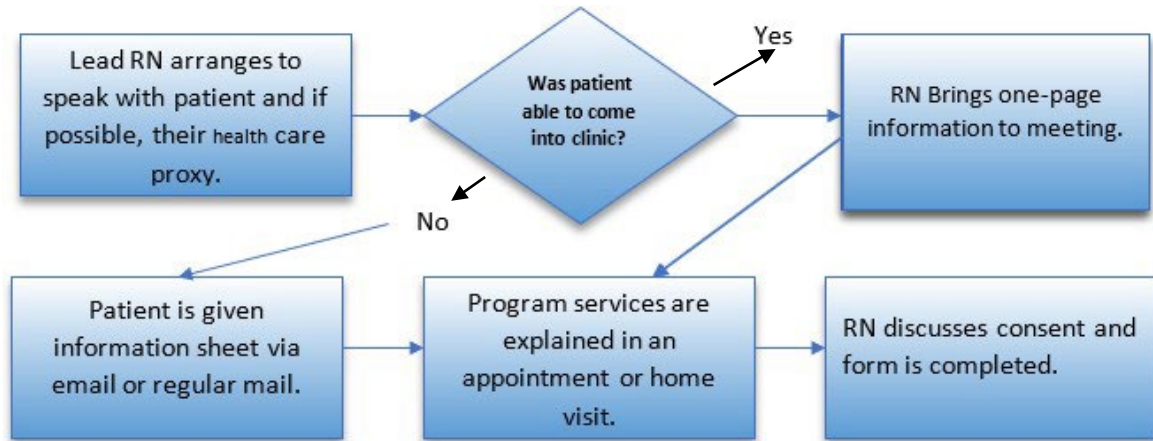
- **Steps are not always sequential**, and you can use a high-level workflow with bullets under the main steps for non-sequential steps. A patient hospital admission is a good example, where some steps may be sequential but many of the tasks can be done in any order.
- **Every handoff is a chance for a drop off.** Think about how you can prevent drops in the process. 80 percent of glitches in a workflow can be prevented if you take the time to consider what could go wrong and include prevention, early detection, and mitigation steps.
- If you have a **special cause that would cause variation** in the workflow, do a separate workflow rather than distorting the workflow for most cases. For example, a team working to increase the percentage of breastfeeding moms who have a good latch with their newborns learned that they needed a main process for term deliveries and a separate process for preemies.

Example workflows *(Purpose to offer examples of types of process flows and should not be considered exemplary workflow content.)*

EXAMPLE: High level workflow

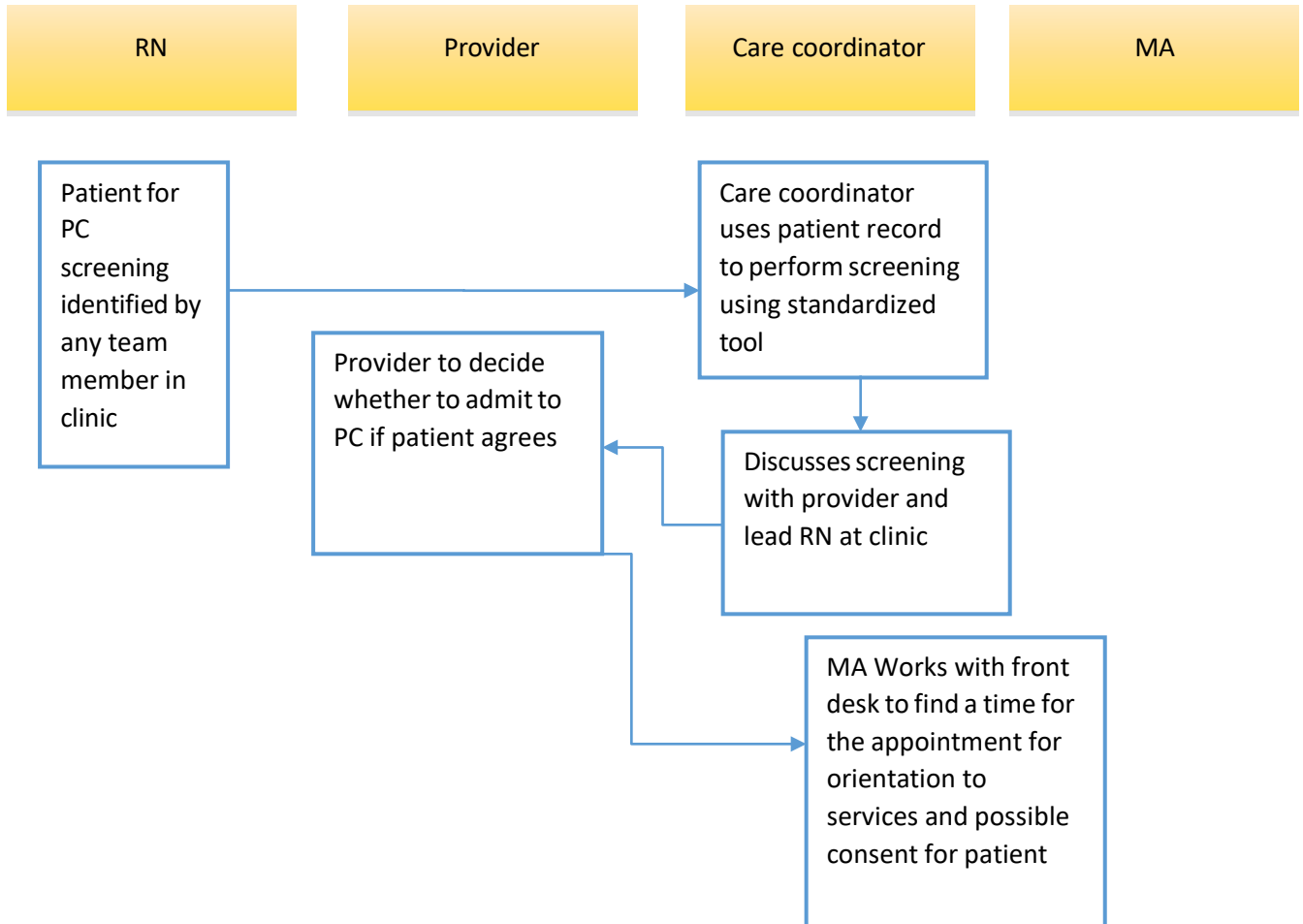


EXAMPLE: Detailed workflow-obtaining patient consent

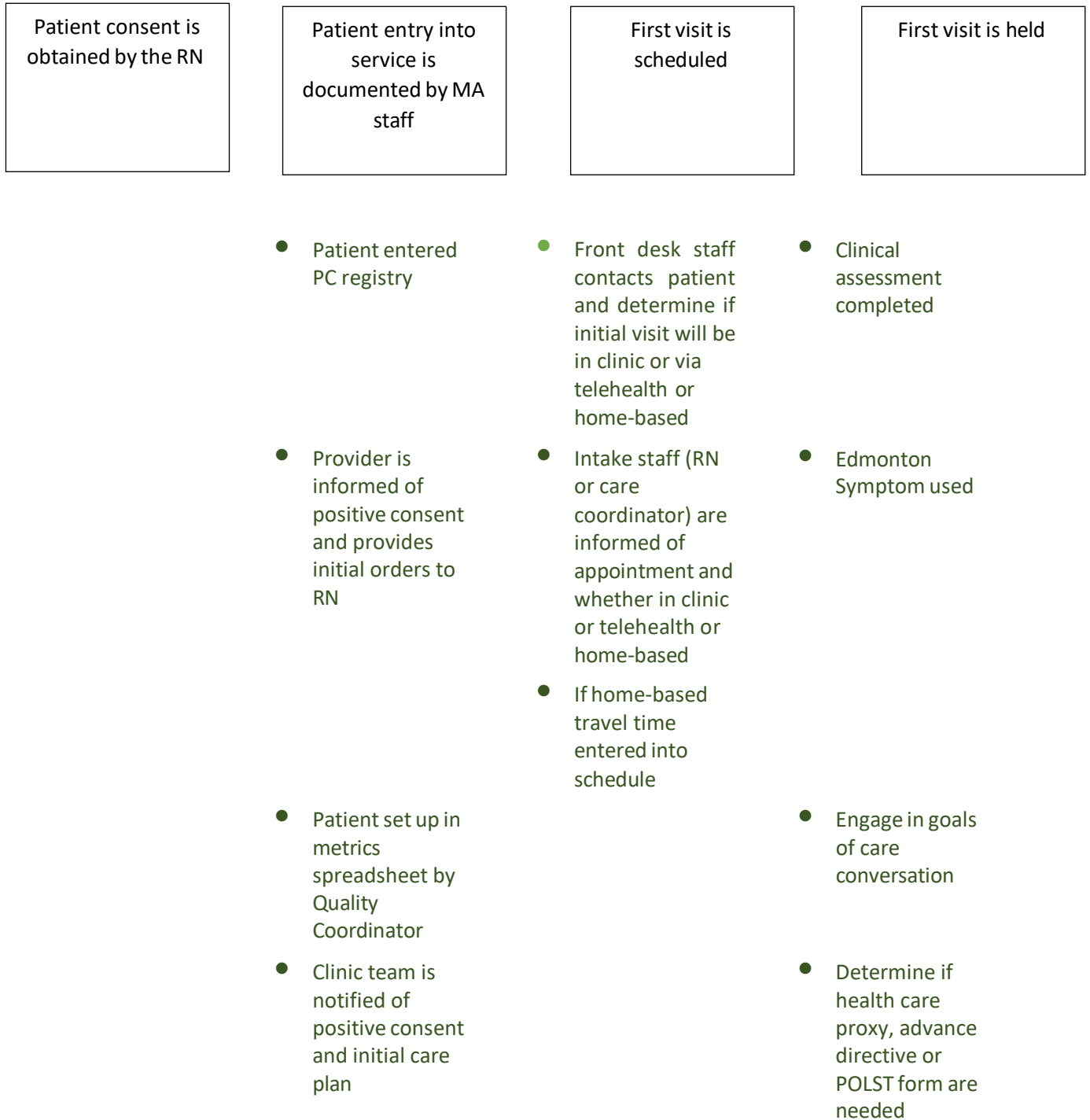


Detail of screening process

EXAMPLE: Swim Lane or responsibility workflow (aka cross-functional)



EXAMPLE: Non-sequential process-patient admission

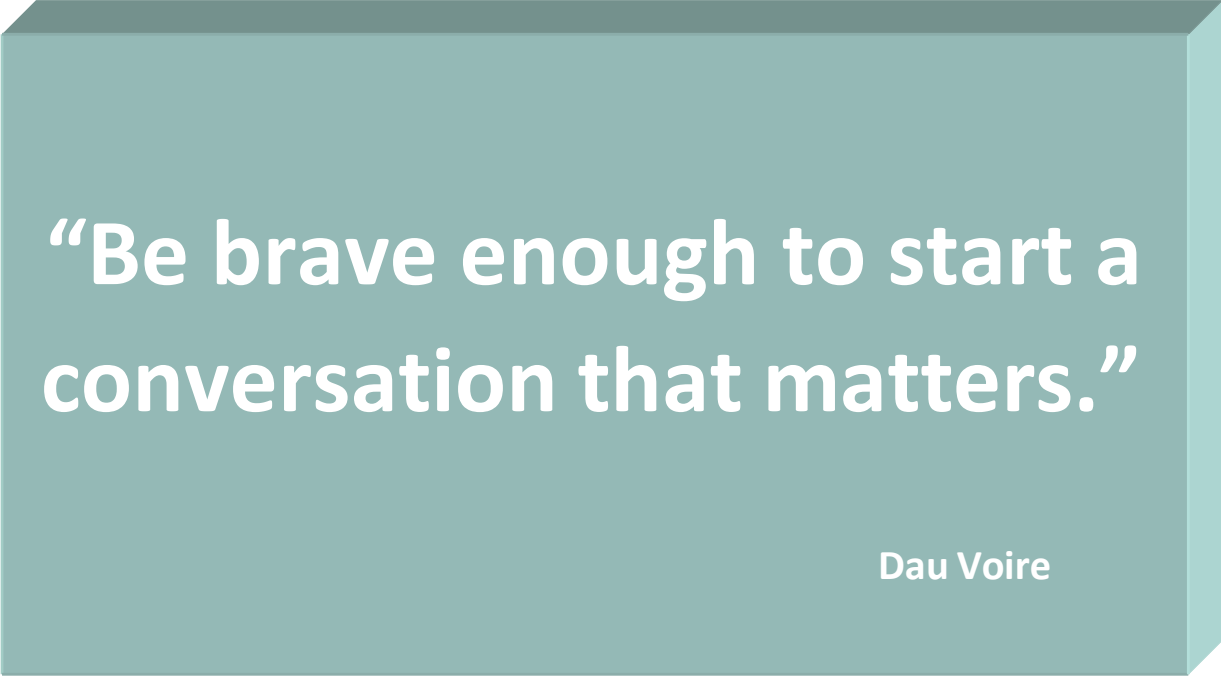


Resources for Workflow AKA Process Mapping

<https://creately.com/blog/diagrams/process-mapping-guide/#types>

<https://www.isixsigma.com/tools-templates/process-mapping/practical-guide-creating-better-looking-process-maps/>

<https://www.apgc.org/resource-library/resource-collection/end-end-process-maps-and-measures>



“Be brave enough to start a conversation that matters.”

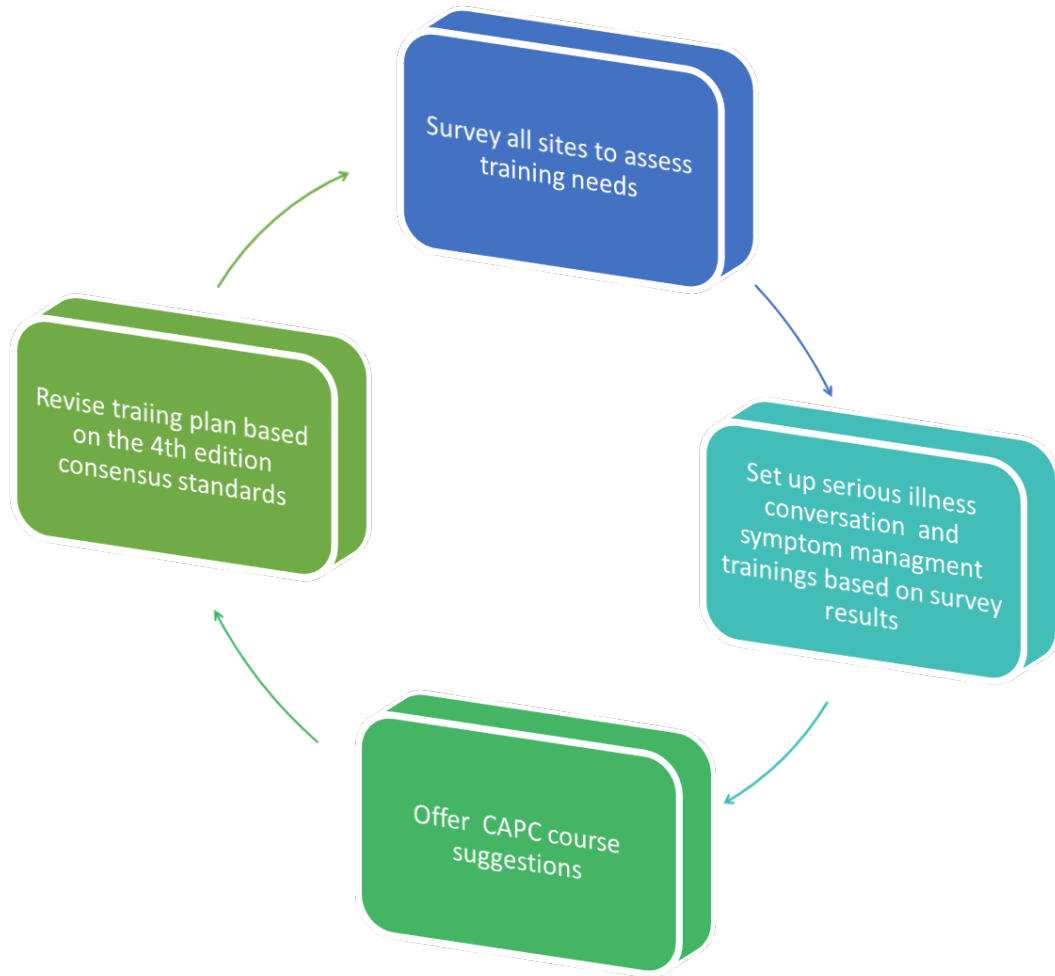
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Education

Training Strategies for the WA Rural Palliative Care Initiative



Training resources

Washington State Hospice and Palliative Care Organization

<https://wshpco.org/>

Webinars, annual conferences

Vital talk has many short videos with skill demonstration and one pagers that summarize skills.

<https://www.vitaltalk.org/resources/>

Palliative Care Institute at Western Washington University

<https://pci.wwu.edu/>

Offers training events

“Our goal is to create a healing community by providing a space where people living with serious illnesses or facing the end of life don’t have to be cured to heal. We build on collaborations among those both inside and outside of the medical industry, reclaiming palliative care as a community responsibility.”

University of Washington

[Graduate Certificate in Palliative Care](#)

[University of WA Cambia Care Center of Excellence](#)

[University of WA Palliative Medicine Fellowship](#)

The Center for the Advancement of Palliative Care

This is a short excerpt from a larger offering of courses.

Some of the suggested courses will require a CAPC membership
(Highly recommended)

You can make training assignments for your team members. Consider your priority audiences for training and assign courses. Make a target date for completion and check back to debrief key lessons learned, this helps the learner be accountable to complete the course. Courses offer CME, Nursing Contact, NASW Social Work credit, NYSED social work, and certified case manager hours.

Suggested general and clinical courses

<https://www.capc.org/pathways/>

Introduction to Palliative Care

<https://www.capc.org/training/learning-pathways/introduction-palliative-care/>

Communication Skills for Conversations about Serious Illness (8 modules)

<https://www.capc.org/training/learning-pathways/communication-skills-conversations-about-serious-illness/>

Pain Management (14 modules)

<https://www.capc.org/training/pain-management/>

Relief of Suffering Across the Disease Trajectory (3 modules)

<https://www.capc.org/training/relief-of-suffering-across-the-disease-trajectory/>

Operational courses available

<https://www.capc.org/operational-courses/>

- Community-Based Program Design
- Introduction to Palliative Care in the Community
- Needs Assessment: Ensuring Successful Community-Based Palliative Care
- Office-Based Palliative Care Program Design
- Program Design for Palliative Care Delivered in the Home
- Building the Business Plan for Community-Based Palliative Care
- Operational – Leadership Support Improving Team Performance
- Consult Etiquette: Communicating with Referring Providers

Concepts of Community-Based Palliative Care Program Design 101 (self-paced learning activity estimated at 12 hours)

<https://www.capc.org/toolkits/concepts-of-community-based-palliative-care-program-design-101/>

Gathering support from leaders

The Case for Community-based Palliative Care

<https://www.capc.org/documents/download/867/>

Ariadne Labs

Ariadne Labs is a joint center for health systems innovation at Brigham and Women’s Hospital and the Harvard T.H. Chan School of Public Health. With a mission to save lives and reduce suffering, Ariadne has a vision that health systems equitably deliver the best possible care for every patient, everywhere, every time. Ariadne Labs was founded in 2012 by Atul Gawande, MD, MPH, and Bill Berry, MD, MPA, MPH, as a first-of-its-kind joint center for health systems innovation. Serious Illness Care is a topic of focus and the lab offers tools and resources and also training and education events.

<https://www.ariadnelabs.org/serious-illness-care/>

California State University Shiley Haynes Institute for Palliative Care

A full-course catalogue and online offerings by clinical discipline, offers an Advanced Practice certificate.

https://csupalliativecare.org/career-development/?gclid=EAIaIQobChMI9eqnirDg-gIVHCmtBh0tgAFKEAAYASAAEgL-ZvD_BwE

Programs leading to academic credentials

[University of Colorado](#)

[California State University Shiley Haynes Institute for Palliative Care](#)

Includes an ARNP Certificate in Palliative Care

[University of Maryland.](#)

Chicago. [The Coleman Palliative Care Training Program.](#)

The American Academy of Family Physicians list of programs

<http://aahpm.org/training/advanced-training>

Other examples of physician fellowship programs

[University of Wisconsin School of Medicine and Public Health](#)

[University of Miami Miller School of Medicine](#)

[University of Nebraska College of Medicine](#)

[American Academy of Hospice and Palliative Care Fellowship Programs](#)

ARNP Advanced Palliative Care Programs

[“20 Best” Nurse Practitioner Programs in Palliative Care](#) (Nursing Process, accessed 12/02/2022)

LIST OF THE 20 MOST POPULAR PALLIATIVE CARE NURSE PRACTITIONER PROGRAMS FOR 2023

(The following Certificates, Fellowships, and Residency Training Palliative Care Programs are ideal for individuals who aspire to become a Palliative Care Nurse Practitioner.)

1. [NYU Rory Meyers College of Nursing](#) - New York, NY

Program Type:

Certificate

2. [University of Pennsylvania School of Nursing](#) - Philadelphia, PA *Program Type:*

Certificate

3. [Duke University School of Nursing](#) - Durham, NC

Program Type:

Certificate

4. [University of South Alabama](#) - Mobile, AL

Program Type:

Advanced Practice

5. [University of Illinois](#) - Chicago, IL

Program Type:

Advanced Practice

6. [University of Michigan](#) - Ann Arbor, MI

Program Type:

Nurse Practitioner Fellowship Program in Hospice and Palliative Care

7. [Harvard Medical School Center for Palliative Care](#) - Boston, MA *Program Type:*

Palliative Care Fellowship

8. [University of Washington](#) - Seattle, WA

Program Type:

Certificate

9. [Medical University of South Carolina](#) - Charleston, SC

Program Type:

Post-MSN to DNP in Palliative Care

10. [Mayo Clinic College of Medicine & Science](#) - Rochester, MN

Program Type:

Fellowship

11. [University of Alabama at Birmingham](#) - Birmingham, AL

Program Type:
Post-MSN Subspecialty

12. [University of Colorado Anschutz Medical Campus](#) - Aurora, CO

Program Type:
Certificate

13. [Central Connecticut State University](#) - New Britain, CT

Program Type:
MSN in Hospice and Palliative Care

14. [University of Pennsylvania School of Nursing](#) - Philadelphia, PA

Program Type:
Certificate

15. [Pennsylvania State University](#) - State College, PA

Program Type:
Certificate

16. [Atrium Health](#) - Charlotte, NC

Program Type:
Palliative Care Advanced Practice Provider (APP) Fellowship

17. [Massachusetts General Hospital](#) - Boston, MA

Program Type:
Palliative Care Nurse Practitioner Fellowship

18. [Medstar Health](#) - Columbia, MD

Program Type:
MedStar Health/Washington Hospital Center Palliative Care Nurse Practitioner Fellowship

19. [Memorial Sloan Kettering Cancer Center](#) - New York, NY

Program Type:
Advanced Practice Provider Fellowship in Hospice and Palliative Care

20. [Providence Hospice & Palliative Medicine Fellowship](#) - Anchorage, AK

Program Type:
Hospice & Palliative Medicine Fellowship

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Metrics

Why We Measure

Each metric selected must satisfy one or more of the following cardinal purposes:

- 1) **Quality Improvement:** The results will drive and inform quality improvement within and across sites.
- 2) **Program Evaluation:** The results will help evaluate the initiative and whether the processes and leadership of the change work has been performed effectively.
- 3) **Knowledge contributions:** The results will contribute to healthcare and public health care knowledge in ways that strengthen the efficacy of services.
- 4) **Business Case:** The results prove the return on investment or otherwise make the business case to fund palliative care services to senior leaders, payers, and policy makers, which results in improved health plan benefits and policy changes that facilitate funding of palliative care services.

Principles for Washington Rural Palliative Care Initiative Measures

- Any selected measure should satisfy one and ideally several of the goals for metrics stated above. “Good or interesting to know” is not a reason.
- The work to collect the measure should be equal to the value from the resulting data.
- Burden of measurements should be continually minimized and to the extent possible embedded in existing systems and documents.

How it works

We ask that all teams who are seeing patients consider participating in our common measures. As you all know, small sample sizes in rural can lead to wonky data or unreliable results. By selecting a small set of measures for all teams to use, the resulting data will create a larger data set.

The Metrics Work Group can orient you to the password protected site we use on our Portal (Palliative Care Data Team) and can help you join that team so you can view and use the site to upload data. Information about those measures follows.

The Department of Health contributes an epidemiologist or data consultant to aggregate and display the data.

Equally important are stories, which enter an audience differently than numbers, moving the heart in ways that can build tangible support and a resolve to contribute to solutions. We offer you a story template and will send regular prompts for stories.

- If possible, we love photos to go with the story. We will need a photo consent, and an information release if you intend to use the patient and family’s real name and include any identifiable health information.

- Otherwise, you will need to change some key details, like age, gender etc. and assign a pseudonym. Ask a colleague from another team in your health system if they know who it is by reading your story. If they do, disguise more details.

The Core WRPCI Measures

For all measures, the denominator is all patients currently receiving PC Services from the organization providing the data.

Demographics

- Date of enrollment in services
- End of data collection
- Name of patient

Clinical measures

- POLST form documented
- Advance Directive documented
- Spiritual discussion/assessment documented
- Goals of Care discussion documented

Data Before Enrollment

- Number of Emergency Department visits before enrollment (up to six months before)
- Number of hospital inpatient stays before enrollment (up to six months before)

Data After Enrollment

- Number of ED visits after enrollment (up to six months after)
- Number of hospital inpatient stays after enrollment (up to six months after)

About the Edmonton Symptom Assessment System (ESAS)

“...the ESAS continues to dominate the symptom assessment field in advanced cancer and palliative care. It is brief, comprehensive, and practical; relevant to palliative care; and entails minimum patient burden, which is particularly important for patients at end of life.”²⁰

The tool assesses the following symptoms:

²⁰ <https://www.albertahealthservices.ca/assets/info/peolc/if-peolc-ed-esasr-admin-manual.pdf> Accessed 10/20/2022

Pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety, and overall well being.

A copy of the tool with user manual can be found at

<https://www.albertahealthservices.ca/assets/info/peolc/if-peolc-ed-esasr-admin-manual.pdf>

Also please see Addendum E, **page 148**

The core measure set we ask all sites to use may be augmented by any other measures your program wants to use. Some options are below, we have excluded measures already included in our core set.

Metrics Quick Reference Chart-Optional Measures

Measure number	Measure domain and topic	Measure statement
2	CLINICAL Pain	Average first, 30-day, and final ESAS-r score for pain
3	CLINICAL Dyspnea	Average first, 30-day, and final ESAS-r score for shortness of breath
4	CLINICAL Pain screening	Percentage of palliative care patients who were screened for pain during the palliative care initial encounter.
5	CLINICAL Dyspnea screening	Percentage palliative care patients who were screened for dyspnea during the palliative care initial encounter.
8	CLINICAL Emotional or psychological needs	Percentage of seriously ill patients receiving palliative care with chart documentation of a discussion regarding emotional or psychological needs
9	PATIENT EXPERIENCE Satisfaction or experience survey	Percentage of patients who rate their satisfaction as X .
11	UTILIZATION Readmissions within 30 days-all cause	The 30-day All-Cause Hospital Readmission measure is a risk-standardized readmission rate for beneficiaries aged 65 or older who were hospitalized at a short-stay acute-care hospital and experienced an unplanned readmission for any cause to an acute care hospital within 30 days of discharge.
13	UTILIZATION Transfers to tertiary hospitals	Percentage of patients with decrease in transfers to hospitals outside the community using a one year look back.
14	UTILIZATION Total cost of care	Percentage of patients with decrease in total cost of care using a one year look back.
15	UTILIZATION Total cost of care Case Study	Total reduction in inpatient, ED and 911 utilization or Total reduction cost of all care For an individual patient using a six month to one year look back.

Measure number	Measure domain and topic	Measure statement
16	TELEHEALTH CONSULTATION- Participant confidence	Number of rural clinical team members who rate their confidence to provide palliative care as improved as a result of participation in telehealth case consultation.
17	OPERATIONAL Patient demographics	List of data elements associated with each patient includes: primary referral source to primary care, primary reason for PC consult, primary patient diagnosis, patient residence at time of initial consult, reason for discharge from PC, average length of stay in PC, patient referral to resources and services.
18	UTILIZATION	Average length of inpatient stay per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care

To learn more about different measure sets for palliative care please visit the portal. <https://waportal.org/partners/washington-rural-palliative-care-initiative/tools/metrics>

Patient Centered Outcome Measures

People often land on surveys to measure patient satisfaction, but the key is to listen closely to the patient and family voice so that it drives continual improvement to care.

The closer you can come to real time, where clinical team members and others can link their service directly to the feedback, the more likely the feedback will drive important changes.

By contrast, large surveys reported quarterly make no authentic connection between the care delivered, and the response, in the perceptions of those who delivered the care. Feedback stays in the abstract and therefore so do the solutions.

Surveys such as HCAHPS often perform poorly in rural settings where the number of patients prohibits meaningful reports. Surveys are in some ways the least dynamic way to gather data about patient and family experience and satisfaction. When someone you have served is unhappy, long turnaround times prevent the kind of responsive service recovery that can prevent damage to relationships.

Also, satisfaction surveys typically measure how well the patients regard what you do, but it does not tell you if you are doing the things that matter most to patients and families.

Patient-Reported Outcome Measures for Palliative Care

The two approved [patient-reported outcomes](#) performance measures (PRO-PMs) were finalized by the American Academy of Hospice and Palliative Care Medicine(AAHPCM). These measures were designed with partial funding by CMS and developed in partnership with the National Coalition for Hospice and Palliative Care and the RAND Corporation. The measures are open to comment until May 2, 2023 by the National Quality Forum as NQF #3665 and NQF #3666. These measures are for ambulatory settings.

NQF #3665 Ambulatory Palliative Care Patients' Experience of Feeling Heard and Understood

NQF #3666 Ambulatory Palliative Care Patients' Experience of Receiving Desired Help for Pain

<https://patientengagementhit.com/news/new-palliative-care-patient-reported-outcomes-measures-launch>

<http://aahpm.org/quality/cms-quality-reporting>

For more information consider this study, *Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting Scale*

<https://www.sciencedirect.com/science/article/pii/S0885392415006077>

Consider alternatives to surveys such as:

- Key informant interviews, in person or via online video or via telephone.
- Focus groups
- Kiosks electronically or within buildings can facilitate point of service responses to only one to three key questions. The questions can change weekly if needed

Here is a three-question interview, this can be adapted for specific topics or used at a general level.

- What pleased you about your care?
- What do you wish had been different?
- What would it take to truly impress you, to exceed your expectations?

You can use these three questions to drill into virtually any topic. For example, maybe you have learned that patients in your PC service are not happy with the pain control overall.

Modified example:

- What pleased you about your pain control?
- What do you wish had been different related to pain control??
- What would it take to truly impress you, to exceed your expectations related to pain control?

Satisfaction Versus Experience: What's the Difference?

These terms are sometimes used interchangeably but when wanting to gather patient and family feedback it can be helpful to distinguish between the two.

Patient experience is framed by expectations about needs. You can disappoint, meet, or exceed expectations about many facets of care such as timeliness, warmth and respect, easy access, and clear communication. You must understand what patients most need and want, their priorities, to evaluate patient experience accurately. Some say patient experience is a qualitative measure and satisfaction is quantitative. Experience can however measure things quantitatively and concretely, for example, in a busy Emergency Department experiencing surge, how long did you wait to see the physician? More than four hours, two to four hours, one to two hours or less than one hour.

Patient satisfaction is how well the patient liked what you did, or more concretely, the things you ask them to rate. You can achieve high satisfaction scores but still not be delivering what is most important to patients. Satisfaction is typically measured using a Likert Scale for example a patient might be asked how they rated the admission process, excellent, good, fair, and poor. Or how satisfied were you; very satisfied, satisfied, neutral, dissatisfied, very dissatisfied.

The Story Collector

Imagine your audience does not understand medical terminology and uses everyday language.

See the next page for two examples.

Briefly describe the patient's health using symptoms rather than diagnosis unless the diagnosis is commonly known by name. Example: Not COPD, call it shortness of breath or air hunger.

Bring attention to what symptoms cause the patient to suffer.

Describe the patient and family situation before Palliative Care services, mentioning quality of life, utilization of 911, ED and inpatient hospital, and fears.

In the goals of care conversation, what did the patient identify as most important?

How did palliative care change the patient and family's life?

Example stories from *another group*:

Here are examples of the palliative care stories we used in the focus groups in 2019 and 2020. People found these so appealing they were almost hard to believe! If we described palliative care this way consistently, I think more of the public would be asking for it.

2019- Laura, 72, enjoyed her retirement until she noticed she was having trouble keeping up with her friends on their walks. She went to her primary care doctor, and then a heart specialist, who found out that she had experienced a silent heart attack. A few weeks later, Laura had another heart attack and ended up in the hospital with heart failure. A nurse, Nicole, came to see Laura. Nicole explained that she was a nurse on the palliative care team, which meant focusing on helping people live well, even with a serious illness. Nicole asked Laura what was most important to her about her care, and then arranged support that Laura didn't know existed. That included giving her medication for nausea, helping her with how to talk about her illness with her grandchildren, and a social worker to provide support to Laura's husband. A few weeks after starting palliative care, Laura is starting to feel normal again and back to enjoying many of the activities she used to do.

2020/Covid- Bobbie, a 75-year-old grandmother, lives with lung and kidney problems. Until COVID-19, she was very good about seeing her doctors. Although she's been careful, four weeks ago she began to feel sick and her test for COVID-19 was positive. That terrified her, and she called her doctor's office. When she told the nurse that she didn't want to go to the hospital, the nurse said, "I'd like to put you in touch with a nurse practitioner who works with us. She's from a palliative care team and is really good at managing things like breathing problems." Bobbie said, "Do you think I really need that?" The nurse said, "There's a good chance you can do okay at home. This nurse practitioner and her team will help us do that." Bobbie didn't realize what a palliative care team could do. They helped her get the right medicine for her breathing and explained everything she wanted to know. Now, four weeks after her test, Bobbie thinks she's through the worst of it. She takes comfort in knowing that whatever happens, her doctor and palliative care team will have her back.

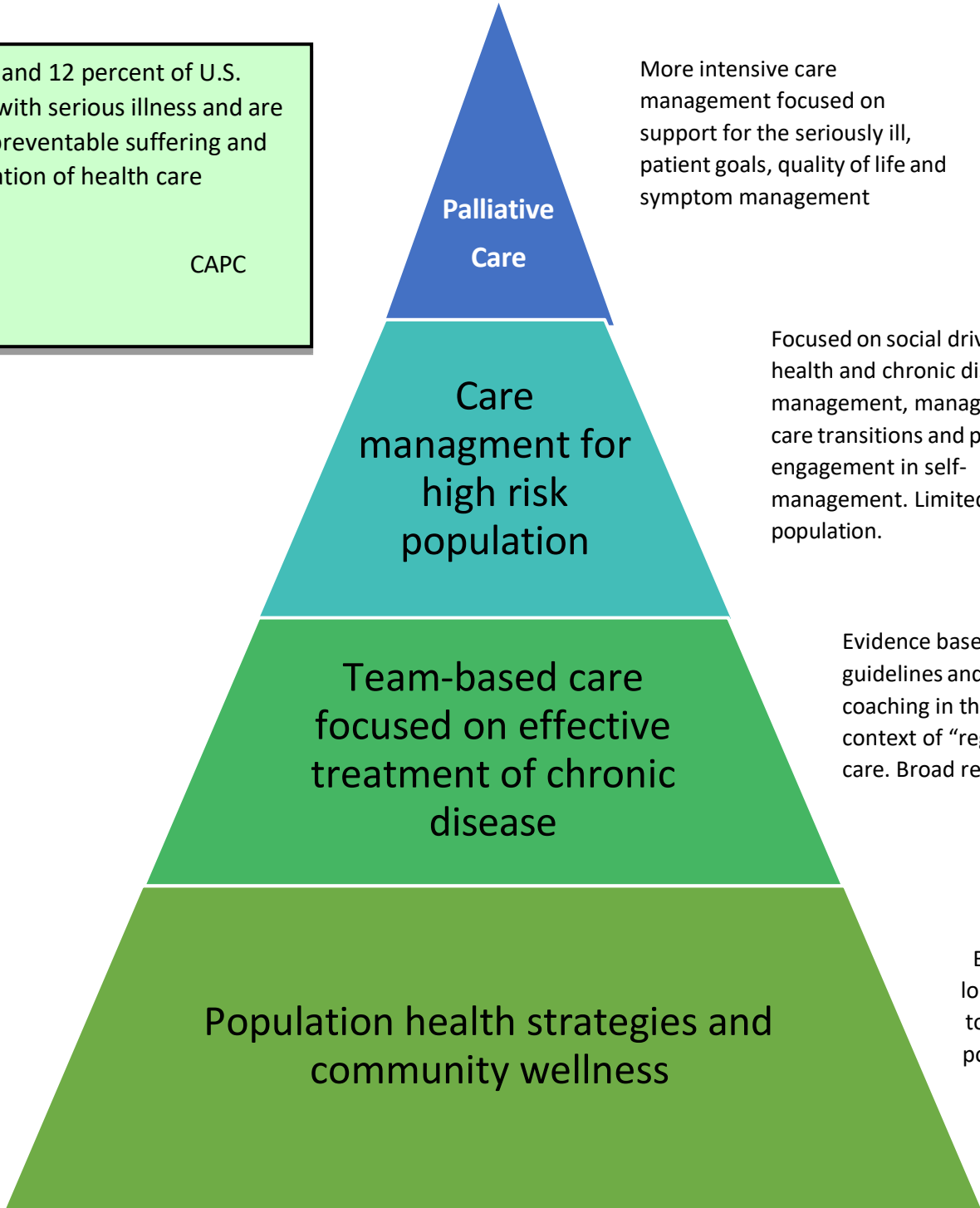
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Patient Selection

Between 5 and 12 percent of U.S. adults live with serious illness and are at risk for preventable suffering and crisis utilization of health care services.

CAPC



Adapted from work by Stratis Health entitled Palliative Care in Alignment with other Population Health Services

Levels of Care

A standardized screening tool: why?

All communities are asked to use the tool on the next page but can dynamically set the scoring threshold to match their current capacity for services. This tool can be useful even if you will refer patients elsewhere for services. It does not require a patient interview and can be completed in just a few minutes provided the clinical data is available in the health record.

- The tool can be branded with your organization's logo. It was adapted from a national tool through a thorough testing process with Cohort 1, and at least one community (Dayton) has elected to integrate it into templates of their electronic health record.
- We ask that you initially pick out which population you will target to screen, and then do a mock screening of a sample of those patients. This will give you some clearer ideas about who your target population is and how you might select who does or does not access services.
- We suggest you screen patients in 2-3 settings across your health system even though we will ask you to pilot in one setting.
- You may be surprised at how many community members might benefit from services. With a small capacity to offer services in the beginning, it is natural to feel the pressure of more needs that you can fill.
- Because active, curative treatments can occur concurrently, palliative care can be preferred rather than hospice and also leads to earlier and a greater number of hospice referrals.

Selection of the palliative care population is perhaps the largest debate in national policy and payment work. This tool provides a data-driven way to sort out who could benefit from palliative care versus those who might need chronic care management or pain clinic services. It helps your care team begin to understand where this service belongs in a continuum of services, and that the needs might be for the population in your community.

You can also find this tool on the portal:

<https://waportal.org/sites/default/files/documents/NewRevised-WRPCI.pdf>

Washington State Rural Palliative Care Initiative

Palliative Care Screening Tool

Organization graphic identity here

Patient Name: _____ Date: _____

(Not a permanent part of the medical record)

Criteria – Please consider the following criteria when determining the palliative care score of this patient			
SECTION 1-BASIC CONDITION <input type="checkbox"/> Cancer (Metastatic/Recurrent) <input type="checkbox"/> Advanced COPD (SOB in conversation or at rest/continuous O ₂) <input type="checkbox"/> Stroke (with decreased function by at least 50%) <input checked="" type="checkbox"/> End stage renal disease (Stage 4)	<input type="checkbox"/> Late-stage dementia (decreased verbalization/ambulation) <input type="checkbox"/> Advanced cardiac disease – i.e., CHF severe CED, CM (LVEF < 25%) <input type="checkbox"/> Other life-limiting condition	SCORING Score 2 Points Each _____	
If the score for Section 1 above is zero, the patient does not meet the basic definition of seriously ill. STOP HERE IF SCORE IS 0 FOR SECTION ONE			
SECTION 2-COMORBIDTY CONDITIONS <input type="checkbox"/> Liver disease <input type="checkbox"/> Moderate renal disease <input checked="" type="checkbox"/> Moderate COPD	<input type="checkbox"/> Moderate congestive heart failure <input type="checkbox"/> Other condition complicating cure <input checked="" type="checkbox"/> Early to mid-stage dementia	Score 1 Point Overall _____	
SECTION 3 FUNCTIONAL STATUS OF PATIENT Using ECOG Performance Stratus (Eastern Cooperative Oncology Group)			Score as specified below
ECOG Grades		Score	ECOG score _____
0	Fully Active, able to carry on all pre-disease activities without restriction.	0	
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.	1	
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.	2	
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours	3	
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.	4	
SECTION 4 OTHER CRITERIA TO INCLUDE IN SCREENING			Score 1 point EACH
Unacceptable level of pain or other uncontrolled symptoms			
Unresolved psychosocial or spiritual issues			
Frequent visits to the Emergency Department and or hospital admissions			
Prolonged hospital stays			
Family/caregiver limitations or lack of consensus related to planning or prognosis			
Lacks advanced directive and or identified healthcare agent			
Other complex situations or significant limitations			
TOTAL SCORE			
SCORING GUIDELINES	Scoring schema inserted by organization		

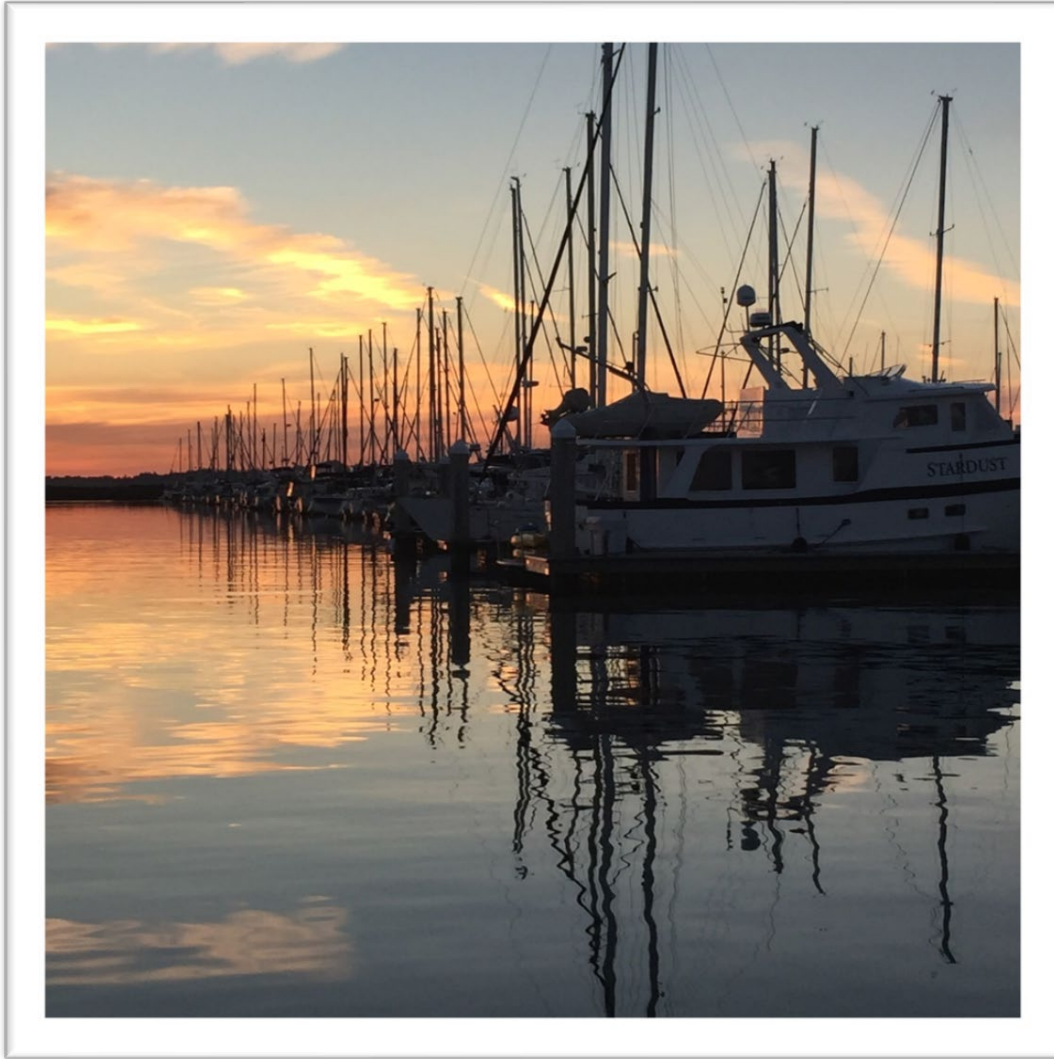


Washington Rural Palliative Care Initiative

Telehealth case consult template

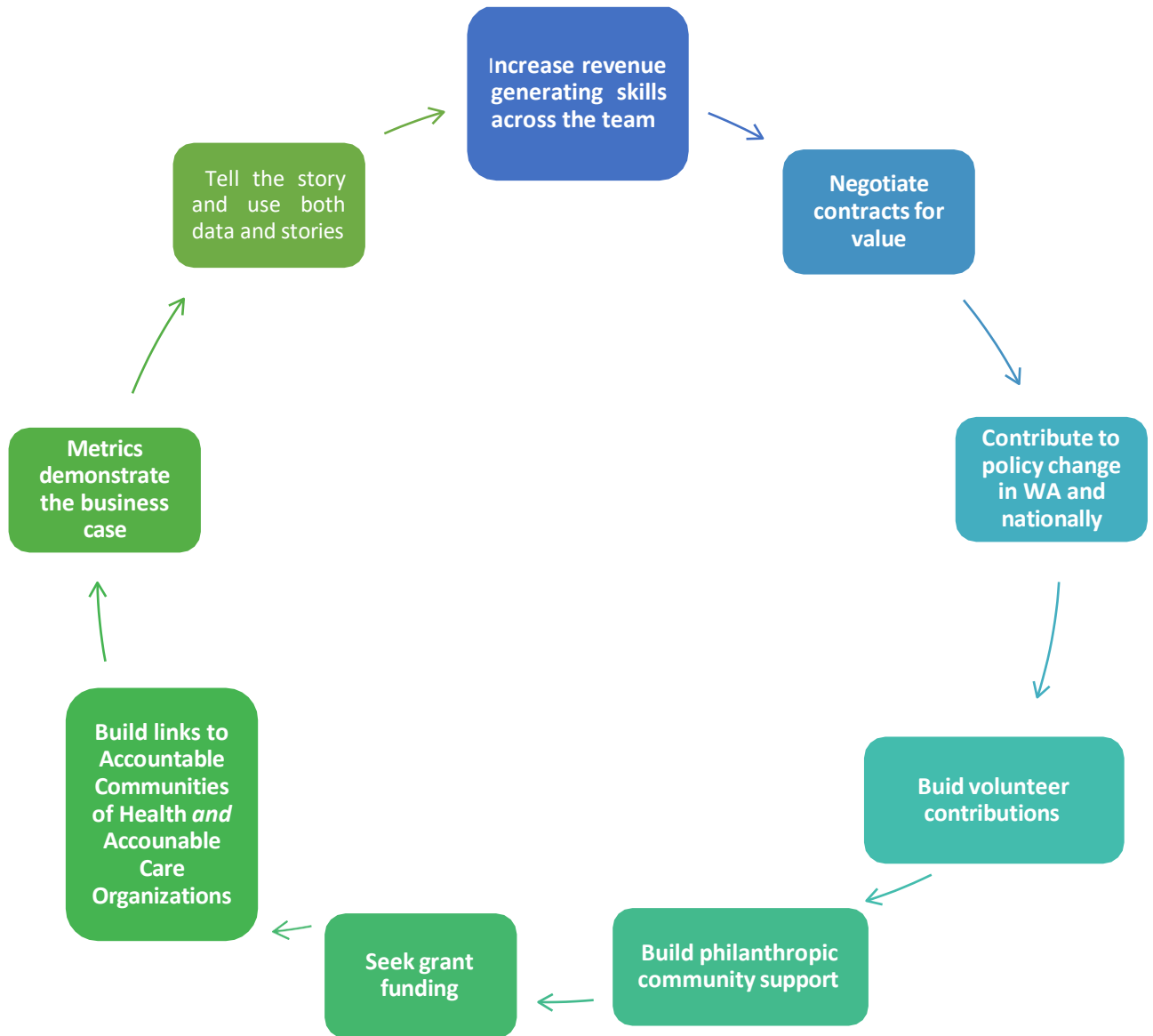
<u>1-2 questions for Panelists: What are you hoping to gain from the consultation? What questions remain or need answered?</u>
<u>Brief summary of presenting health problem(s) [H&P, Diagnosis, etc.]:</u>
ACP/POLST/Code Status:
<u>Functional Status:</u>
<u>Patient/Family Goals of Care; Involvement in care and decision-making; family meeting held:</u>
Decision-Making:
<u>Patient and family understanding of the condition and prognosis:</u>
<u>Are there any cultural aspects to consider?</u>
<u>Strategies used and effectiveness of each in providing relief from symptoms and stress of illness (please include current list of medications):</u>
<u>Efforts to improve quality of life and their effectiveness:</u>
<u>Overall, what is the one thing you're most proud of/pleased by the result?</u>
<u>Overall, what didn't go so well or what challenges persist?</u>
<u>What healthcare disciplines were involved in the case (Circle or highlight all involved):</u> MD consult/ARNP psych/PA PCP Psychologist RN/LPN NA-C MA Respiratory PT/OT/ST MSW/SW Spiritual Care Nutrition Hospice Diabetic Educator Community Volunteer Pharmacy

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Sustainability

Sustainability Model: Tell the Story



Stratis Health, the Quality Improvement Organization for Minnesota, is a national leader in rural palliative care, beginning their work in 2009. Stratis held two roundtable discussions with rural palliative care services in MN, and used that input to develop [Sustainability Strategies for Community-Based Palliative Care: A Blueprint for Supporting Rural Palliative Care Services- Updated 2021](#)

Tell the Story: Why Palliative Care Matters

Until policies catch up, most approaches to sustainable funding will be driven by your ability to briefly tell the story about why palliative care matters. Below we offer some talking points you can use to create something that works for you and matches the language of your audience.

- Palliative care prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual.
- Palliative care improves the quality of life, comfort, and resilience of seriously ill patients as well as their families.
- Palliative care not only improves the quality of life of patients and their families by reducing mental and physical distress and discomfort but may also [help patients live longer](#).
- Patients don't have to choose between treatment for their illness and palliative care; they can have both.
- Palliative care offers honest and sensitive discussions about serious illness, including delivering difficult news, discussing goals of care, and helping patients communicate their wishes. This makes it more likely that people with serious illness will experience care that aligns with their values and preferences.
- Palliative care is available to all patients with serious illness regardless of age, prognosis, disease stage, or treatment choice. It is ideally provided early, only as frequently as the patient's condition indicates, throughout the illness.
- Palliative care reduces unnecessary hospital admissions, emergency department visits, and the use of health services that are unlikely to be helpful.

Seek grant funding

Grants can help you build your program, however. It is difficult to sustain grant funding over time, so it is most helpful to think of it as a bridge. DOH State Office of Rural Health can offer consultation on grant applications and can perform review of applications by request and is always happy to contribute a letter of support.

Federal grants

<https://www.grants.gov/>

Federal Rural Health Grants from the Health Services Resources Administration (HRSA)

<https://www.hrsa.gov/rural-health/grants>

Foundation grant directories

[Grantsmanship Center](#)

[GrantStation](#)

[Foundation Directory](#)

[Instrumentl](#)

[GrantScape](#)

[Grant Forward](#)

[Grant Select](#)

[Grant Watch](#)

Rural Focused Grants-Public and Private

Description of federal grants for rural from the Health Services Resource Administration

[RHlhub](#)

Build Philanthropic Community Support

A community meeting with key leaders in your community can lead to local funding. Your CEO or Foundation Director may be able to approach wealthy matrons or patrons in your community. If you have a hospital foundation, set up a way for grateful patients and families to contribute. One rural palliative care organization in Oregon calls them “Gifts of Gratitude.”

There is a not particularly well-known banking regulation monitored by the Federal Reserve that obligates banks to contribute to community projects. Talk to your local banks.

Develop succinct, great-looking materials to explain the need, how your program will meet the need, and what outcomes you expect based on national studies. CAPC has some great publications and DOH can contribute slides or one pagers to profile the WA Rural Palliative Care Initiative if desired.

Build Volunteer Contributions

Volunteers can give your program an incredible boost, but their contributions come with some important responsibilities. The people who receive palliative care services are especially vulnerable and we suggest looking for retired health care or mental health professionals in your community. The [Department of Health funds a program called Volunteer and Retired Providers](#), and the work is carried out by [Washington Healthcare Access Alliance \(WHAA\)](#). DOH pays for malpractice insurance and, if the volunteer has no paid work, will pay for license renewal. WHAA approves sites and volunteers. These licensed volunteers staff free clinics, charitable health events, camps for children with diabetes and more. Your palliative-care service could become a VRP site and use licensed volunteers.

Community volunteers without a healthcare background will need careful screening, supervision, and support. This is not to be underestimated in terms of the time this may take. If your organization has a volunteer coordinator, this may be a more workable solution. Volunteers who may screen out of direct patient contact, might be able to assist with other tasks that help the program. Your team could identify different jobs or tasks and write up descriptions for the job as well as the qualifications to do that job.

Contribute to Policy Change Activity

Become a member of the WA State Hospice and Palliative Care Organization and learn what you can do to help advocate for palliative care. Or work with a national organization of your choice, please see the **National Resources Page 89** for ideas.

The most common policy efforts are about education of professionals and health plan benefits.

Negotiate Contracts for Value

If your organization belongs to an Accountable Care Organization (ACO) you already have incentives to change how care is delivered. When your organization negotiates contracts with health plans ask your leadership to consider a value-based approach to palliative care that rewards you for saving the health plan costs. Otherwise, savings on the total cost of care will mostly, if not wholly, benefit health plans.

Increase revenue generating skills across the team

At the time of writing, the Washington State Hospice and Palliative Care Organization is working to develop a statewide palliative care benefit. One health plan, Regence BlueShield, offers palliative care coverage and calls it supportive care.

Stratis Health discusses challenges related to billing:

“Rural community-based palliative care teams face several challenges related to financing and reimbursement:

- Only some members of an interdisciplinary palliative care team can bill for direct services and there are limited codes that allow a clinician to bill for oversight of another team member.
- Medicare and most other payers do not offer a distinct benefit for palliative care services.
- Critical access hospitals do not have the same financial incentives as larger hospitals to reduce readmissions or hospital length of stay.”

The portal features our [Medicare billing guide](#), which covers multiple healthcare settings, and the page also features [a four-hour recorded training on documentation and coding for rural palliative care](#). This training had excellent reviews.

Stratis Health used the same educator as our initiative, Tammy Norville, now Executive Director of the National Organization of State Offices of Rural Health and has a video of her session.

[Documentation and Coding for Palliative Care](#). A one-hour, recorded webinar provides practical tips to build your program’s capacity from a national expert, Tammy Norville.

Documentation, coding, and billing practices to support successful revenue cycle management can help support the effective provision of Palliative Care and related services. (Stratis Health), 2020.

Financial reimbursement for palliative care services is generally under the Medicare physician fee schedule: billing fee-for-service (FFS) visits, and billing for care management.

The most used codes are:

- Advance Care Planning

TIP:

Include medical billers and coders in meetings when developing the palliative care program. They can provide essential input to identify ways to finance palliative care services.

- Chronic Care Management and Complex Care Management
- Transition Care Management
- Prolonged Services, which is added to the primary code.

The portal also features a handbook and education recording called [Community-Based Billing Fee-for-Service Strategies for a Financially Sustainable Model](#). The Acevedo Consulting Group, with national expertise in palliative care billing, presented the training for the California Health Care Foundation.

Tell the story

The [story template](#) is designed to help you gather succinct tales that illustrate the value of your palliative care services. The voice of the patient and family, with direct quotes, can be a valuable way to express how your services change lives for the better.

Please remember that stories are powerful, and more likely than numbers to engage the audience at an emotional and lasting way. We offer a template for stories on **page 70** and would ask that you not only keep those for your use, but also send to [Pat Justis](#), WRPCI leader at the Department of Health for use with other data to influence policy makers and other key audiences.

Collect data

When the initiative was part of a three state project with [Stratis Health](#), the grant dollars at Stratis Health funded an [evaluation](#) and integrated the selection of measures. The other two states in the three-year project were North Dakota and Wisconsin.

On **page 65** you will find the list of core measures selected by the WRPCI metrics work group. We encourage each site to measure what they believe is essential to continuous quality improvement for their program. We request that all sites who are seeing patients report on the WRPCI core measure set. When your team is ready, we will provide training on how to collect and upload the measures.

Build links to Accountable Communities of Health and Accountable Care Organizations

The WA State Health Care Authority (HCA) formed the regional [Accountability Communities of Health \(ACH\)](#) as a part of Medicaid healthcare transformation. Each ACH has their own [website](#), in addition to the pages on the HCA site linked above.

“ACHs are independent, regional organizations. They work with their communities on specific health care and social needs-related projects and activities. This work seeks to improve the health of people in Washington State. ACHs play an integral role in Washington’s Medicaid Transformation Project (MTP) efforts. Although MTP is Medicaid-focused, ACHs are working in many ways to improve the health of their communities as a whole.”

<https://www.hca.wa.gov/about-hca/programs-and-initiatives/medicaid-transformation-project-mtp/accountable-communities-health-achs> accessed 12/06/2022

The ACHs are working to diversify their funding in tandem with multiple partners in their regions. The alignment with palliative care may vary by ACH, but for those focusing on transformation of healthcare, chronic illness or care transitions, palliative care may offer strong alignment. Whatever may come of the relationship, it is important that your ACH knows about your palliative care goals, your need for funding, and is educated about how you are measuring the impact of your work. If you need assistance preparing communication products, please [contact Pat Justis](#) the initiative leader from DOH for assistance.

Accountable Communities of Health Map



Accountable Care Organizations (ACOs)

Some rural health system leaders understand that by providing the right care, to the right patients, at the right time with palliative care; they have aligned with the goals of an ACO and can demonstrate how transformed care leads to the opportunity for shared savings.

The American Academy for Family Physicians note the following areas of focus, for the primary care role in ACOs, which are relevant to a palliative care service in any setting. The last item was modified to increase relevance

- Increased access
- Continuity of care
- Coordination of care across the medical neighborhood
- Risk-stratified care management
- Patient and caregiver engagement
- Planned care for serious illness

<https://www.aafp.org/family-physician/practice-and-career/delivery-payment-models/acos.html#types> accessed 12/30/2022



Resources

Telehealth Resources

The Covid-19 pandemic swiftly increased uptake on telemedicine services. WRPCI had been ~~moving to direct palliative care telemedicine~~ before the pandemic and foresees that telemedicine and telehealth will be integral to rural palliative care services moving forward.

Below you will find telehealth and telemedicine resources.

Northwest Regional Telehealth Resource Center (NWTRC)-serves AK, WA, OR, ID , MT , WY, and UT. NWTRC is one of X resource centers funded to assist with all forms of telemedicine, telemonitoring and telehealth. Centers from other regions may hold educational events of interest and can be found on the National Consortium site below.

nrtrc.org

National Consortium of Telehealth Resource Centers

The National Consortium of Telehealth Resource Centers is a collection of 12 regional centers and 2 national centers.

<https://telehealthresourcecenter.org/>

National Technology Center – Telehealth Technology Assessment Resource Center

<https://telehealthresourcecenter.org/centers/national-telehealth-technology-assessment-cent>

Center for Connected Health Policy

Final CY 2023 Physician Fee Schedule Fact Sheet

<https://www.cchpca.org/2022/11/FINAL-2023-MEDICARE-PHYSICIAN-FEE-SCHEDULE.pdf>

CAH Telehealth Guide and Tools

<https://nrtrc.org/resources/resources.shtml#cah>

WA State Telehealth Information and Resources

<https://doh.wa.gov/public-health-healthcare-providers/telehealth>

Telehealth.HHS.gov

<https://telehealth.hhs.gov/>

The subpage below provides access to research studies funded through Health and Human Services

<https://telehealth.hhs.gov/for-researchers/>

Rural Telementoring Training Center

Provides free training tools and technical assistance to support the implementation and evaluation of telemonitoring programs for rural and remote healthcare workers.

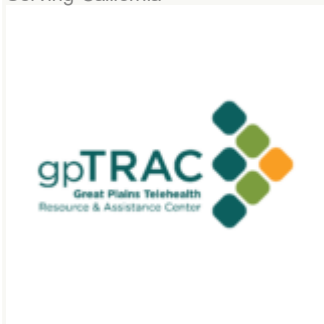
<https://ruraltelementoring.org/>

Other Regional Telehealth Centers



[California Telehealth Resource Center](#)

Serving California



[Great Plains Telehealth Resource & Assistance Center](#)

Serving North Dakota, South Dakota, Minnesota, Iowa, Wisconsin, Nebraska



[Heartland Telehealth Resource Center](#)

Serving Missouri, Oklahoma, Kansas



[Mid-Atlantic Telehealth Resource Center](#)

Serving Delaware, District of Columbia, Kentucky, Maryland, New Jersey, North Carolina, Pennsylvania, Virginia, West Virginia



[Northeast](#)

[Telehealth Resource Center](#)

Serving Connecticut, Maine, Massachusetts, New Hampshire, New York, Rhode Island, Vermont



[Southeastern Telehealth Resource Center](#)

Serving Georgia, South Carolina, Alabama, Florida, Puerto Rico, US Virgin Islands



[Pacific Basin Telehealth Resource Center](#)

Serving Hawaii, Guam, American Samoa, Commonwealth of the Northern Mariana Islands, Freely Associated States of the Republic of Palau, Republic of the Marshall Islands, Federated States of Micronesia



[Southwest Telehealth Resource Center](#)

Serving Arizona, Colorado, New Mexico, Nevada, Utah



[South Central Telehealth Resource Center](#)

Serving Arkansas, Mississippi, Tennessee



[TexLa Telehealth Resource Center](#)

Serving Texas, Louisiana



[Upper Midwest Telehealth Resource Center](#)

Washington State Palliative Care Resources

Washington Rural Palliative Care Initiative

Washington Rural Palliative Care Initiative Collaboration Portal

The portal is a rich source of palliative care resources specifically gathered and curated for rural communities and health organizations. A blog, research articles, clinical tools, videos, books, training resources and more are offered to aid local efforts to integrate palliative care.

<https://waportal.org/partners/home/washington-rural-palliative-care-initiative>

Washington State Hospice and Palliative Care Organization (WSHPCO)

The Washington State Hospice & Palliative Organization (WSHPCO) is a nonprofit 501(c) (3) organization committed to taking a leadership role in improving end-of-life care through education and advocacy efforts. WSHPCO provides information and referral services to the public and supports the professional services at Washington state's hospice and palliative care organizations. WSHPCO holds an annual conference at Lake Chelan in October. They also host regular educational webinars.

<https://wshpco.org/>

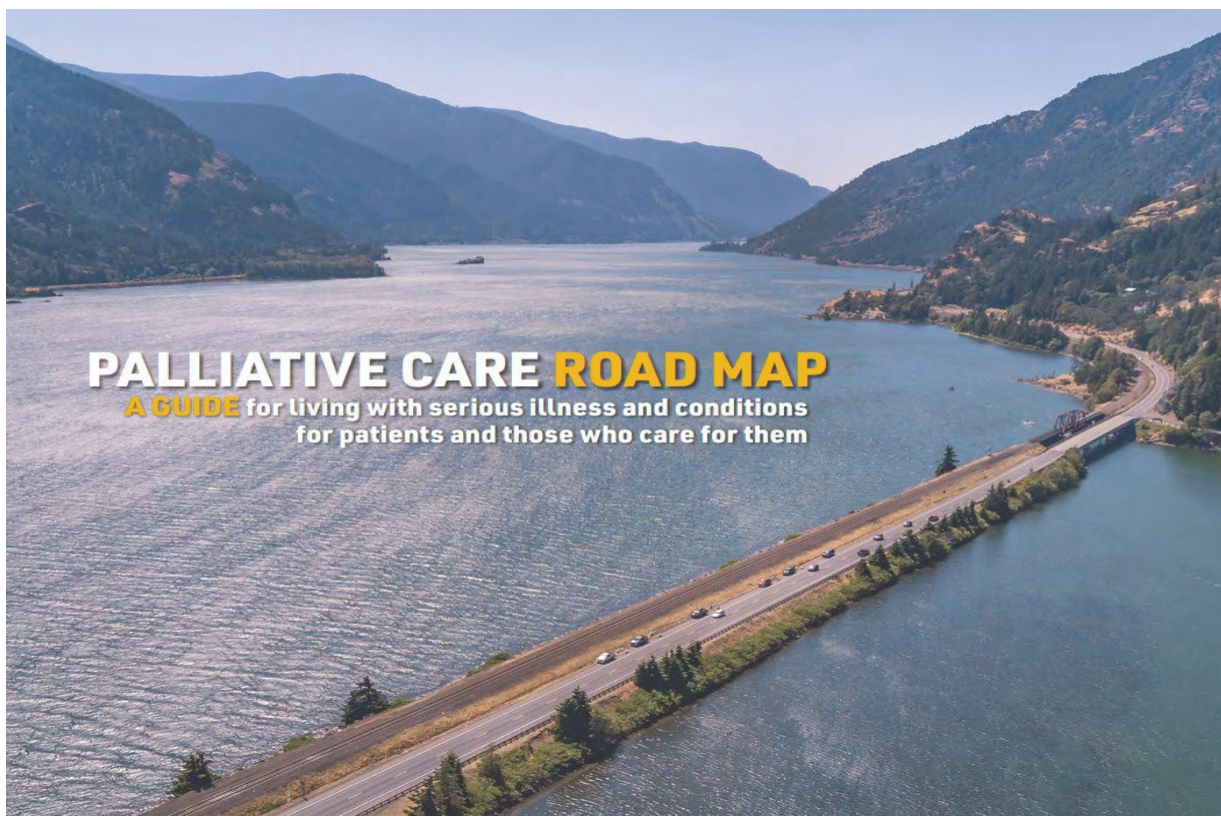
Cambia Palliative Care Center of Excellence -University of Washington

The [Cambia Palliative Care Center of Excellence](#) at the University of Washington was launched in 2012 with the goal of giving every patient with serious illness access to high-quality palliative care focused on relieving symptoms, maximizing quality of life, and ensuring care that concentrates on patients' goals. The Cambia Palliative Care Center of Excellence is supported by the University of Washington and directed by Drs. J. Randall Curtis and Anthony L. Back, both national leaders in palliative care. The Center enhances research, education, and patient-centered care for patients with severe illness and their families. In addition, the Center integrates, coordinates, and augments the clinical palliative care provided throughout UW Medicine and in the region. The Center offers education and training in palliative care across the UW Health Science Schools focusing on interprofessional education and developing programs.

The University of WA [Palliative Care Training Center](#) offers a nine-month graduate certificate program and has recently begun to offer rural focused programs at regional locations in WA and ID.

The Palliative Care Roadmap

The [Palliative Care Road Map](#) is a publication to help patients, and the people they love, sort through the experience of serious illness and conditions. Healthcare teams may find it a useful tool for assisting their patients. Each section offers empathy and information to help make sense of how serious illnesses and conditions unfold over time, with listed resources and key terms defined.



Palliative Care Institute at Western Washington University

Focused on “creating a palliative community where people with serious illnesses don’t have to be cured to heal.” The Palliative Care Institute at Western Washington University is a partnership with Northwest Life Passages Coalition and other community agencies and volunteers to transform palliative care in Whatcom County and support human responses to living and dying. The group builds on collaborations among those both inside and outside of the medical industry, reclaiming palliative care as a community responsibility. The Institute sponsors ongoing education and an annual education event.

<https://cedar.wvu.edu/pci/>

Northwest Life Passages Coalition

In 2014, Whatcom Alliance for Health Advancement (WAHA) convened a task force composed of experts and community leaders who were asked what it would take to transform Whatcom County into a center of end-of-life excellence. Focusing on advance care planning force drafted a [Blueprint](#) to kick-start the vision; moving toward a community-wide system of services designed to be the best in America. In the ensuing years, the Northwest Life Passages Coalition was formed and has been working to begin to achieve the recommendations within the Blueprint.

Work includes an Advance Directive campaign, developing a community-based outpatient palliative care service (Northwest Life Passages at Home), establishing basic palliative care competencies for clinicians in all disciplines, specialties, and practice settings, working collaboratively with the Palliative Care Institute at WWU and others to develop a comprehensive approach community education and activation, and developing a coordinated approach to shorter term philanthropic funding of the recommendations while simultaneously exploring opportunities for piloting innovative care payments models.

<http://whatcomalliance.org/northwest-life-passages/>

Home Care Association of Washington (HCAW)

HCAW represents Home Health, Home Care, and Hospice providers. Members also include affiliated healthcare professionals, providers, consultants, and vendors. HCAW actively promotes partnership development within their membership and with external providers. HCAW provides advocacy, education, and support to members to work together to achieve the triple aim of healthcare: improved quality, reduced cost, and improved health.

<https://www.hcaw.org/>

Vital Talk

Nationally known, Vital Talk is a Seattle based training group that offers evidence-based training “to make communication skills for serious illness learnable.” National Institute of Health funded research has proven that clinicians can learn the core communication skills used in palliative care. This 501(c) (3) was founded to disseminate the research into the “real world.” They have apps available to offer communication tips and cues. There are free tools including videos available on the site. Vital Talk offers train-the-trainer courses, direct clinician training, E-learning options, and mentoring solutions. The Cambia Center for Palliative Care Excellence integrates aspects of Vital Talk in their curriculum.

<http://vitaltalk.org>

Honoring Choices Pacific Northwest

A joint Initiative of WA State Hospital Association and Washington State Medical Association, Honoring Choices Pacific Northwest focused on conversations about care when people are at the end of their life or otherwise unable to speak for themselves about the care they want. This comprehensive initiative used a variety of approaches, such as an advance care planning program, community engagement, physician education, advocacy, and a central repository.

Honoring Choices Pacific Northwest helps the public make informed choices about end-of-life care and help health care organizations and community groups discuss, record, and honor people's end-of-life choices. Recently a partnership with Ariadne Labs focused on Serious Illness Training using the *Serious Illness Conversation Guide* developed by Ariadne Labs. At the time of this writing the future of Honoring Choices Northwest is uncertain, but they maintain an excellent website with resources.

<https://www.honoringchoicespnw.org>

National Resources

Stratis Health

The Palliative Care web page on the Stratis Health web site includes a comprehensive list of information and resources pertaining to palliative care in general and rural palliative care specifically. It includes links to all the resources listed here.

<http://www.stratishealth.org/palcare>

Palliative Care Leadership Centers

Fairview Health Services' Palliative Care Program is designated as one of seven national Palliative Care Leadership Centers (PCLCs) by the Center to Advance Palliative Care (CAPC). These programs host site visits, including training and technical assistance for hospitals and other institutions seeking to start or strengthen their own palliative care programs.

<http://www.fairview.org/Services/PalliativeCarein/dex.htm>

The Center to Advance Palliative Care (CAPC)

This site provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other community-based health care settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious, complex illness.

<http://www.capc.org/>

Ariande Labs

Ariadne Labs is a joint center for health systems innovation at Brigham and Women’s Hospital and the Harvard T. H. Chan School of Public Health. The Labs are focused on scalable solutions and tools and have a number of topic areas including Serious Illness. Dr. Atwul Gande has been a leader in this work at Ariande Labs.

The Serious Illness Conversation Guide developed by Ariadne Labs has been included in [Appendix X](#)

<https://www.ariadnelabs.org/serious-illness-care/serious-illness-care-program/>

End of Life/Palliative Education Resource Center

EPERC shares educational resource material among the community of health professional educators involved in palliative care education. Its series of fact sheets provide concise, practical, peer-reviewed, and evidence-based summaries on key topics important to clinicians and trainees caring for patients facing life-limiting illnesses. Fast Facts are designed to be easily accessible and clinically relevant monographs on palliative care topics. They are designed to be quick teaching tools for bedside rounds, as well as self-study material for health care professional trainees and clinicians who work with patients with life-limiting illnesses.

<http://www.mypcnow.org/>

The National Quality Forum (NFQ) established a set of 38 best practices for improving palliative care programs outlined in “A National Framework and Preferred Practices for Palliative and Hospice Care Quality”. Health care organizations that provide palliative care should offer the following services:

- Comprehensive, 24-hour availability of palliative care through an interdisciplinary team of trained and certified palliative care professionals.
- Timely communication of patients' goals and care plans in transfers between health care settings.
- Assessments of patients' pain, anxiety, and other symptoms that respect their cultural and individual preferences.
- Social and spiritual care plans for patients.
- Continuing professional education and support for caregivers on topics such as symptom management and communication.

http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

National Consensus Project for Quality Palliative Care

Clinical Practice Guidelines for Quality Palliative Care, 3rd edition, 2013.

The mission of the National Consensus Project for Quality Palliative Care is to create clinical practice guidelines that improve the quality of palliative care in the United States. Specifically,

the clinical practice guidelines promote quality palliative care, foster consistent and high standards in palliative care, and encourage continuity of care across settings. Since there is shared responsibility for palliative care across health care settings, the emphasis is on collaborative partnerships within and between hospitals, community centers, hospices, and home health agencies to ensure quality, continuity, and access to palliative care.

There are eight domains of care:

Domain 1: Structure and Processes of Care	Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects	Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious, and Existential Aspects of Care	Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient at the End of Life	Domain 8: Ethical and Legal Aspects of Care

The domains are described in detail, and the elements of best practice are included. *The Clinical Practice Guidelines* serve as a manual or blueprint to create new programs and guide developing programs.

http://www.nationalconsensusproject.org/guidelines_download2.aspx

National Palliative Care Registry™ Center to Advance Palliative Care Profession-Specific Resources Nurses

End-of-Life Nursing Education Consortium (ELNEC)

ELNEC, an American Nurses Association project, is a national education initiative to improve end-of-life care in the United States.

<https://www.aacnnursing.org/ELNEC>

Hospice and Palliative Nurses Association

This organization is for individual members of the nursing team working in the specialty of hospice and palliative care across life. The site lists curriculum and other resources specific to advanced nurses, generalist nurses, licensed practical/vocational nurses, and nursing assistants.

[Home \(advancingexpertcare.org\)](http://advancingexpertcare.org)

Pharmacists

Universities offer on-line and on campus certificate programs in palliative and hospice care for pharmacists.

CAPC offers members a "learning pathway" designed for pharmacists.

<https://www.capc.org/training/learning-pathways/pharmacy/>

The University of Health Sciences and Pharmacy in St. Louis offers a 20-hour CE on line certificate program for pharmacists in Hospice and Palliative Care.

<https://uhsp-ce.learningexpressce.com/index.cfm?fa=view&eventID=15680>

The Society of Pain and Palliative Care Pharmacists offers education events and an annual conference.

https://www.palliativepharmacist.org/site_home.cfm

The Coleman Palliative Medicine Training Program offers courses and programs for pharmacists.

<https://colemanpalliative.org/profession/pharmacist>

Education in Palliative and End-of-Life Care (EPEC)

EPEC is an online program designed to train physicians on the essential clinical competencies required to provide quality end-of-life care. A handbook and video version of the training are both available, as well as slide sets on many palliative care topics. Continuing Medical Education (CME) available. <http://www.epec.net/>

Physicians

End-of-Life Curriculum

This 16-hour web-based curriculum incorporates basic material designed for use by physicians in any area of expertise. Developed by the Stanford Faculty Development Center, this eight-module curriculum is implemented as a PowerPoint slide presentation, with slides and teachers' notes on both the content and teaching process. The modules are:

https://med.stanford.edu/sfdc/additional_programs/eol_care.html

1. Overview: Death and Dying in the USA
2. Pain Management
3. Communicating with Patients and Families
4. Making Difficult Decisions
5. Non-Pain Symptom Management
6. Venues and Systems of Care
7. Psychiatric Issues and Spirituality
8. Instituting Change

American Academy of Hospice and Palliative Medicine

This is the professional organization for physicians specializing in hospice and palliative medicine. Membership also is open to other health care providers who are committed to improving the quality of life of patients and families facing life-threatening or serious conditions.

<http://www.aahpm.org/>

Patients and Their Families

Get Palliative Care is an online resource that provides clear, comprehensive palliative care information for people coping with serious, complex illness. Key components of the site include a Palliative Care Directory of Hospitals, a definition of palliative care, and a detailed description of what palliative care is and how it is different from hospice. It also provides an interactive questionnaire to assist people in determining whether palliative care is appropriate for them or their loved ones. Provided by the Center to Advance Palliative Care.

GetPalliativeCare.org

PalliativeDoctors.org

This consumer web site explains the specialty of hospice and palliative medicine and its benefits to patients and families. Developed by American Academy of Hospice and Palliative Medicine, the web site:

- Highlights palliative medicine and its broader role in helping patients with all types of serious illness
- Provides information on how to find a hospice and palliative medicine specialist
- Includes links to various hospice and palliative care resources and related sites

www.palliativedoctors.org

Chaplains:

The Spiritual Care Center at the Healthcare Chaplaincy Network offers chaplains a Palliative Care Certificate Course

<https://www.healthcarechaplaincy.org/>

Social workers:

The Social Work Hospice & Palliative Care Network offers education including the Core Curriculum for Hospice & Palliative Care Social Work

General Rural Resources

Federal Office of Rural Health
Policy

www.hrsa.gov/ruralhealth/

The Rural Health Research
Gateway

[www.ruralhealthresearch.](http://www.ruralhealthresearch.gov)

Rural Health Information Hub

www.ruralhealthinfo.org/

National Rural Resource Center

<https://www.ruralcenter.org/>

Am I rural? Tool

<https://www.ruralhealthinfo.org/am-i-rural>

3RNet-recruiting for rural and
urban underserved workforce

<https://www.3rnet.org/>

National Association of Rural
Health Clinics

<https://www.narhc.org/narhc/default.asp>



Addendums

- A. Ariadne Lab Serious Illness Conversation Guide
- B. Communication talking points
- C. Evidence
- D. Video with discussion guides
- E. One pager for the community
- F. Edmonton Symptom Assessment System instructions and instrument

Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2. Assess understanding and preferences

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6. Document your conversation

7. Communicate with key clinicians



Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

“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?**”

ASSESS

“What is **your understanding** now of where you are with your illness?”

“How much **information** about what is likely to be ahead with your illness would you like from me?”

SHARE

“I want to share with you **my understanding** of where things are with your illness...”

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.”

EXPLORE

“What are your most important **goals** if your health situation worsens?”

“What are your biggest **fears and worries** about the future with your health?”

“What gives you **strength** as you think about the future with your illness?”

“What **abilities** are so critical to your life that you can’t imagine living without them?”

“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”

“How much does your **family** know about your priorities and wishes?”

CLOSE

“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.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”



Serious Illness Conversation Guide

CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

“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?**”

2. Assess understanding and preferences

“What is your **understanding** now of where you are with your illness?”

“How much **information** about what is likely to be ahead with your illness would you like from me?”

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

“I want to share with you **my understanding** of where things are with your illness...”

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.”

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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.”

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

“What are your most important **goals** if your health situation worsens?”

“What are your biggest **fears and worries** about the future with your health?”

“What gives you **strength** as you think about the future with your illness?”

“What **abilities** are so critical to your life that you can’t imagine living without them?”

“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”

“How much does your **family** know about your priorities and wishes?”

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

“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.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”

6. Document your conversation

7. Communicate with key clinicians



Serious Illness Conversation Guide

CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

1. *Set up the conversation*

- Introduce purpose
- Prepare for future decisions
- Ask permission

“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?**”

2. *Assess understanding and preferences*

“What is your **understanding** now of where you are with your illness?”

“How much **information** about what is likely to be ahead with your illness would you like from me?”

3. *Share prognosis*

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

“I want to share with you **my understanding** of where things are with your illness...”

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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.”

4. *Explore key topics*

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

“What are your most important **goals** if your health situation worsens?”

“What are your biggest **fears and worries** about the future with your health?”

“What gives you **strength** as you think about the future with your illness?”

“What **abilities** are so critical to your life that you can’t imagine living without them?”

“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”

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5. *Close the conversation*

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

“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.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”

6. *Document your conversation*

7. *Communicate with key clinicians*



Addendum B

Talking Points

Washington Rural Palliative Care Initiative

Definitions

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.²¹

Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care

Hospice care is a well-known and comprehensive delivery model of palliative care, but it is limited to terminally ill patients near the end of life. Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Adapted from <http://www.nhpco.org/about/hospice-care> and <https://www.capc.org/>

²¹ Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Ca

Family: means not only blood relatives and spouses or domestic partners, but any person who the patient considers important to their support and healing.

Healing: May be or not be related to physical condition and includes emotional, social, and spiritual wholeness. Healing and dying can co-exist.

What is the problem and why does it matter?

- “Find it and fix it” is one way used to describe healthcare focused on acute illness and injury. Chronic conditions call for a different approach, and particularly those serious illnesses that have a large effect on quality of life. Patients with chronic serious illnesses must find a way to control symptoms and live the best life they can with their conditions.
- While serious illness can hit at any age, older adults are at highest risk. About 80 percent of older adults have at least one chronic disease, and 77 percent have at least two.²²
- The number of Americans ages 65 and older is **projected to more than double by 2060**.
- Chronic diseases account for 75 percent of the money our nation spends on health care.²³
- Thirty-five percent of rural home health Medicare beneficiaries have seven or more chronic conditions.
- The lack of palliative care understanding, and approach can lead to unwanted and unnecessary transfers to tertiary centers for active treatment of serious chronic and life limiting conditions.
- This exposes people to a risk of hospital acquired infections.
- Patients and families may face unnecessary and expensive harsh medical interventions that diminish rather than enhance quality of life, particularly if transferred to a tertiary medical center.
- Patients and families commonly do not understand there are other options for both care and symptom control without active interventions or concurrent with active treatment. When given fully informed consent, patients often chose less invasive forms of care.²⁴

²² Dartmouth Atlas, <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1> accessed 3/6/201

²³ ibid

²⁴ Dartmouth Atlas, <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1> accessed 3/6/201

- Home health and hospice level of service and coverage varies by community and may serve a different group of patients (with some overlap) than could benefit from palliative care further upstream integrated into Rural Health Clinic (RHC) primary care and Critical Access Hospital (CAH) and community- based care. Palliative care in long term care settings can prevent unwanted hospital transfers for symptom control.
- Many clinical teams do not understand palliative care models outside more imminent death and hospice. Rural health care teams may struggle to understand or identify options that resonate with their ethical sense of a humane response to patients and loved ones other than end stage hospice care. They want to do something for these patients and are at risk to grasp at the interventions they know, the “find it and fix it” model.
- "As chronic disease progresses, the amount of care delivered, and the costs associated with this care increase dramatically. Patients with chronic illness in their last two years of life account for about 32% of total Medicare spending, with much of it going toward physician and hospital fees (Medicare Part A and Part B) associated with repeated hospitalizations". The Dartmouth Atlas of Healthcare.
<http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1>
- Across the country recognition of the value of palliative care has steadily increased. In 2000, only 25 percent of hospitals with 50 beds or more had palliative care programs and currently more than two thirds have programs. The population living with serious chronic illnesses is growing and hospitals with less than 50 beds, as well as all parts of rural health systems, deserve support to develop this important care.

Why is it a top priority for rural health?

- Rural counties have a higher percentage of older adults, these health systems will face an even greater influx of patients with needs.
 - Data from 2017 shows Washington’s rural communities include 20.3 percent of the population aged 65 and older compared to 14 .6 percent in urban areas.
-

- By 2040, it is estimated that 25 percent or more of the population will be age 65 and older in 22 of the 30 rural counties in Washington state.
- Rural Medicare beneficiaries have more prevalence of diabetes, COPD, cancer, heart failure, stroke, complete or partial paralysis, and Alzheimer’s Dementia.

“Many rural counties are becoming naturally occurring retirement communities (NORCs), or geographically defined communities with a large proportion of older persons.³ Unlike planned housing communities for the elderly such as retirement communities and assisted living, NORCs are not designed specifically for older residents. Rather, they have evolved over time due to “aging-in-place” and migration patterns in which older people have moved in and younger residents have moved out.⁴”

Marianne Baernholdt, PhD, MPH, RN,^{1,2} Guofen Yan, PhD,² Ivora Hinton, PhD,¹ Karen Rose, PhD, RN,¹ and Meghan Mattos, MSN, CNL, RN¹
Quality of Life in Rural and Urban Adults 65 Years and Older: Findings From the National Health and Nutrition Examination Survey, The Journal of Rural Health, VL 28, IS 4, Blackwell Publishing Inc., SN - 1748-0361UR - <http://dx.doi.org/10.1111/j.1748-0361.2011.00403.x>

Accessed 3/2/2019

- For rural residents, transfer to an urban tertiary center can present enormous challenges to family and other loved ones when it is most needed.
- Studies show that people facing serious illness prefer to be in their own environment.²⁵
- Because of workforce recruitment challenges, low patient volumes and lean, multi-role staffing; rural health systems in nearly all communities but the largest, will find it impossible to support a stand-alone palliative care service. Integrated models using existing medical staff and clinical teams will be most feasible.
- Because palliative care measures are not well known or visible, data does not yet impel system improvements and prioritization of palliative care. Small rural data sets need relevant strategies to avoid volatile and less reliable results.
- The State Office of Rural Health (SORH) is using this initiative as a vehicle to also assess and facilitate increased use of telehealth and telemedicine, prepare health systems for value-based population health strategies, and help communities think more broadly about community multi-sector response to key population health issues, including the integration of non-medical strategies.

²⁵ https://www.capc.org/topics/palliative-care-community/?gclid=EAlalQobChMIpKn7j6LI2QIVBCIpCh2g2AhyEAAYyAAEgJEK_D_BwE accessed 3/11/2018

“You shouldn’t be days or weeks from death to have your symptoms managed and pain taken care of.” R. Sean Morrison, director of the National Palliative Care Research Center
<https://khn.org/news/palliative-care-for-seriously-ill/>
accessed 3/20/2018

The value of palliative care for serious illness

- Scibetta et al. (2016) found that among cancer patients who died, early referral to specialty palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer.
- The average per-patient per-admission net cost saved by hospital palliative care consultation has been estimated as \$2,659 (Morrison et al., 2008).

Aetna Medicare Advantage Compassionate Care Program

- 81% decrease in acute care days
- 86% decrease in ICU days
- High member satisfaction
- 82% hospice election rate
- \$12,600 in savings per person
- No patient complaints in 10 years

ProHealth Accountable Care Organization Supportive Care Program

- 37% decrease in hospital admission rate
- 20% decrease in ED visit rate
- High patient satisfaction
- 34% increase in hospice enrollment, with a 240% increase in hospice length of stay
- \$12,000 in savings per person

<https://www.capc.org/payers-policymakers/value-proposition>

- Home-based palliative care within an Accountable Care Organization (ACO) was associated with significant cost savings (Lustbader et al., 2016).
 - The cost per patient during the final three months of life was \$12,000 lower with home-based palliative care than with usual care (\$20,420 vs. \$32,420; p = 0.0002); largely driven by a 35% reduction in Medicare Part A (\$16,892 vs. \$26,171; p = 0.0037).

- Home-based palliative care also resulted in a 37% reduction in Medicare Part B in the final three months of life compared to usual care (\$3,114 vs. \$4,913. $p = 0.0008$).
- Home-based palliative care resulted in a 35% increased hospice enrollment rate ($p = 0.0005$) and a 240% increased median hospice length of stay compared to usual care (34 days vs. 10 days; $p < 0.0001$).
- Rabow et al. (2013)'s review of the literature found that evidence is sufficient to conclude that outpatient palliative care can improve symptom control and quality of life. This review included four well designed, prospective, controlled studies, as well as several other studies demonstrating a positive effect.
- Communicating with the caregiver about palliative care may be instrumental to improving palliative care utilization among patients and families, as lack of information about palliative care may be a significant barrier to utilization (An et al., 2014).

Integrating palliative care into the care of the top 5-10 percent of spenders in the U.S. can improve the quality of care delivered. Palliative care results in fewer symptom crises, reducing unnecessary utilization and bending the cost curve.”

<https://www.capc.org/payers-policy-makers/value-proposition/>

For more evidence:

<https://www.capc.org/providers/palliative-care-resources/palliative-care-articles/>

<https://www.capc.org/payers-policy-makers/value-proposition/>

<https://registry.capc.org/metrics-resources/research-in-the-field>

A more detailed description of how palliative care looks.

- Delivered typically by an interdisciplinary team including a provider, nurse, social worker, chaplain, pharmacist and sometimes medical specialties or behavioral health. In rural some disciplines may not be present or may participate via telehealth.
- Often a consultative model that works with recommendations to primary care.
- Can be initiated at the time of diagnosis of a serious illness or at any stage
- Communications focuses around the “goals of care” conversations in which the team learns how the patient views their illness, what is most important, and how values and preferences should influence care decisions.
- In addition to hospitals, palliative care in the community can be delivered at home, residential facilities, long term care settings, outpatient clinics, office practices and other community settings. Palliative care can relieve suffering and support quality of life for nursing home residents and their families.

How do you decide which patients receive palliative care?

- Different programs may vary in their exact approach. Some limit services to specific diagnoses, but more commonly a screening tool is used to assess multiple factors such as seriousness of condition, patterns of health care use and quality of life. Other considerations might be difficult to manage symptoms or difficult with complex health care decisions related to serious illness. Some screening tools use a score to identify patients with the highest level of need.
- Some palliative care programs do use an end-of-life perspective that is longer than the six months used with the hospice benefit for Medicare. This is commonly called “the surprise question”; would you be surprised if this patient died in the one or two years?
- Others want to move away from an end of life reference to push further upstream to the time a serious illness is diagnosed. This can enable a patient to have a wider perception of care choices over time and build rapport with the palliative care team, leading to earlier and more frequent hospice referrals when and if the time is right.

Objectives of the WA Initiative

- Design a telehealth/ clinical consultation service for rural providers and clinical teams to link them to education and case consultation offered by experts in palliative care, improving skills over time.
- Design and deliver palliative care training and technical assistance to rural health clinical teams to drive both culture change and specific clinical skills, processes, and care standards.
- Test delivery of telemedicine palliative care to patients/loved ones in clinical settings and the home.
- Engage the rural community through education and dialogue with particular attention to public hospital district boards and formal and informal community leaders.
- Assess the capacity of and partner with long term care, local home health and hospice agencies, rural EMS agencies, and other relevant community organizations in the rural health care continuum.
- Define a structure for continuous and coordinated quality improvement in rural palliative care across settings.
- Negotiate payer pilots and ongoing participation for a favorable ROI and ROH (Return on Humanity).
- Negotiate a relationship to Healthier WA, Accountable Communities of Health, and Medicaid Waiver dollars.
- Fund evaluation/research for national dissemination and or to meet payer expectations to prove ROI.
- Identify policy and payment barriers and develop strategies for sustainable funding
- Establish at least 4-6 “Centers of Excellence for Rural Integrated Palliative Care” to develop a structure that:
 - Facilitates transfer of practices and peer consultation
 - Builds a regional resource for rural residents who live in a community that does not wish to participate in building capacity for integrated palliative care.

Description of the WA Initiative

- Our goal is to develop Washington rural communities that can capably, in the community, serve people with life limiting serious illnesses, and their loved ones.
- Our vision is that rural patients and their families will be at the center of decision-making and, if they wish, receive care provided by a local healthcare team with palliative care skills focused on comfort and healing rather than cure.
- Patients at any age can receive palliative care at any stage in a serious illness.
- Palliative care can be provided at the same time as curative treatments as well as in the final stages of life.
- Rural Critical Access Hospitals (CAHs) and Rural Health Clinics (RHCs) are being invited to work with their communities to form Rural Palliative Care Community Teams.
- In addition to CAHs and RHCs, participants may include home health, hospice, Emergency Medical Services, long term care facilities, home care, human/social services organizations, churches, Honoring Choices trainers, volunteer programs, public boards and whomever the community wants to invite.
- These community teams will develop a work plan that supports community education and conversation sessions about palliative care and promotes coordination of plans and linkages to improve and develop smooth pathways for patients and families which address both medical and non-medical needs associated with serious illness.
- In addition to working with their communities, RHCs and CAHs are invited to participate in activities that will help them integrate palliative care into their practices, including:
 - Sending clinical teams and providers to specialized palliative care training,
 - Working to change their organization's culture to integrate palliative care,
 - Adopting ways to identify patients who might benefit,
 - Developing clinical standards, order sets and protocols,
 - Participating in a telehealth palliative care case consultation and education service like Project Echo,
 - Developing direct palliative care telemedicine services for patients, and
 - Joining efforts to advance palliative care health plan benefits and contracts from commercial and public payers in Washington State.

How will success be measured?

- Improvements to symptoms assessment and control
- Improvements to patient quality of life
- Improved patient and family care experience

- Decrease in total cost of care by:
 - Reduced hospital days
 - Reduced ED visits
 - Reduced readmissions
 - Reduced tertiary transfers
- Process measures
 - Increased number/percentage of patients identified by standardized palliative care triggers/decision aids.
 - Percentage and number of rural health organizations who:
 - Identify provider, nursing, and MSW/Care Coordinator clinical champions for palliative care
 - Develop clinical protocols for palliative care including a standing order set.
 - Adopt the National Quality Forum Preferred Palliative Care Standards or another equivalent national care standards with rural modifications.
 - Design, test, and implement a palliative care patient and family education strategy.
 - Inform and educate public hospital district community boards and community members about integrated palliative care.
 - Develop and or use a palliative care skill competency assessment for clinical teams and providers.
 - Provide integrated palliative care services to patients and families in coordination with Hospice and other relevant organizations.

What specific help will the Palliative Care Rural Health Integration Advisory Team offer?

While healthcare organizations and the wider community will choose their own priorities, goals, pace, and path forward, they will have access to a framework, resources, knowledgeable coaches, and palliative care clinical expertise, including:

- A playbook of phased strategies with a toolkit, and annotated guides to resources
- Linkage to speakers, media, or other needed elements to educate and engage the community.
- Connections to palliative care expertise for information, consultation, and telemedicine services
- Supported set up for telehealth case consults and direct telemedicine

- Access to national palliative care evidence-based care standards, tools and protocols, and assistance with design and redesign of care
- Facilitation of peer exchanges with other participating communities
- Technical assistance and coaching
- Grant funding development as well as statewide approaches and negotiations with health plans.
- Possible instigation of multi-state approaches to Medicare.
- Measure sets and data dictionary, with both outcome and process measures. Technical assistance with metric set up and analysis.
- A quality improvement approach based on iterative, data-driven tests of change.

Policy changes needed

- Make palliative care services a standard health plan benefit that can be used in any health care setting
- Pay for interdisciplinary team support, not just provider billing.
- Recognize symptom control and quality of life as authentic treatment goals under Medicare.
- Reimburse at levels under Medicaid to support realistic costs of service provision.
- Direct the federal Centers for Medicare and Medicaid Services to include relevant palliative care and serious illness measures and benefits in all value-based programs for all care settings.
- Move from provider-based payment to provider- and team-based payments for palliative care benefits under Medicare
- Drop the outdated homebound regulation for home health, which acts as a barrier to care.
- Strengthen rural home health-the least expensive post-acute setting with the best outcomes struggles with negative margins and administrative burden. Rural home health needs the rural-add on payment not only reinstated but increased to compensate for long travel distances.
- Direct the Office of the National Coordinator for Health Information Technology (ONC) to create a certified health electronic record technology (CEHRT) standard that requires an immediately accessible link to any advance care planning document within an electronic health record.
- Incentivize federal agencies to provide grants for rural demonstrations of palliative care.

- Require more coursework in palliative care in training programs for health professions and incentivize health professions skills training in communications and pain/symptom management.

Case examples

Marie Green is 38 years old and has lived with MS for four years. Lately the symptoms have ramped up and her pain levels have become unmanageable. She also uses a wheelchair full-time now, when previously it was only during a flare. She lives with her husband Don, and he is very quiet and non-communicative, and she is terrified her illness is going to drive him away. About a month ago, she was told she had developed late onset Type I diabetes and that felt like a huge blow. She works part-time but is struggling with concentration. She was recently told she scored high on a depression screen she took at her primary care doctor's office. She feels like her symptoms are ruining her life.

John Clark is 78 years old and smoked for 30 years. He quit at age 55, and he is proud he did but now has developed Chronic Obstructive Pulmonary Disease (COPD) and his symptoms are increasingly severe. He lives with his adult son, Lenny, who has some physical disabilities from a car accident years ago but moves around well enough to be a help to John. John's shortness of breath is so intense he feels he cannot leave his chair, let alone his house. He worries a lot. Lenny tries to help him, but John is increasingly consumed with his long list of concerns. Poor air exchange is starting to escalate his anxiety. He is starting to worry if his medications are secure enough and wonder if Lenny is helping himself to the muscle relaxants and pain pills John has from an episode of back problems. He does not know how to talk to Lenny.

Madeline Appleby is 62 years old and has kidney disease caused by decades of high blood pressure. She is not yet on dialysis, but her nephrologist has told her the day will come sooner than later. She has just been told she is in "stage 4 kidney failure." She also has severe arthritis in her hands and hips. Her wife, Camille, works full-time, but Madeline took an early retirement six months ago. She is somewhat resigned to her situation but wishes she could have help with decision making. Every specialist she sees seems to have their own agenda for her care, and her primary care physician seems to think she has become too complicated to manage in primary care. Her back and hips hurt all the time and she is having terrible fatigue. Plus, every time she eats, she bloats up, and her face is puffy all the time. She is starting to lose her appetite and cannot sleep for more than an hour two without waking up.

Ron Gleason is 81 years old, and his congestive heart failure (CHF) has progressed to the point where he has no energy and spends a lot of time watching sports on the television. It is hard to get out because his feet are so swollen that his shoes will not fit, and he gets too short of breath. He has recently been told he has prostate cancer, and all the treatment choices were confusing. He does not know what he wants to do about that. His wife, Ruby, has dementia, and he has recently admitted he could no longer care for her. For now, she is living with their adult daughter until they can find a place that is right for her, but he wants to stay at home and misses her terribly even though her care is too much for him.

Addendum C **Evidence summary**

A summary of evidence for palliative care

“Involving palliative care clinicians in the care of patients with advanced cancer, beginning at the time of diagnosis and continuing throughout cancer treatment, can help improve patients’ symptoms, quality of life, and the care they receive at the end of life. Studies show that, compared to patients with advanced lung cancer who do not see palliative care clinicians along with their oncology clinicians, those who do receive “early integrated palliative care” have better quality of life and mood, are more likely to engage in conversations about their end-of-life care wishes, and receive hospice services for longer periods. Even the family and friends of these patients have better experiences when their loved ones receive early integrated palliative care. Unfortunately, the number of palliative care clinics in the United States is insufficient for all patients with advanced cancer to receive early integrated palliative care, despite the proven benefits of such services for patients and their families.

[Comparative Effectiveness of Early Integrated Telehealth versus In-Person Palliative Care for Patients with Advanced Lung Cancer | Emory School of Medicine. accessed 10/6/17](#)

Washington hospice services are currently not meeting the needs of residents to the extent possible. Only Puerto Rico and Alaska spend less time with patients than Washington hospice programs. Statewide 19.8 % of all hospital Medicare FFS discharged are hospice eligible and only 2.8 % are discharged to hospice. Every single one of WA’s 39 counties admits fewer patients to home health per 1,000 Medicare beneficiaries than the national average of 111.

- Earlier palliative care consultation during hospital admission lowers costs and improves outcomes:
 - May et al. (2015) found that earlier palliative care consultation during hospital admission is associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis:

- Intervention within 6 days is estimated to reduce costs by $-\$1,312$ (95% CI, $-\$2,568$ to $\$56$; $p = 0.04$) compared with no intervention and intervention within 2 days by $-\$2,280$ (95% CI, $-\$3,438$ to $-\$1,122$; $p < .001$)
- These reductions are equivalent to a 14% and a 24% reduction, respectively, in cost of hospital stay.
- Scibetta et al. (2016) found that among cancer patients who died, early referral to specialty palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer
 - Per-patient costs in the early palliative care group was $\$19,067$ versus $\$25,754$ for patients in the late palliative care group ($p < 0.01$). Direct outpatient costs were similar in the two groups ($\$13,040$ versus $\$11,549$, $p = 0.85$).
 - Early palliative care patients had lower rates of inpatient (33% versus 66%, $p < 0.01$), ICU (5% versus 20%, $p < 0.01$), and ED utilization (34% versus 54%, $p = 0.04$) in the last month of life than late palliative care patients.

Inpatient palliative care consultations result in cost avoidance.

- Starks et al. (2013) found that inpatient palliative care programs at two academic medical centers saved about $\$1.46$ million for LOS under a week and about $\$2.5$ million for LOS of 8 to 30 days.
 - Among inpatient stays of 1 to 7 days, costs were lower for all palliative care patients by 13.0% ($\$2,141$), and for survivors by 19.1% ($\$2,946$). For stays of 8 to 30 days, costs were lower for all palliative care patients by 4.9% ($\$2,870$), and for survivors by 6.0% ($\$2,487$). Extrapolating the per admission cost across the PC patient groups with lower costs, these programs saved about $\$1.46$ million for LOS under a week and about $\$2.5$ million for LOS of 8 to 30 days.
 - The average per-patient per-admission net cost saved by hospital palliative care consultation has been estimated as $\$2,659$ (Morrison et al., 2008).
- Telehealth technologies are being used increasingly in rural and underserved areas to expand access to palliative care services.
 - In their systemic review of the effect of telehealth interventions on caregiver outcomes, Zheng, Head and Schapmire (2016) found caregiver satisfaction to be associated with these programs. However, more

research is needed to determine whether telehealth programs achieve high quality outcomes in other domains.

- A recent evaluation of a pilot videoconferencing project conducted among cancer patients in rural Alberta, Canada, Watanabe et al. (2013) found promising results in multiple domains:
 - Scale scores for anxiety and appetite among patients were statistically significantly improved at the first follow-up visit ($p < 0.01$ and $p = 0.03$, respectively).
 - Average per visit savings for patients seen by telehealth versus attending the cancer center were 471.13 km, 7.96 hours, and Canadian \$192.71, respectively.
 - Patients and referring physicians indicated a high degree of satisfaction with the clinic.

Hospital-based palliative care is increasing nationally (Dumanovsky et al., 2016).

- Two-thirds (67%) of hospitals nationwide have palliative care programs, an increase from 53% of hospitals in 2008; and a substantial increase from 15% of hospitals in 2001.
 - Nearly all (90%) of hospitals with 300 or more beds have palliative care programs, as compared to about half (56%) of hospitals with fewer than 300 beds.
 - Hospitals with 300 or more beds were 7.0 times as likely as smaller hospitals to have a palliative care program (95% CI 5.4, 9.1, $p < 0.001$).
 - Sole Community Provider hospitals were significantly less likely than other hospitals to have a palliative care program.
- Predictors of palliative care programs within hospitals included region (New England, Pacific, and mid-Atlantic regions having the highest palliative care prevalence; the West and East South-Central regions have the lowest) and tax status (not-for-profit hospitals and public hospitals were 4.8 times and 7.1 times, respectively, more likely to have a palliative care program as compared to for-profit hospitals).

When examined by medical specialty, **palliative care's reach is highest in surgery, followed by oncology and family medicine**, and lowest in nephrology, followed by emergency medicine and neurology (Hughes and Smith, 2014).

Closed health systems are most likely to have complete service reach (Hughes and Smith, 2014).

- *Kaiser Permanente*, an insurer, and provider of medical care made palliative care standard in all areas for which Kaiser Permanente has a significant market share. The adoption was based on an RCT that demonstrated savings of \$5,000-\$7,000 per person (Smith et al., 2012).
- *The Sutter Health Program of Advanced Illness Management (AIM)*, serving Medicare beneficiaries in northern California, is now system wide. Expansion was possible through a grant from the Center for Medicare and Medicaid Innovation, based on the successful demonstration of a 54% reduction in hospital admissions, 80% reduction in ICU days, and 26% (2 days) reduction in inpatient length of stay. Physicians also noted a 52% reduction in visits, whereas home care had a 60% increase in hospice enrollment and a 49% increase in home health enrollment (Meyer, 2011).
- *Gunderson Health System in Wisconsin* achieved high community-wide penetration of advanced care planning (90% of patients having advance directives, with 99% of those directives available on admission to hospital) (Hammes, Rooney & Gundrum, 2010)

Outpatient and community-based palliative care services are less prevalent than services in inpatient settings. (Rabow, O’Riordan and Pantilat, 2014). In a statewide survey of adult and pediatric outpatient palliative care services among California hospitals:

- Of 136 hospitals with an adult palliative care program, only 18% (n = 24) had an outpatient program.
- Of 42 hospitals offering a pediatric palliative care program, only 19% (n = 8) offered outpatient services.
- Adult and pediatric outpatient palliative care services care primarily for patients with cancer, operate part-time with modest staffing, and are funded primarily by their institution.
- These figures have not changed significantly since 2007

Composition of the palliative care team **depends on the system** in which it is implemented:

- Within hospitals, the primary model of care delivery is the interdisciplinary consultation team. Large hospitals and mature programs may also include dedicated inpatient units. New service-delivery models and innovations include dedicated ICU teams, co-management models in which a palliative care specialist joins an existing specialty team (e.g., oncology), and triggers for automatic palliative care referrals (Kelley and Morrison, 2015).

- In the Kaiser Permanente system, where palliative care was made standard based on a successful RCT, the interdisciplinary team includes a physician, an advance practice nurse, a social worker, and a chaplain. By contrast, in a more limited application of a palliative care model in the community-based US Oncology healthcare network, a physician and nurse practitioner were added to the oncology office (Hughes and Smith, 2014).

Few hospitals palliative care programs meet national staffing recommendations (Spetz et. al, 2016):

- Only 25% of participating National Palliative Care Registry programs met the Joint Commission’s standard of including at least one physician, an advanced practice or other registered nurse, a social worker, and a chaplain, based on funded positions.
- Even when unfunded (in-kind or volunteer) positions were included only 39% of programs met the Joint Commission’s standards for palliative care team staffing.
- Larger palliative care programs were more likely than smaller ones to include a funded physician position, while smaller programs were more reliant upon advanced practice and registered nurses.

An inadequate medical and nursing workforce with expertise in palliative care is one of the greatest barriers to palliative care access; furthermore, growth in the number of hospice programs (and patients served) has rapidly outstripped growth in the number of trained professionals (Meier, 2011; Lupu, 2010).

- A shortfall of 6,000–10,000 palliative care specialist physicians and an equal number of advanced practice nurses is anticipated (Hughes and Smith, 2014).
- The most recent nationwide estimate of palliative care specialists is 4,400 hospice and palliative medicine (HPM) physicians. This is equivalent to 1 HPM physician for every 20,000 older adults with a life-limiting illness, and 1 HPM physician for every 11,000 Medicare deaths (Enguidamos, Vesper & Lorenz, 2012; Lupu, 2010).

Salaries and fellowships for hospital and palliative medicine (HPM) specialists may not be sufficient to attract high-caliber candidates (Hughes and Smith, 2014).

- Board certification is only available through fellowship training, yet fewer than 200 fellowships are available in HPM each year in the US.

Funding for palliative care research is limited (Hughes and Smith, 2014)

- Less than 1% of the National Institutes of Health (NIH) budget is dedicated to palliative care, although there have been substantial increases (240%) in NIH-funded investigators (now 294) and grants (now 391) since 2006.

Health centers and other care settings are **developing and integrating different models or formulas to estimate staffing needs** based on their own experience.

- Using a trigger-based model, Hua et al. (2014) found that one in seven ICU admissions met a single set of criteria for palliative care consultation. Using multiple sets of triggers, one in five ICU admissions (up to 20% of ICU admissions) met criteria for consultation.

More training is needed for primary care practitioners to reduce attitudinal barriers that impact primary and secondary palliative care (Hughes and Smith, 2014).

- ICU-based palliative care consultation may decrease hospital LOS (Aslakson et al., 2014).
 - Of 14 interventions that measured hospital LOS, 8 found a decrease in hospital LOS associated with the intervention.

Early initiation of palliative care consultation may decrease hospital LOS.

- Early palliative care consultation in the emergency department was associated with a significantly shorter LOS for patients admitted to the hospital, by 3.6 days ($p < 0.01$), as compared to patients receiving a palliative care consultation after transfer from the emergency department to the ICU or the medical/surgical department (Wu et al., 2013).
 - Mean LOS for the intervention and control groups were 4.32 and 8.29 days, respectively ($p < 0.01$), and LOS was consistently lower in the intervention group regardless of whether participants were in an acute palliative care swing bed or on a non-palliative care unit.

Home-based palliative care services may decrease hospital LOS.

- In a pilot study evaluating LOS among older patients receiving home-based palliative care during a six-month period as compared to those not receiving such services, the average number of hospital admissions was 0.35 versus 1.36 days ($p < 0.001$). Total hospital days were reduced by 5.13 for patients receiving palliative care (Chen et al., 2015).

ICU-based palliative care consultation may decrease ICU LOS.

- In a systematic review of 22 studies examining ICU LOS, Khandelwal et al. (2015) concluded that palliative care interventions consistently showed a pattern toward reduced ICU length of stay.
 - A 26% relative risk reduction in LOS with palliative care interventions was detected overall.
- When restricting to palliative care interventions in the ICU setting that were directly targeted at the level of individual patients, the mean relative risk reduction was 33%.
 - In a review of 21 interventions that measured ICU LOS, Aslakson et al. (2014) reported that 13 found a decrease in ICU LOS associated with the palliative care intervention.
- In nine of 12 studies that used an integrative model of palliative care, a decrease in ICU LOS was detected.
- In six of nine studies exploring the consultative model of palliative care, a decrease in ICU LOS was found.
- Due to methodological variation, it is not possible to detect whether the integrative or consultative model is more effective.

Cost Savings

Inpatient specialist palliative care consultation teams have been found to be significantly less costly than usual care comparators in the range of 9%-25% for hospital costs, in a variety of settings and for various populations. (May, Normand & Morrison, 2014; Albanese et al., 2013; Armstrong et al., 2013; Starks et al., 2013; Wu et al., 2013)

- Recently, McCarthy et al. (2015) found overall cost savings from palliative care of \$3,426 per patient for those dying in the hospital. No significant cost savings were found for patients discharged alive; however, significant cost savings for patients discharged alive could be achieved for certain diagnoses, palliative care team structures, or if consults occurred within 10 days of admission.
- In New York State, Tangeman et al. (2014) found that on average, cost per admission was \$1,401 (13%) lower among patients receiving palliative care than comparison patients ($p < 0.05$). Cost reductions were evident within intensive care and laboratory services.

Provision of palliative care services may lower costs for all hospitalized patients receiving them.

- In a study of hospitalized patients at two Mayo clinic sites in Minnesota, costs were lowered for patients whether discharged dead or alive (Whitford et al., 2014).
 - Costs for patients seen and discharged alive were US \$35,449 (95% confidence interval [CI] US \$34,157-US \$36,686) compared to US \$37,447 (95% CI US \$36,734-US \$38,126), without palliative care consult service (PCCS) consultation.
 - Costs for PCCS patients that died during hospitalization were US \$54,940 (95%CI US \$51,483-US \$58,576) and non-PCCS patients were US \$79,660 (95% CI US\$76,614-US \$83,398).
- Among Medicaid patients in four New York State hospitals (2004-2007), on average, patients who received palliative care incurred \$6,900 less in hospital costs during a given admission than a matched group of patients who received usual care (Morrison et al., 2011).
 - These reductions included \$4,098 in hospital costs per admission for patients discharged alive, and \$7,563 for patients who died in the hospital.
 - The authors estimated that reductions in Medicaid hospital spending in New York State could eventually range from \$84 million to \$252 million annually (if 2 percent and 6 percent of Medicaid patients discharged from the hospital received palliative care, respectively), if very hospital with 150 or more beds

Earlier palliative care consultation during hospital admission lowers costs and improves outcomes:

- May et al. (2015) found that earlier palliative care consultation during hospital admission is associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis:
 - Intervention within 6 days is estimated to reduce costs by -\$1,312 (95% CI, -\$2,568 to \$56; p = 0.04) compared with no intervention and intervention within 2 days by -\$2,280 (95% CI, -\$3,438 to -\$1,122; p < .001)
 - These reductions are equivalent to a 14% and a 24% reduction, respectively, in cost of hospital stay.
- Scibetta et al. (2016) found that among cancer patients who died, early referral to specialty palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer.
 - Per-patient costs in the early palliative care group was \$19,067 versus \$25,754 for patients in the late palliative care group (p < 0.01). Direct outpatient costs were similar in the two groups (\$13,040 versus \$11,549, p = 0.85).

- Early palliative care patients had lower rates of inpatient (33% versus 66%, $p < 0.01$), ICU (5% versus 20%, $p < 0.01$), and ED utilization (34% versus 54%, $p = 0.04$) in the last month of life than late palliative care patients.

Inpatient palliative care consultations result in cost avoidance.

- Starks et al. (2013) found that inpatient palliative care programs at two academic medical centers saved about \$1.46 million for LOS under a week and about \$2.5 million for LOS of 8 to 30 days.
 - Among inpatient stays of 1 to 7 days, costs were lower for all palliative care patients by 13.0% (\$2,141), and for survivors by 19.1% (\$2,946). For stays of 8 to 30 days, costs were lower for all palliative care patients by 4.9% (\$2,870), and for survivors by 6.0% (\$2,487). Extrapolating the per admission cost across the PC patient groups with lower costs, these programs saved about \$1.46 million for LOS under a week and about \$2.5 million for LOS of 8 to 30 days.
- The average per-patient, per-admission net cost saved by hospital palliative care consultation has been estimated as \$2,659 (Morrison et al., 2008).

In hospitals that have dedicated palliative care units, transferring hospitalized patients to a palliative care unit result in cost savings (Smith and Cassel, 2009).

- For patients transferred to a hospital's acute palliative care unit, Albanese et al. (2013) found cost savings even when conservative pre-transfer cost measures were used and when patients with varying diagnoses and discharge outcomes are included.

Hospice enrollment reduces hospitalization costs.

- Among Medicare beneficiaries, Kelley et al. (2013) found \$2,561 in savings to Medicare for each patient enrolled in hospice 53-105 days before death, compared to a matched, non-hospice control. Even higher savings were seen with more common, shorter enrollment periods: \$2,650, \$5,040, and \$6,430 per patient enrolled 1-7, 8-14, and 15-30 days prior to death, respectively.

Home-based palliative care within an Accountable Care Organization (ACO) was associated with significant cost savings (Lustbader et al., 2016).

- The cost per patient during the final three months of life was \$12,000 lower with home-based palliative care than with usual care (\$20,420 vs. \$32,420; $p = 0.0002$); largely driven by a 35% reduction in Medicare Part A (\$16,892 vs. \$26,171; $p = 0.0037$).
- Home-based palliative care also resulted in a 37% reduction in Medicare Part B in the final three months of life compared to usual care (\$3,114 vs. \$4,913; $p = 0.0008$).
- Home-based palliative care resulted in a 35% increased hospice enrollment rate ($p = 0.0005$) and a 240% increased median hospice length of stay compared to usual care (34 days vs. 10 days; $p < 0.0001$).

Home-based palliative care may reduce care costs over time.

- For adult patients, Hopp et al. (2014) showed that home-based palliative care services are associated with reductions in health care utilization and reduced costs over time. Average 6-month costs per month significantly declined for patients older than 65 years of age from 1 HMO (\$9,300 – \$5,900, $p = 0.001$)
- For adult patients, a recent study found that home-based palliative care was associated with statistically significant reductions in total charges for hospital-based care, with reductions were more pronounced in the non-cancer group. Non-cancer patients with at least six months of palliative care exposure showed an average decrease in total hospital charges of nearly \$275,000 (Postier et al., 2014).

Partnerships between community-based hospice providers and palliative care programs may achieve cost savings.

- Kerr, Donohue et al. (2014) showed cost savings in the last three months of life for palliative care enrollees in the amount of \$6,804 per member per month (PMPM) versus \$10,712 for usual care.
 - During the last two weeks of life, total allowed PMPM was \$6,674 versus \$13,846 for usual care. Enhanced hospice entry (70% versus 25%) and longer length of stay in hospice (median 34 versus 9 days) were observed.

Readmissions

- O'Connor et al. (2015) found that hospitalized patients seen by inpatient palliative care had a lower 30-day readmission rate-adjusted odds ratio (AOR) 0.66, 0.55-0.78; $p < 0.001$) than patients who had no palliative care consultation. Consultations that involved goals of care discussions were associated with a lower readmission rate (AOR 0.36, 0.27-0.48; $p < 0.001$)
- Lustbader et al. (2016) found that home-based palliative care within an Accountable Care Organization (ACO) was associated with fewer hospitalizations. Hospital admissions were reduced by 34% in the final month of life for patients enrolled in home-based palliative care.
- A propensity-matched study comparing readmission rates among palliative home care patients to usual home care patients found that the 30-day readmission probability for palliative home care patients was 9.1%, as compared to a probability of 17.4% in the usual home care group (average treatment effect on the treated (ATT): 8.3%; 95% confidence interval [CI] 8.0%-8.6%). This effect persisted after adjustment for visit frequency. (Ranganathan et al., 2013)
- Enguidanos, Vesper & Lorenz (2012) found that patients discharged home with hospice had a 5% 30-day readmission rate, as compared to 8% among those

discharged with palliative care. Patients discharged with no services had a 25% 30-day readmission rate.

- In western New York State, readmission rates were significantly lower among palliative care patients discharged with hospice care (1.1%) than comparison patients (6.6%), but significantly higher among palliative care patients discharged to other locations (12.1%) (Tangeman et al., 2014).
- In a hospital-based multicenter RCT, Gade et al. (2008) showed that patients receiving interdisciplinary palliative care services had fewer ICU hospital readmission (12 versus 21, $p = 0.04$), and 6-month net cost savings of \$4,855 per patient ($p = 0.001$).
- In an observational study of 5 VA hospitals, Penrod et al. (2010) found that palliative care patients were 43.7% less likely to be admitted to ICU during the hospitalization than usual care patients ($p < 0.001$).

In-patient palliative care may reduce readmissions.

- O'Connor et al. (2015) found that hospitalized patients seen by inpatient palliative care had a lower 30-day readmission rate-adjusted odds ratio (AOR) 0.66, 0.55-0.78; $p < 0.001$) than patients who had no palliative care consultation. Consultations that involved goals of care discussions were associated with a lower readmission rate (AOR 0.36, 0.27-0.48; $p < 0.001$)

Home-based palliative care and home-based hospice care reduces the likelihood of readmission:

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Receipt of inpatient palliative care (IPC) services reduces the likelihood of ICU readmission:

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- In an observational study of 5 VA hospitals, Penrod et al. (2010) found that palliative care patients were 43.7% less likely to be admitted to ICU during the hospitalization than usual care patients ($p < 0.001$).

Inpatient palliative care has been found to improve QOL and symptom burden.

- Among patients over 65 years old at a Los Angeles medical center receiving treatment from an inpatient palliative care team, mean pain was significantly different between baseline ($1.56 + 2.79$) and two hours ($0.91 + 1.59$; $p < 0.001$), 24 hours ($0.77 + 1.58$; $p < 0.001$), and hospital discharge ($0.40 + 1.09$; $p < 0.001$). Mean pain 10 days after discharge ($2.04 + 2.79$; $p < 0.001$) was significantly higher than mean pain at discharge (Laguna et al., 2012).
- In a rural hospital setting, Armstrong et al. (2013) found a significant improvement in pain scores and symptom burden within 5 days of referral to the palliative care program.
- Among heart failure patients, Sidebottom et al. (2015) found that QOL scores increased by 12.92 points in the intervention group as compared to 8 points in the control group at 1 month (difference = + 4.92, $p < 0.001$). Improvement in symptom burden was 8.39 in the intervention group and 4.7 in the control group at 1 month (+3.69, $p < 0.001$).

Outpatient and home palliative care may improve patient quality of life.

- A meta-analysis of outpatient and home palliative care studies found that despite some methodological concerns, the current state of palliative care research supports the conclusion that early outpatient and home palliative care may improve patient quality of life (Davis et al., 2015).
- Rabow et al. (2013)'s review of the literature found that evidence is sufficient to conclude that outpatient palliative care can improve symptom control and quality of life. This review included four well designed, prospective, controlled studies, as well as several other studies demonstrating a positive effect.
- Among heart failure patients, new models integrating home-based palliative care and standard heart failure care have been shown to be effective in reducing both physical and psychological symptoms in patients (Enguidamos and Portanova, 2015).
- Kerr, Tangeman et al. (2014) found that among patients with life-limiting or serious illness enrolled in a blended outpatient/home palliative care program, symptomology improved in six of eight domains: anxiety, appetite, dyspnea, well-being, depression, and nausea.

Home-based palliative care may increase the chance of dying at home and reduce symptom burden, for patients with cancer (Gomes et al., 2014; Kerr, Tangeman et al., 2014).

Among patients with potentially curable cancer, palliative care may improve the likelihood that individuals will complete the treatment regimen.

- Cheville et al. (2015) demonstrated that patients undergoing chemoradiation who received a structured multidisciplinary QOL-directed intervention were significantly more likely to complete their chemoradiation as planned than patients who did not receive the QOL intervention.

Substantial evidence demonstrates that **palliative care leads to better patient and caregiver outcomes**. These include improvement in symptoms, QOL, and patient satisfaction, with reduced caregiver burden (Smith et al., 2012).

- Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care.
 - In a comparison of early palliative care consultation to consultation after 3 months, earlier palliative care consultation led to improved survival rates after one year among the cancer patients in the study. Overall median survival was 18.3 months for the early group (n = 50) and 11.8 months for the delayed group (n = 59) (Bakitas et al, 2015).

Integration of palliative care into health systems has led to significant improvements in the quality of patient care while also reducing costs (Smith, Bernacki and Block, 2015; Kamal et al., 2014; Meier, 2011).

- According to Smith, Bernacki and Block's (2015) review of the literature:
 - Multiple RCTs of specialist palliative care team interventions have shown improved outcomes, including improved quality of life, greater satisfaction with care, increased hospice utilization, reductions in family distress, and even improved survival.
 - Inpatient palliative care services have been associated with improved communication between patients and doctors; enhanced patient perception of emotional support; higher patient satisfaction; and decreased pain, dyspnea, and nausea.
- Among cancer patients, Kamal et al. (2014) found that oncology care that routinely incorporated palliative care principles improved patient outcomes:
 - Assessment of comprehensive symptoms, fatigue and constipation assessment, timely management of pain and constipation, and timely emotional well-being assessment were associated with highest levels of quality of life (all ps < .05).
 -]In a multivariate model (C-stat = 0.66), performance status (odds ratio [OR], 5.21; p = 0.003), estimated life expectancy (OR, 22.6; p = 0.003), conformance

to the measure related to emotional well-being assessment (OR, 1.60; $p = 0.026$), and comprehensive screening of symptoms (OR, 1.74, $p = 0.008$) remained significant.

- In their study of cancer patients who died, Scibetta et al (2016) found that early referral for specialty palliative care for cancer patients resulted in improved performance on the National Quality Forum (NQF)'s End of Life (EOL) quality measures, with less aggressive medical care in the final month of life.

Palliative care in the ICU does not increase mortality.

- A review of 37 ICU-based interventions concluded that better palliative care in the ICU benefits patients, families, and health care systems without increasing mortality (Aslakson et al., 2014).

Early palliative care may prolong life for some patient populations

- Bakitas et al. (2015) found that in comparing early to delayed palliative care consultation in hospital for cancer patients, the Kaplan-Meier 1-year survival rates were 63% in the early group and 48% in the delayed group (difference, 15%; $p < 0.038$).
- In a study of patients with newly diagnosed metastatic non-small-cell lung cancer, Temel et al. (2010) found that despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, $p = 0.05$), median survival was approximately two months longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $p = 0.02$) and was accompanied by clinically meaningful improvements in QOL and mood.

Home-based palliative care has been shown to achieve diverse markers of quality.

- Irrespective of age, gender, and type of tumor, patients taken into care by the palliative home-care team were more likely to die at home, less likely to be hospitalized, and spent fewer days in hospital in the last 2 months of their life (Riolfi et al., 2014).

Patients receiving a hospital-based palliative care consultation rate the quality of care higher than patients who do not receive palliative care.

- Casarett et al. (2010) found that patients who received a palliative consultation had significantly higher scores for five of the six domains studied: information and communication ($p < 0.001$), access to home care services ($p = 0.007$), emotional and spiritual support ($p < 0.001$), well-being and dignity ($p = 0.001$) and care around the time of death ($p < 0.001$)

Inpatient palliative care services have been associated with improved communication between patients and doctors; enhanced patient perception of emotional support; and higher patient satisfaction (Smith, Bernacki and Block, 2015).

Communicating with the caregiver about palliative care may be instrumental to improving palliative care utilization among patients and families, as lack of information about palliative care may be a significant barrier to utilization (An et al., 2014).

Palliative care volunteers reduce caregiver burden. According to Claxton-Oldfield (2015)'s review of the literature, the benefits of palliative care volunteers include:

- respite or breaks from the caregiving role
- emotional support
- advocacy and intervention with the professional palliative care team
- practical assistance with errands and other logistical matters
- spiritual/religious support, if desired

Among bereaved families, dedicated palliative care units may be associated with higher overall satisfaction and emotional support, as compared to a consultation service or usual care (Roza et al., 2015).

- Family members of patients who died on the Mt Sinai Medical Center palliative care unit were more likely to report that their loved one's end-of-life medical care had been "excellent" as compared to family members of patients who received palliative care consultation or usual care (adjusted OR, 2.06; 95% CI, 1.17–3.61).
- Family members of palliative care unit patients also reported greater satisfaction with emotional support before the patient's death (adjusted OR, 1.71; 95% CI, 1.01–2.90).

Among family members, earlier palliative care consultation has been associated with higher satisfaction with care (Casarett et al., 2008).

Palliative specialist consultations have been associated with **reductions in family distress** (Smith, Bernacki and Block, 2015).

Pediatric Palliative Care Programs are becoming more common in children's hospitals.

However, there is evident variation across these programs (Feudtner et al., 2013).

- Of the 162 hospitals surveyed, 69% reported having a pediatric palliative care program, with the rate of creation of new programs peaking in 2008.
- Most of these programs only offered inpatient services during the regular work week and rely heavily on hospital funding.
- While the number of consults varied substantially, it was positively associated with hospital size and number of funded staff members.

Outpatient and community-based palliative care services are less prevalent than services in inpatient settings (Rabow, O’Riordan and Pantilat, 2014). In a statewide survey of adult and pediatric outpatient palliative care services among California hospitals:

- Of 42 hospitals offering a pediatric palliative care program, only 19% (n = 8) offered outpatient services.
- Outpatient palliative care services care primarily for patients with cancer, operate part-time with modest staffing, and are funded primarily by their institution.
- These figures have not changed significantly since 2007

For pediatric patients, palliative care may improve quality of life.

- Evidence from two studies that explored measures related to emotional and physical well-being showed that palliative care for pediatric patients with life-limiting illness may improve quality of life for children and their parents. More research is needed in this area (O’Quinn and Giambra, 2014).
- In a survey of bereaved parents, Friedrichsdorf et al. (2015) found that children with cancer who participated in a palliative home care program were more likely than children who did not to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%).

Pediatric palliative care (PPC) may have a measurable long-term impact on hospital use in seriously ill children.

- Hospital pediatric palliative care involvement may contribute to decreased hospital and ED use, without escalating costs. These outcomes are most evident in patients who survived two or more years following PPC enrollment. (Ananth et al., 2017).

Home-based palliative care services may decrease hospital LOS. For pediatric patients, a recent study found that home-based palliative care was associated with statistically significant reductions in hospital LOS, with reductions were more pronounced in the non-cancer group. Non-cancer patients with at least six months of palliative care exposure showed a significant decrease in total LOS from pre- to post-program admission by an average of 38 days (Postier et al., 2014).

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Addendum D: Video and discussion Guide
Discussion Guide for Offering Palliative Care in Rural
Communities

(5 min 29 sec)

<https://youtu.be/0-9HQyfDQUk>

Mysteries Of the Universe, What Is Palliative Care?

1 min 38 sec

Okanogan Palliative Care Team

The following questions are suggestions only and can be replaced by questions more relevant to your specific audience. Following the questions are a few talking points prepared to respond to FAQ from the audience.

Community audience	Healthcare audience
How has serious illness touched your lives?	How has serious illness touched your lives?
Why do you think palliative care is important? What did you think before seeing the video?	Why do you think palliative care is important? What did you think before seeing the video?
What opportunities are there for care for serious illness in your community?	What opportunities are there for care for serious illness in your community?
If you could add services in your community, what would you add?	If you could add services in your community, what would you add?
Would you want palliative care for yourself or a loved one? Why or why not?	How would you envision an ideal community system of palliative care?
What myths might get in the way of people with serious illness receiving the supports they need to stay in the community and at home?	How can your health care teamwork in closer coordination with human service agencies that might provide non-medical supports to community members with serious illness?
What might community organizations	Who is most likely to identify opportunities to

contribute?	serve people with serious illness, which teams or settings?
What myths might get in the way of people with serious illness receiving the supports they need to stay in the community and at home?	What myths might get in the way of people with serious illness receiving the supports they need to stay in the community and at home?

FAQ for Discussion Facilitators’ Use

How do you bill for palliative care?

Billing for palliative care is called a patchwork. Some care is billed like any other care related to a patient diagnosis. Some use the advanced care planning, transitions, and chronic care management codes. There is no question that value-based contracts offer the best flexibility for a team approach. Medicaid is coming out with adult palliative care rules, and we will be working to get more coverage and contracting in WA.

How do you decide which patients receive palliative care or not?

A standard screening tool looks at the kind of illness and what stage it is, use of health care, and other factors that add complexity to the patient’s ability to manage. Palliative care is not for pain management without other services, and each organization ultimately decides what capacity they can manage and prioritizes patients in greatest need based on criteria in the screening tool.

How do you define palliative care?

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.²⁶

“You shouldn’t be days or weeks from death to have your symptoms managed and pain taken care of.”

R. Sean Morrison, director of the National Palliative Care Research Center
<https://khn.org/news/palliative-care-for-seriously-ill/>
 accessed 3/20/2018

²⁶ Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Palliative Care Research Center. <https://khn.org/news/palliative-care-for-seriously-ill/> accessed 3/20/2018

Is there proof that palliative care really works?

Yes, multiple studies show increased quality of life, improved satisfaction with care, fewer crises with poorly controlled symptoms, and therefore decreased use of emergency departments and hospitals. Studies also show increases in eventual hospice enrollment and length of participation in hospice. These effects result in decreased overall cost of care.

Why does palliative care matter in rural communities?

- Rural counties have a higher percentage of older adults and so the health systems will face an even greater influx of patients with needs.
- Rural Medicare beneficiaries have more prevalence of diabetes, COPD, cancer, heart failure, stroke, complete or partial paralysis and Alzheimer’s Dementia than urban.
- Studies show that people facing serious illness prefer to be in their own environment.²⁷

Addendum for clinical audience

Discussion Guide for *Offering Palliative Care in Rural Communities*

(5 min 29 sec)

<https://youtu.be/0-9HQyfDQUk>

The value of palliative care for serious illness

- Scibetta et al. (2016) found that among cancer patients who died, early referral to specialty palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer.
- The average per-patient per-admission net cost saved by hospital palliative care consultation has been estimated as \$2,659 (Morrison et al., 2008).

Aetna Medicare Advantage Compassionate Care Program

- 81% decrease in acute care days
- 86% decrease in ICU days
- High member satisfaction
- 82% hospice election rate
- \$12,600 in savings per person

ProHealth Accountable Care Organization Supportive Care Program

- 37% decrease in hospital admission rate
- 20% decrease in ED visit rate
- High patient satisfaction
- 34% increase in hospice enrollment, with a 240% increase in hospice length of stay
- \$12,000 in savings per person

²⁷ https://www.capc.org/topics/palliative-care-community/?gclid=EAIalQobChMIpKn7j6LI2QIVBCIpCh2g2AhyEAAYAAEgJEK_D_BwE accessed 3/11/2018

- No patient complaints in 10 years
<https://www.capc.org/payers-policymakers/value-proposition>
- Home-based palliative care within an Accountable Care Organization (ACO) was associated with significant cost savings (Lustbader et al., 2016).
 - The cost per patient during the final three months of life was \$12,000 lower with home-based palliative care than with usual care (\$20,420 vs. \$32,420; $p = 0.0002$); largely driven by a 35% reduction in Medicare Part A (\$16,892 vs. \$26,171; $p = 0.0037$).
 - Home-based palliative care also resulted in a 37% reduction in Medicare Part B in the final three months of life compared to usual care (\$3,114 vs. \$4,913; $p = 0.0008$).
 - Home-based palliative care resulted in a 35% increased hospice enrollment rate ($p = 0.0005$) and a 240% increased median hospice length of stay compared to usual care (34 days vs. 10 days; $p < 0.0001$).
- Rabow et al. (2013)'s review of the literature found that evidence is sufficient to conclude that outpatient palliative care can improve symptom control and quality of life. This review included four well designed, prospective, controlled studies, as well as several other studies demonstrating a positive effect.
- Communicating with the caregiver about palliative care may be instrumental to improving palliative care utilization among patients and families, as a lack of information about palliative care may be a significant barrier to utilization (An et al., 2014).

“Integrating palliative care into the care of the top 5-10 percent of spenders in the U.S. can improve the quality of care delivered. Palliative care results in fewer symptom crises, reducing unnecessary utilization and bending the cost curve.”

<https://www.capc.org/payers-policymakers/value-proposition/>

- **For more summarized evidence**

<https://www.capc.org/providers/palliative-care-resources/palliative-care-articles/>

<https://www.capc.org/payers-policymakers/value-proposition/>

<https://registry.capc.org/metrics-resources/research-in-the-field>

How do you decide which patients receive palliative care?

- Different programs may vary in their exact approach. Some limit services to specific diagnoses, but more commonly a screening tool is used to assess multiple factors such as seriousness of condition, patterns of health care use, and quality of life. Other considerations might be difficult to manage symptoms or difficult with complex health care decisions related to serious illness. Some screening tools use a score to identify patients with the highest level of need.
- Some palliative care programs use an end-of-life perspective that is longer than the six months used with the hospice benefit for Medicare. This is commonly called “the surprise question”; would you be surprised if this patient died in the one or two years?
- Others want to move away from an end of life reference to push further upstream to the time a serious illness is diagnosed. This can enable a patient to have a wider perception of care choices over time and build rapport with the palliative care team, leading to earlier and more frequent hospice referrals, when and if the time is right.

See next page for Addendum E:-one pager for education of the public.

Washington Rural Palliative Care Initiative

SPONSORED BY THE WASHINGTON STATE OFFICE OF RURAL HEALTH

The **Washington Rural Palliative Care Initiative** (WRPCI) is an effort to better serve patients with serious illness in rural communities. Led by the Washington State Office of Rural Health at the Washington State Department of Health, this public-private partnership involves over 24 different organizations to assist rural health systems and communities to integrate palliative care in multiple settings, such as emergency department, inpatient, skilled rehabilitation, home health, hospice, primary care, and long-term care.

What is Palliative Care?

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.






What's the difference between Palliative Care and Hospice and Primary Care?

Many people confuse palliative care and hospice. Hospice care is one kind of palliative care focused on serving patients and families at the end of their lives and usually considered in the last six months of a serious illness. Palliative care can be used at any stage of serious illness and, unlike hospice, can be offered at the same time as curative treatments. Both palliative care and hospice use a team approach to focus on quality of life including the active management of pain and other symptoms, as well as the psychological, social and spiritual issues often experienced with serious illness. While excellent primary care may have some overlaps with palliative care, primary care is more comprehensive and also includes preventive care. Palliative care can be offered within primary care or as a specialty consultative service that supports overall care.



**A public-private
partnership of over 24
different organizations**

To better understand how these programs differ, take a look at this table.

	PALLIATIVE CARE	HOSPICE	PRIMARY CARE
ELIGIBILITY	 <p>Palliative care is for people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening. If you or a loved one are suffering from symptoms of a disease or disorder, be sure to ask your current healthcare provider if a palliative care consult would be helpful. Some palliative care programs may have certain eligibility criteria.</p>	<p>Specific to the Medicare Hospice Benefit, a patient is eligible for hospice care if two physicians certify that the patient has six months or less to live if the illness runs its normal course. Patients must be re-assessed for eligibility at regular intervals in order to meet ongoing coverage criteria, but there is no limit on the amount of time a patient can be on the hospice benefit.</p>	<p>Everyone is eligible for primary care, throughout the lifespan. Primary care focuses on preventative care, care for acute illnesses, and management of chronic conditions.</p>
TIMING	 <p>There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not. Should the patient's serious illness become terminal with a prognosis of six months or less, it may be appropriate to consider a referral to hospice care.</p>	<p>Although end-of-life care may be difficult to discuss, it is best for family members to share their wishes long before it becomes a concern.</p>	<p>Most people seek out primary care for preventative visits (e.g. vaccines, well child checks, well woman exams, Medicare wellness exams). They also use primary care when they are not feeling well with an acute illness or are managing a chronic illness such as diabetes.</p>
PAYMENT	 <p>Some commercial insurance companies cover palliative care for their beneficiaries. However, Medicare coverage for palliative home care may be challenging due to eligibility requirements. These requirements may include but are not limited to being homebound. If you are unsure of coverage, contact your insurance company.</p>	<p>For those on Medicare, there is a Medicare Hospice Benefit available for patients whose life expectancy is six months or less, as determined by their healthcare provider. Medicaid hospice coverage is the same as the Medicare benefit. Also, most commercial insurance companies also offer hospice coverage. If you are unsure of coverage, contact your insurance company.</p>	<p>Most insurance covers primary care.</p> <p>If you are unsure of coverage, contact your insurance company.</p>
LOCATION	 <p>It is most common to receive palliative care through your healthcare provider's office, home care services, hospitals, nursing homes or the patient home.</p>	<p>In most cases, hospice is provided in the patient's home—wherever they may call home which may include their own home/residence, an assisted living facility, a group home or a nursing home. Hospice care is also provided in freestanding hospice facilities, hospitals, or nursing homes.</p>	<p>Primary care is delivered most commonly in clinics. Primary care providers also travel to nursing homes and sometimes make home visits.</p>
TREATMENT	 <p>Palliative care focuses on symptom management rather than treatment of disease. It also includes discussions of goals of care at all stages of a disease, and, when appropriate, discussion of choices towards the end of life. Curative treatment can occur concurrent with palliative care.</p>	<p>Hospice programs concentrate on comfort rather than cure. By electing not to receive extensive life-prolonging treatment, hospice patients and their families can concentrate on getting the most out of the time they have left, without some of the negative side-effects that life prolonging treatments may have. Hospice patients may achieve a level of comfort that allows them and their families to concentrate on the emotional and practical issues of dying. The focus of hospice care is more on the quality not the quantity of the life remaining.</p>	<p>Primary care is the day-to-day healthcare given by a clinician; this person may be a physician, a nurse practitioner or a physician assistant. Typically, this provider acts as the first contact and principal point of continuing care for patients within a healthcare system and coordinates other specialist care that the patient may need. A primary care provider is likely to be the person who helps coordinate or refers a patient to palliative care or hospice services. A patient can continue receiving care from their primary care provider while obtaining palliative care or hospice services.</p>

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Edmonton Symptom Assessment System – Revised (ESAS-r)

Administration Manual

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1. Introduction

The Edmonton Symptom Assessment System – Revised (ESAS-r) Administration Manual was developed to provide a guiding framework for the use of the ESAS-r. Through further refinement, we hope that this manual will ultimately facilitate the consistent and psychometrically sound use of this instrument. This manual consists of three key sections: (1) Background, (2) Edmonton Symptom Assessment System – Revised, and (3) Frequently Asked Questions (FAQs). The first section provides foundational information for the development of the original Edmonton Symptom



Assessment System. The second section describes the subsequent development of the Edmonton Symptom Assessment System – Revised (ESAS-r) and process for completing the instrument. The final section consists of examples of frequently asked questions to further clarify the administration and use of the ESAS-r.

2. Background Information

2.1 Development of the Edmonton Symptom Assessment System

One out of every four Canadians will die from cancer, with an estimated 80,800 cancer deaths occurring in Canada in 2017 [1]. Prior to death, many advanced cancer patients experience significant symptom burden. Patients within three months of death are two to four times more likely to report moderate to severe symptoms than patients earlier in the cancer trajectory [2]. Approximately 60% to 80% of patients will experience pain before death [3]. Other debilitating symptoms, including anorexia, nausea, asthenia, dyspnea and delirium, occur with similar or higher frequencies [4-6]. Psychological distress, such as depression or anxiety, is often associated with these debilitating symptoms [7-12]. Up to 30% of patients will experience an adjustment disorder [11], while 10% to 20% will develop a major depressive episode [9]. Despite this substantive symptom burden, advanced cancer patients' quality of life may be enhanced through appropriate symptom assessment and management [13].

The need for routine symptom assessments in advanced cancer was well recognized over twenty-five years ago, when Bruera and colleagues [14] developed the Edmonton Symptom Assessment System (ESAS). Although there are many cancer symptom assessment tools [15], the ESAS continues to dominate the symptom assessment field in advanced cancer and palliative care. It is brief, comprehensive and practical; relevant to palliative care; and entails minimum patient burden, which is particularly important for patients at end of life. The ESAS is used in palliative care and oncology programs throughout Canada [16, 17]. As of April 2017, cancer centres in eight out of ten provinces have implemented the ESAS-r for routine screening of symptom distress; in Ontario and Quebec, the ESAS-r is collected electronically by direct patient entry; in other provinces, the information is collected on paper only, or on paper with subsequent electronic entry. In a bibliometric analysis of the ESAS [20], 311 unique documents, published between 1991 and 2006, directly cited or made an uncited reference to the original paper. Since its inception, it is used extensively for clinical, research and administrative purposes [16, 21-25].

The substantive symptom burden in advanced cancer, with escalating symptom frequency and severity as patients approach death, challenges the palliative care community to develop systematic symptom assessment approaches as the first critical step to appropriate symptom management. Although this is a well-recognized need [26,

27], there is no universally accepted symptom assessment tool in advanced cancer and palliative care. The multidimensionality of symptoms; fluctuating, unpredictable course; subjective nature of the symptom experience; and frailty associated with advancing disease create significant challenges [26, 28]. To address these unique challenges of this vulnerable population, a symptom assessment tool needs to be comprehensive, dynamic, able to capture patients' subjective experiences and psychometrically sound, while still being practical and brief, with minimal patient burden.

The complexities of symptom assessment are reflected in the diversity of symptom assessment tools. In a systematic review of cancer symptom assessment instruments, Kirkova et al. [15] identified 21 instruments, with 15 of the 21 assessing multiple (five or more) symptoms. These 15 measures varied in terms of content (ranging from 9 to 65 items), scale format (numerical, categorical, visual analog), symptom dimensions (prevalence, severity, distress, frequency, interference), time frame (ranging from “at present time” to “weeks”) and assessor (patient, caregiver, family member). A conceptual overlap between symptom assessment and quality of life, particularly health-related quality of life [29], adds to this diversity. In a systematic review of quality of life measures in palliative care, Albers et al. [30] evaluated 29 instruments. Six instruments, including the ESAS, were included in this study, as well as Kirkova et al.'s [15] systematic review. In both studies, the authors could not recommend an “ideal” or single specific instrument (see Appendix A, Table A-1 for comparison of measures).

Although there may not be an ideal instrument, there are some pivotal reasons as to why the ESAS has had such a significant widespread uptake [20]. The ESAS [14] is a comprehensive, yet brief and practical self-reporting tool of symptom severity (intensity) for nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, shortness of breath), with the option of adding a tenth patient-specific symptom. The original version used visual analog scales, ranging from 0 (no symptom) to 100 mm (worst possible symptom), which have subsequently been changed to 11-point numerical rating scales, with higher scores representing worse symptom intensity [31]. A unique feature of the ESAS, which is not a component of other symptom assessment tools, is the ability to capture the fluctuation of symptoms over time, through the use of a graphing system (see Appendix A, Figure A-1.). Unlike some instruments that were developed in different contexts and then applied to palliative care (e.g. Symptom Distress Scale), the original ESAS was expert-derived and based on clinical experiences of caring for advanced cancer and palliative care patients.

No single tool will ever be able to capture the extensive complexities of symptom assessment in advanced cancer and palliative care patients [15, 32]. There will always be a trade-off between comprehensiveness and practicality. The ESAS was developed as a symptom screening tool, which ideally needs to be integrated within an in-depth clinical interview process. Its focus on a single dimension of symptom assessment (i.e. severity) with nine common symptoms is a compelling feature, in comparison with other more burdensome tools that are longer and combine different symptom assessment dimensions, such as intensity, distress and frequency. Kirkova et al. [28] recommend starting with a single dimension, such as severity or distress, which provides decision making information and can subsequently lead into a more in-depth assessment. They also suggest that the concomitant use of similar but separate scales (for severity and distress) can be confusing and an increased burden for patients. Health care providers value the ESAS for its brevity, practicality for identifying patient care issues, engagement of patients in symptom assessment and use as a teaching tool [24]. In a recent review of clinical instruments for hospice and palliative care [33], out of 129 instruments, the ESAS scored above the 75th percentile, receiving one of the highest scores (16/19) in terms of psychometric soundness and potential application in clinical quality measurement.

Reported barriers to implementing the ESAS extend beyond the features of the tool, itself, to concerns regarding implementation and relevancy in clinical practice. These include, but are not limited to, the lack of understanding regarding frequency of assessments, interpretation of the numerical rating scales and incorporation of patient preferences for symptom relief [24, 34]. In one study [24], participants reported concerns about high symptom ratings being interpreted as poor quality of care, as opposed to patients' preferences or expected changes associated with advancing disease. Attitudinal issues, such as viewing routine assessments as "unnatural" [24] or preferences to use own symptom assessments [34], reflect the limited knowledge translation activities associated with the ESAS dissemination. In our ESAS survey of palliative care and pain specialists [35], participants identified the need for better initial training and follow-up educational activities, to ensure its proper use in practice. This concern is being addressed in one of our group's studies, through the development of knowledge translation strategies.

Despite this substantive endorsement of the ESAS, there are inherent problems associated with how the tool is currently being used. Our research group has undertaken a series of studies to review the current status of the ESAS, identify

problematic areas associated with its use in clinical practice and develop a revised version, the ESAS-r. Based on this work, we have identified three key challenges with the rapid widespread uptake and current clinical use of the ESAS: (1) Extensive modifications made to the ESAS with little if any validity evidence to support these changes; (2) Problematic items that could lead to misinterpretation; and (3) Potential perception of the ESAS as a well validated tool with no further need to do validation studies.

Since its inception, the ESAS has undergone a variety of modifications, with little, if any, validity evidence to support these changes. Based on our literature review [36], we identified 13 validation studies published between 1991 and 2006. An update of this review (1991-2010), with seven additional psychometric studies published since 2007, appears in Table A-2 (see Appendix A). Sixteen studies used an English version, while four studies used a French [37], Italian [38], Spanish [39] or Turkish [40] translation. Of the 16 English studies, we identified eight different versions of the ESAS. Sources of variability included scale format, number of items, scale anchors, types of symptoms assessed and symptom order. In one study, symptoms were assessed over a 24 hour time period, as opposed to time of assessment, as originally intended [41]. Some studies collapsed continuous responses into categorical variables. A number of studies used a total symptom distress score as a measure of overall symptom burden, while other studies focused on independent symptoms. In some cases, modifications were made without direct reference in the text, resulting in potential misinterpretation of findings and inability to make cross study comparisons. There is no other tool that we are aware of that has undergone such profound changes without any supportive validity evidence.

Although the ESAS was designed for self-reporting, concerns have been raised about the potential for symptom reporting errors. In a nursing survey in the Edmonton Zone Palliative Care Program (EZPCP), only 14 of 48 staff (29%) agreed with the statement “The ESAS is easy for patients to understand” [42]. The two most frequent comments were patients’ difficulty in understanding the term, wellbeing, and confusion of tiredness and drowsiness. Garyali et al. identified potential errors in patient self-reports using the ESAS, including reverse scoring for sleep and appetite, inconsistent time frames for pain ratings and low specificities for fatigue, drowsiness, appetite and sleep [41]. In our think aloud study with 20 advanced cancer patients [43], problematic characteristics included confusing terminology (drowsiness vs. tiredness, depression, anxiety, wellbeing), reverse scoring for wellbeing and appetite, lack of coherent item order,

unclear time frame and need to include additional symptoms. Many of these concerns were confirmed in a replication think aloud study involving 11 Norwegian advanced cancer inpatients [44], as well as a survey of 84 health care providers working in palliative care and chronic pain [35].

Validity evidence has lagged behind the rapid, widespread uptake of the ESAS. In our initial literature review of validation studies (1991-2006) [36], 10 of the 13 identified studies were published eight or more years after the initial ESAS publication in 1991. Table A-3 summarizes the psychometric evidence for the ESAS, based on our literature review [36], plus seven additional psychometric studies published between 2007 and 2010 (see Appendix A). None of the earlier studies published between 1991 and 2006 addressed any of these concerns about problematic items, yet these references are often cited in the literature as supporting the ESAS as being a well-validated tool. Although this earlier work was foundational, a standardized version that addresses these concerns needs to be validated further, using more heterogeneous advanced cancer patients in both inpatient and outpatient settings.

3. Edmonton Symptom Assessment System – Revised

3.1 Development of the Edmonton Symptom Assessment System – Revised

Based on the concerns raised in the literature [41], the findings of our think aloud study [43] and our literature review of validation studies [36], a revised version of the ESAS, the ESAS-r (see section 3.3, page 9), was created. The ESAS-r retains the core elements of the ESAS, with key revisions as follows:

- The timeframe for symptom ratings is specified as “now”.
- Brief definitions have been added for the following symptoms: tiredness (lack of energy), drowsiness (feeling sleepy), depression (feeling sad), anxiety (feeling nervous) and wellbeing (how you feel overall). “Appetite” has been changed to “lack of appetite”.
- Related symptoms (e.g. tiredness and drowsiness; nausea and appetite; depression and anxiety) are grouped together, and “wellbeing” is now the ninth symptom at the end of the instrument.
- The example of “constipation” has been added to the tenth scale, “other symptom.”

In our multicentre study comparing the ESAS and ESAS-r in 160 palliative care patients [31], the ESAS-r was significantly easier to understand ($p=.008$) and preferred

($p < 0.001$) than the ESAS. Further validity evidence supports the adoption of the ESAS-r (see Appendix B).

3.2 Guidelines for Completion of the ESAS-r

(see Appendix C for ESAS-r Clinical Assessment Guide)

What is the ESAS-r?

The ESAS-r helps to assess nine common symptoms in palliative care patients. The ESAS-r is one valuable part of a holistic clinical assessment. It is not a complete assessment in itself.

Why?

The goal of this tool is to retrieve the patient's perspective of symptoms. It helps to direct treatment and to assess for treatment effects.

How?

The patient should be instructed to rate the severity of each symptom on a 0 to 10 scale, where 0 represents absence (or best possible intensity) of the symptom and 10 represents the worst possible severity. The number should be circled on the scale. The circled numbers can be transcribed onto the ESAS-r graph. The patient should be instructed to rate each symptom according to how s/he feels now. The health care professional may choose to ask additional questions about the severity of symptoms at other time points (e.g. symptom severity at best and at worst over the past 24 hours).

When?

The ESAS-r captures the pattern of symptom severity at a point in time. Repeating the assessment will track the changes over time. It is a good practice to do the ESAS-r at an initial encounter with the patient and during each follow-up telephone or personal contact.

Who?



It is preferable that the patient provides self-ratings of symptom severity. If the patient cannot complete the tool independently but can still provide input, then the ESAS-r is completed with the assistance of a caregiver (a family member, friend, health care professional).

Where?

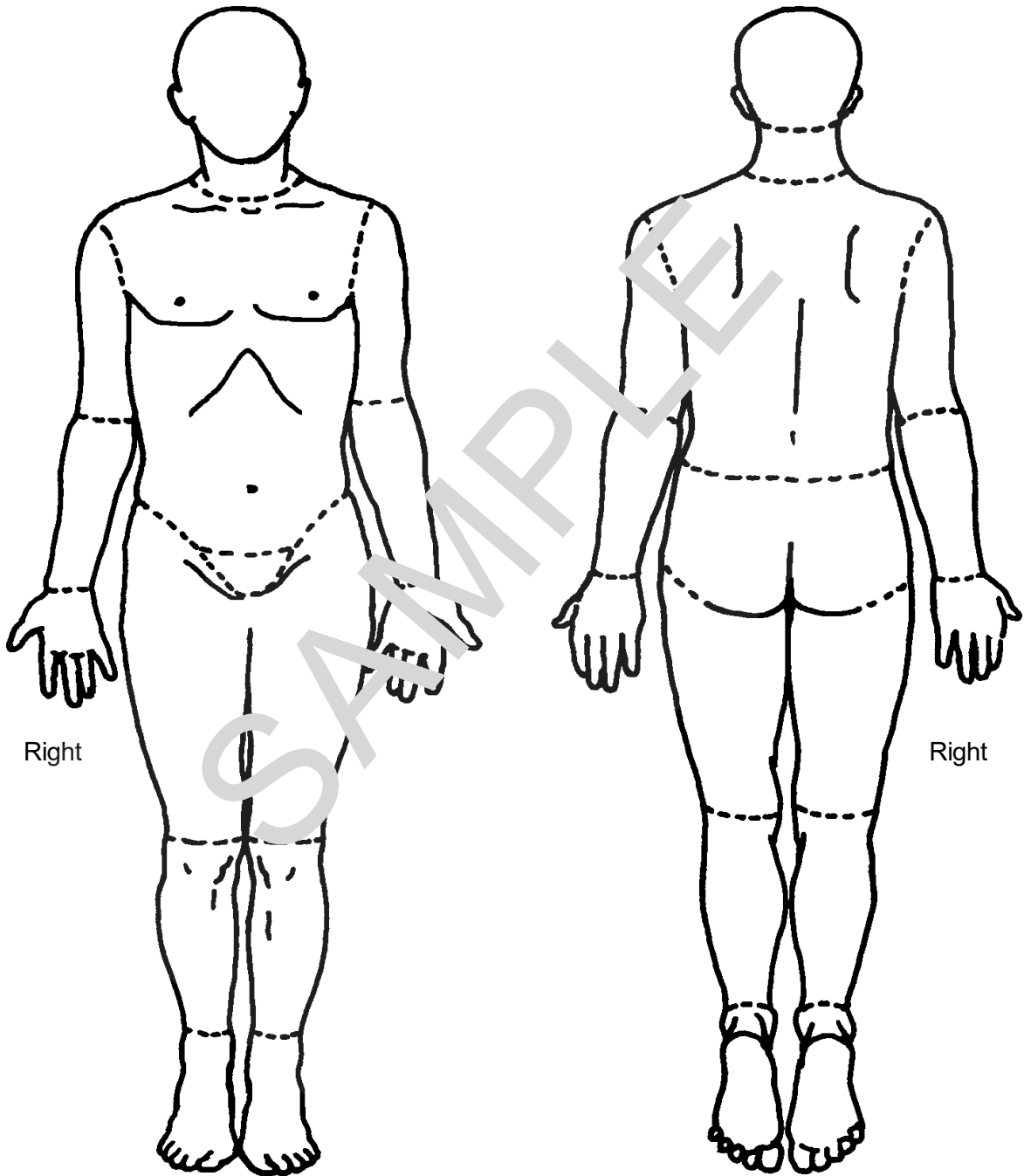
The ESAS-r is used in any setting where palliative care patients are assessed and cared for.

3.3 Sample of the ESAS-r (front and back sides)

A copy of the tool for use can be found at: <https://www.albertahealthservices.ca/frm-07903.pdf>

												
Edmonton Symptom Assessment System: (revised version) (ESAS-R)												
Please circle the number that best describes how you feel NOW:												
No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____
Patient's Name _____		Date _____		Time _____		Completed by (check one):						
						<input type="checkbox"/> Patient <input type="checkbox"/> Family caregiver <input type="checkbox"/> Health care professional caregiver <input type="checkbox"/> Caregiver-assisted						
						BODY DIAGRAM ON REVERSE SIDE						
ESAS-r Revised: November 2010												

Please mark on these pictures where it is that you hurt:



4. Frequently Asked Questions (FAQ)

4.1 Should there be a set time to do the ESAS-r (AM/PM)? Should there be a set frequency for completing the ESAS-r (daily/weekly)?

Each site should decide what time of day is best to administer the ESAS-r. Factors that need to be considered include the following: frequency of clinic appointments, time of day of patients' arrival, patient's cognition and stamina/energy level throughout the day. The frequency with which the ESAS-r should be completed depends on what type of site is administering it. For example, in the Edmonton Zone Palliative Care Program (EZPCP), the Tertiary Palliative Care Unit administers the ESAS-r every day, since the patients have been admitted for intensive symptom management. On the other hand, the University of Alberta Hospital consultation team administers the tool at initial consult with the physicians/nurse consultants, and thereafter when a re-assessment is needed. If symptoms are under good control, then it can be done weekly instead of daily to decrease patient burden. Please see Table A-4 (Appendix A) for a summary of administration processes across the EZPCP sites.

4.2 What are some of the benefits associated with using the ESAS/ESAS-r?

There are many benefits associated with using the ESAS-r:

- ✓ Health care professionals may view the trends of symptoms over time.
- ✓ Health care professionals can obtain a number that reflects how a patient is feeling at the time of the assessment and determine how to best help the patient.
- ✓ The standardized use of the ESAS-r creates consistency among staff members.
- ✓ The ESAS [24]/ESAS-r is brief and easy to use.
- ✓ The ESAS [24]/ESAS-r engages patients in their overall care.
- ✓ The routine use of a symptom assessment tool helps staff care for their patients and their patients benefit from its use [ESAS, 42]

4.3 What are some of the challenges associated with using the ESAS/ESAS-r?

There are some challenges associated with using the ESAS/ESAS-r:

- Some patients decline or are unable to give a specific numerical rating [ESAS, 42].
- There are translation or language issues [ESAS, 24].
- For some staff, it may be "unnatural to use pen and paper," as these assessments are usually done informally [ESAS, 24].

4.4 What kind of training would be best for your site?

There are many ways that staff may learn about the ESAS-r. Some approaches suggested by the EZPCP staff include:

- Group sessions
- One on one sessions
- Webinars
- Shadowing staff who are skilled in using the tool
- Written information distributed in staff mailboxes
- Case scenarios (e.g., on website)
- Online module (e.g., My Learning Link in Alberta Health Services)

4.5 What is the best way to teach the ESAS-r?

In the EZPCP, one way to educate staff about the ESAS-r would be through a health care professional from each site who receives extensive training and returns to his/her home site to train other staff members. Other methods could be a designated trainer (such as a Clinical Nurse Educator/Nurse Practitioner) who travels to each site to teach.

4.6 Who should be completing the ESAS-r?

Ideally, the patient should fill out the ESAS-r on his/her own to reflect his/her experience. When the patient is unable to complete the tool independently, a health care professional may score the ESAS-r, but it should be noted on the form that it was completed by a healthcare professional, rather than the patient.

4.7 What other information of interest could be added to the assessment?

Additional information of interest could include:

- Noting if rating is before or after an intervention
- Noting the best rating and worst rating in the past 24 hours
- Noting if the symptom only occurs with certain triggers

4.8 Which staff member should be in charge of administering the ESAS-r?

This question is site specific. In the EZPCP hospices, the health care aides mainly administer the form, while on the Royal Alexandra Hospital consultation team and the Community Consult Team, the physician and nursing staff administer the ESAS-r. Please refer to Table A-4 for more information on each site.

4.9 How can health care professionals get the most meaningful rating when patients are not able to fill out the ESAS-r on their own (caregivers such as family members or health care professionals rate for the patient)?

Family and health care professionals can each complete the ESAS-r and their corresponding answers can be compared.

4.10 What protocol can be taken to complete the ESAS-r if the patient is in isolation?

The Alberta Health Services (AHS) isolation policy does not address precautions for the use of paper specifically, but in principle, items should not be transferred from the patient room to other care areas.

4.11 What do you do when a patient provides more than one score for a single symptom on the ESAS-r?

If a patient gives more than one score while rating a symptom, then try to get clarification first. If the patient is still not able to provide a single number, the general rule is to take the score that is the worst. That score can then be graphed and compared over time.

4.12 What can you do when a patient is unable to give a numerical rating on the ESAS-r?

If you are completing the tool by pen and paper, then explain to the patient that it is very important that you get a numerical rating. This information is used to compare the trend of the numbers over a period of time. This can help with symptom interventions that ensure patients receive optimal care. It is a good idea to ask them if they need any clarification of the symptoms so that they can give a numerical rating. You may also ask them how a rating from the day in question would compare to an earlier day for which the patients actually gave a rating.

4.13 What rating should we record when a patient and family member disagree on a score given on the ESAS-r?

The patient and family member may disagree on a symptom rating. They may decide to discuss it and come to an answer together that they can report to you. If this is not possible, then the rating should be taken from the patient. If the patient has been filling out the form on a regular basis and there is some trending that could be shown, then the patient can be asked if the symptom was better or worse relative to each time point. Ideally, it would be interesting to report both ratings to better understand the reasons for the disagreement. This may not be practical with the current system, but would be of interest as part of the clinical assessment.

4.14 How can I ask about sensitive symptoms (depression, anxiety, wellbeing)?

It is best to ask the more sensitive questions later on in an interview so a patient does not close off the conversation. All the psychosocial symptoms have been grouped together at the end of the tool to assist with this.

4.15 How can I explain the importance of doing the ESAS-r to patients?

It is important to explain the significance of repeatedly completing the ESAS-r to patients. The main reason is that the tracking of symptoms provides a readily accessible visual representation of the patient's symptom profile over time.

We endeavor to provide the best patient care in a timely manner by capturing symptoms as they arise and avoiding a symptom crisis.

“Did you know....?”

Did you know that if you help a patient record his/her score on the ESAS-r, you should check off completed by the “patient” not “caregiver assisted”?

Did you know that it is important to bring up other symptoms of interest to rate that you may notice the patient having (e.g. coughing)?

Did you know that you do not need to have the patient complete the diagram on the back side of the ESAS-r every time you administer the form (only when a symptom location may change)?

Did you know that electronically administering the ESAS-r may speed up the process of completion?

Did you know that you may learn about the ESAS-r and how it is used in this manual, through our study staff and through the website

<https://www.albertahealthservices.ca/info/Page14546.aspx> (47)?

4.16 For what disease populations can the ESAS-r be used?

Originally, the ESAS was developed to capture symptoms in advanced cancer patients. Over time, its use has expanded to patients earlier in the cancer trajectory (see Table A-5, Appendix A) and with non-cancer diagnoses, such as nephrology (ESAS-r-RD) [54,55], chronic obstructive pulmonary disease [64,65], hepatology, heart failure [64-66], dementia [63] and Parkinson's disease (ESAS-r-PD) [67]. It has also been used in non-cancer settings, such as intensive care and long term care.

4.17 What is the minimal clinically important difference (MCID) in scores for the ESAS/ESAS-r?

A difference of two points on an 11-point (0-10) numerical rating scale or a 30% decrease in pain intensity has generally been recognized as being a minimum clinically important difference (MCID) for pain [61]. In one study of 276 advanced cancer patients receiving palliative radiation therapy who completed the ESAS, the MCID for clinical improvement was 1.1 (depression) and 1.2 (pain), while the MCID for deterioration ranged from 1.1 (depression, anxiety) to 1.8 (tiredness) [62]. In an international multicenter study including 796 advanced cancer patients, the optimal cutoff was ≥ 1 point for improvement and ≤ -1 point for deterioration for all symptoms, based on receiver-operating characteristic curves (68) Since these studies were conducted using the ESAS, further studies using the ESAS-r are warranted.

4.18 Are there copyright issues with using the ESAS-r?

The ESAS-r is in the public domain and freely available for use with appropriate acknowledgement of its source
<https://www.albertahealthservices.ca/info/page14546.aspx>

There is, however, a requesters’ permission form to be completed so its use can be tracked.

4.19 Where can all the translations of the ESAS-r be found?

Other translations of the ESAS-r (and ESAS) are available on the Cancer Care Ontario website. The languages included are:

***Disclaimer:** These tools have not been validated by AHS, nor the principal investigators. They are also not translations of the current version found in this manual.*

Albanian	Italian
Algonquin	Japanese
Arabic	Korean
Armenian	Oji Cree
Burmese	Polish
Chinese	Portuguese
Cree	Punjabi
English	Russian
Estonian	Serbo/Croatian
Farsi	Somali
Finnish	Spanish
French	Tagalog
German	Tamil
Greek	Turkish
Hindi	Ukrainian
Hungarian	Urdu
Inuktitut (Eastern Arctic Dialect)	Vietnamese

<https://www.cancercareontario.ca/en/guidelines-advice/symptom-side-effect-management/symptom-assessment-tool> [48]

4.20 How do we indicate who completed the ESAS-r?

The ESAS-r may be completed by any of the following individuals, depending on the patient's ability to independently provide self-reported symptoms:

- Patient
- Family Caregiver
- Health Care Professional Caregiver
- Caregiver Assisted

Please tick the appropriate box at the bottom of the ESAS-r form.

5. Summary

Canadians are living longer, with more complex conditions, necessitating the need for appropriate and timely access to palliative care services [45]. With our aging population and co-existence of multiple chronic illnesses, many people at the end of life will experience increased symptom burden and would benefit from systematic palliative care assessment and management approaches.

The ESAS-r [31] is a practical and concise screening tool for assessing symptom burden. It offers distinct advantages over the ESAS, while still retaining core elements of the original tool. The inclusion of definitions, reordering of items and clarification regarding time frame will reduce potential patient errors in tool completion and for self-report distress screening programs, such as electronic kiosks or the internet [18], where patients do not have immediate access to a health care professional. These definitions can also be helpful for training new staff in administering the ESAS-r and for ensuring consistency across clinicians in terms of explanations of symptoms.

At the present time, we believe that the ESAS-r offers the best systematic approach for assessing symptoms in patients receiving palliative care. The ESAS-r enhances clinical assessment, enables physicians and the inter-disciplinary team to appropriately manage patients' symptoms, and facilitates better allocation of resources. Further, this system can enable researchers to compare results of outcome surveys and clinical trials in palliative care cancer symptom management.

Our research group has conducted a series of studies for gathering validity evidence for the ESAS and ESAS-r (see Appendix B). Gathering further validity evidence for the ESAS-r will enhance its use in clinical practice, research and administrative settings. Ultimately, these proposed changes will reduce errors in symptom reporting, improve symptom assessment and strengthen its adoption as a standardized symptom assessment and distress screening tool in cancer patients in Canada, with future developments in aging, non-cancer and non-English speaking populations.

6. References

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Appendix A: Tables and Figures

Table A-1. Comparison of Symptom Assessment Measures for Cancer and Palliative Patients

Instrument	Item No.	Scale	Dimensions					Assessor		
			Presence	Severity	Distress	Freq	Interfere	Self	Assist	Caregiver
ESAS	9	NRS (0-10)		✓				✓	✓	✓
CAMPUS-R	10	VAS	✓	✓			✓	✓	✓	
CSS	12	NRS (0-10)	✓		✓			✓		
CSAI	20	LASA (1-15)	✓		✓			✓		
MDASI	19	NRS (0-10)	✓	✓			✓	✓		
MSAS	32	4&5-pt Likert	✓	✓	✓	✓		✓		
MSAS-SF	32	4&5-pt	✓		✓	✓		✓		
CMSAS	14	4&5-pt	✓	✓	✓			✓		
OTTAT	37	5-pt Likert		✓		✓		✓		
POMS	65	5-pt adj Rating						✓		
PSAR	9	NRS	✓	✓						✓
RSCL	30	4-pt Likert		✓				✓		
Reduced E-STAS	12	5-pt Likert	✓	✓	✓	✓				✓
SDS	13	5-pt			✓			✓		
SES	14	Yes/no	✓					✓		
Symptom Monitor	10	NRS (0-10)	✓	✓	✓			✓	✓	✓

Adapted from Kirkova et al [15] & Albers et al [37]-Abbreviations: ESAS, Edmonton Symptom Assessment System; CAMPUS-R, Cambridge Palliative Assessment Schedule; CSS, The Canberra Symptom Score Card; CSAI, Computerized Symptom Assessment Instrument; MDASI, M. D. Anderson Symptom Assessment Inventory; MSAS, Memorial Symptom Assessment Scale; MSAS-SF, Memorial Symptom Assessment Scale-Short Form; CMSAS, Condensed Memorial Symptom Assessment Scale; OTTAT, Oncology Treatment Toxicity Assessment Tool; POMS, Profile of Mood States; PSAR, Pain and Symptom Assessment Record; RSCL, Rotterdam Symptom Checklist; Reduced E-STAS, Reduced Extended Support Team Assessment Schedule; SDS, Symptom Distress Scale; SES, The Symptom Experience Scale; NRS, numerical rating scale; VAS, visual analog scale

Table A-2. Summary of ESAS Modifications (1991-2010)

First Author	Items	Language	ESAS Modifications
Visual Analog Scale			
Bruera [14]	8	English	8-item version used for descriptive study; 9 item version (including shortness of breath) plus “empty VAS” item (other symptoms) also described
Bruera [14], Philip [48], Nekolaichuk [49,50], Chang [51]	9	English	None
Stromgren [52]	9	unspecified	Not administered to patients
Visual Analog Scale/Numerical Rating Scale			
Pautex [36]	9	French	Replaced tiredness with weakness, added pain relief question at the end
Davison [53,54]	10	English	Modified anchor (worst possible to severe), additional symptom (pruritus).
Numerical Rating Scale			
Noguera [38]	6	Spanish	6-item scale limited to two symptoms (depression and anxiety) with 3 different descriptors per symptom; included 3 other questions regarding anorexia, fatigue, difficulty sleeping
Watanabe [42], Selby [55], Gill [56]	9	English	None
Moro [37]	9	Italian	None
Yesilbalkan [39]	9	Turkish	None
Garyali [40]	10	English	Replaced tiredness with fatigue, additional item for sleep, different order (wellbeing at end), modified anchor (worst possible o worst imaginable), symptom ratings over past 24 hours (vs. “now”)
Vignaroli [57]	10	English	Replaced tiredness with fatigue, wellbeing moved to end, main focus on depression & anxiety
Bush [58]	10	English	Additional item for sleep; wellbeing moved to end
Easson [59]	11	English	Additional items for abdominal discomfort/bloating and mobility (i.e. able to move normally)

Table A-3. Summary of Psychometric Evidence for the ESAS (1991-2010)

Year	First Author	Validity Evidence	Reliability
1991	Bruera [14]	Description of instrument	----
1993	Bruera [14]	Concurrent validity	Test-retest (1 hour)
1998	Philip [48]	Concurrent validity	----
1999a	Nekolaichuk [49]	----	Inter-rater
1999b	Nekolaichuk [50]	----	Inter-rater (raters by occasions)
2000	Chang [51]	Concurrent validity	Test-retest (1 day, 1 week) Internal consistency (Cronbach's α)
2002	Stromgren [52]	Content validity	----
2003	Pautex [36]	----	Inter-rater reliability
2006a	Davison [53]	Concurrent validity	Test-retest (1 week)
2006b	Davison [54]	Predictive validity	----
2006	Garyali [40]	Sensitivity & Specificity	Test-retest (same day)
2006	Moro [37]	Concurrent validity Sensitivity, Responsiveness	Test-retest (1 day)
2006	Vignaroli [57]	Concurrent validity Sensitivity & Specificity	----
2007	Easson [59]	Content validity, Responsiveness	Internal consistency (Cronbach's α) ^a
2008	Yesilbalkan [39]	Concurrent validity ^b	Internal consistency (Cronbach's α)
2009	Watanabe [42]	Construct validity	----
2009	Noguera [38]	Concurrent validity Sensitivity & Specificity	----
2010	Selby [55]	Sensitivity & Specificity	----
2010	Bush [58]	Concurrent validity	----
2010	Gill [56]	Concurrent validity	----


Table A-4. Description of EZPCP Site Usage of ESAS-r

EZPCP Site	How Often	Time of day	Who is involved	Other times used
St. Joseph's Hospice	Daily	Morning	Health Care Aids	Patient Bedside Rounds
Tertiary Palliative Care Unit	Daily	Evening	1) Physicians 2) Registered Nurses 3) Licensed Practical Nurses 4) Health Care Aids (usually)	Not reported
Royal Alexandra Hospital	1) Initial consult by physician 2) Then 2X per week by nursing staff 3) If unstable then done as needed	At time of assessment	1) Physician 2) Nursing staff	Not reported
Norwood Hospice	Daily	Alternate days and evenings	1) Health Care Aids (and patients) 2) Registered Nurses 3) Licensed Practical Nurses	Not reported
University of Alberta Hospital	1) Initial consult by physician 2) Then as needed when staff feels reassessment is needed (not often)	At time of assessment	1) Physician 2) Registered Nurses 3) Residents	Not reported
Edmonton General Hospice	Daily	End of day shift	1) Health Care Aids (only using the graph though, not the actual form) 2) Physicians (sometimes) 3) Registered Nurses and Licensed Practical Nurses on admission	Not reported
Cross Cancer Institute: Community Liaison	Initial outpatient assessment and follow-up, in person and by telephone	At time of assessment	Registered Nurses	Not reported
Cross Cancer Institute: Symptom Control	1) Outpatients: triage, initial consultation, follow up; triage and follow up may take place in person or by telephone. 2) Inpatients: initial consultation and follow up	At time of assessment	1) Registered Nurses 2) Pharmacist 3) Physician	Not reported
Community Consult	Initial visit at the beginning of the interview	At time of assessment	1) Registered Nurses 2) Physicians	Not reported
Home Care	Most time staff visit clients' homes	At time of assessment	1) Registered Nurses (majority) 2) Licensed Practical Nurses 3) Respiratory Therapists 4) Occupational Therapists 5) Social workers	Not reported
Cross Cancer Institute: Interdisciplinary Team	1) Only in Pain and Symptom Clinic 2) Can be done by telephone before clinic visit (to see trends/changes)	morning	1) Dieticians 2) Respiratory Therapists 3) Pharmacist 4) Occupational Therapists 5) Physiotherapist 6) Speech Language Pathologists 7) Supportive care council (larger scale) 8) psychosocial staff (psychologists, art therapists, spiritual care)	1) Pharmacist would like to use for inpatients as well. 2) Occupational Therapists may use rating scale for some items in other assessments

Table A-5: ESAS Validation Studies in Early (Non-Palliative) Cancer Populations

First Author	Sample Size	Population	Country	Validity Evidence	Other Measures	Reliability
Chang ¹ (13)	240	inpatients (140) & outpatients (100)	USA	Concurrent	FACT, MSAS, KPS, BPI	Test-retest (2d, 1 wk)
Yesilbalkan (40)	113	inpatients & outpatients, chemotx units	Turkey	Concurrent		Internal consistency
Steinberg (69)	98	lung (new diagnosis)	Canada	Concurrent Predictive	DT	----
Barbera (2)	23,802	outpatients (mixed)	Canada	Discriminant	PPS, gender, comorbidity, survival	----
Granda-Cameron (70)	11	Sarcoma (new diag, on chemo)	USA	Change over intervention	FACT-G	----
Yi (71)	97	Breast cancer survivors	USA	----	QOL-BC	----
Kurt (72)	50	inpatients & outpatients (chemo tx)	Turkey	Change over intervention	----	----
Rhondali ¹ (73)	146	outpatients	Canada	Concurrent Sensitivity Specificity	BEDS	----
Akin (74)	119	patients on chemotx unit	Turkey	----	----	Inter-rater agreement
Bagha ¹ (75)	1215	outpatients (mixed)	Canada	Sensitivity Specificity	GAD-7 PHQ-9 DART	----
Kwon(76)	200	Outpatients, Early vs. late referrals to Supportive Care	USA	Discriminant	----	----

Figure A-1: The Original ESAS



PASTE PATIENT ID LABEL HERE

*SYMPTOM CONTROL & PALLIATIVE CARE
INPATIENT- NEW & FOLLOW-UP*

**Edmonton Symptom Assessment System
Numerical Scale
Palliative Care Program**

DATE: _____

Please circle the number that best describes:

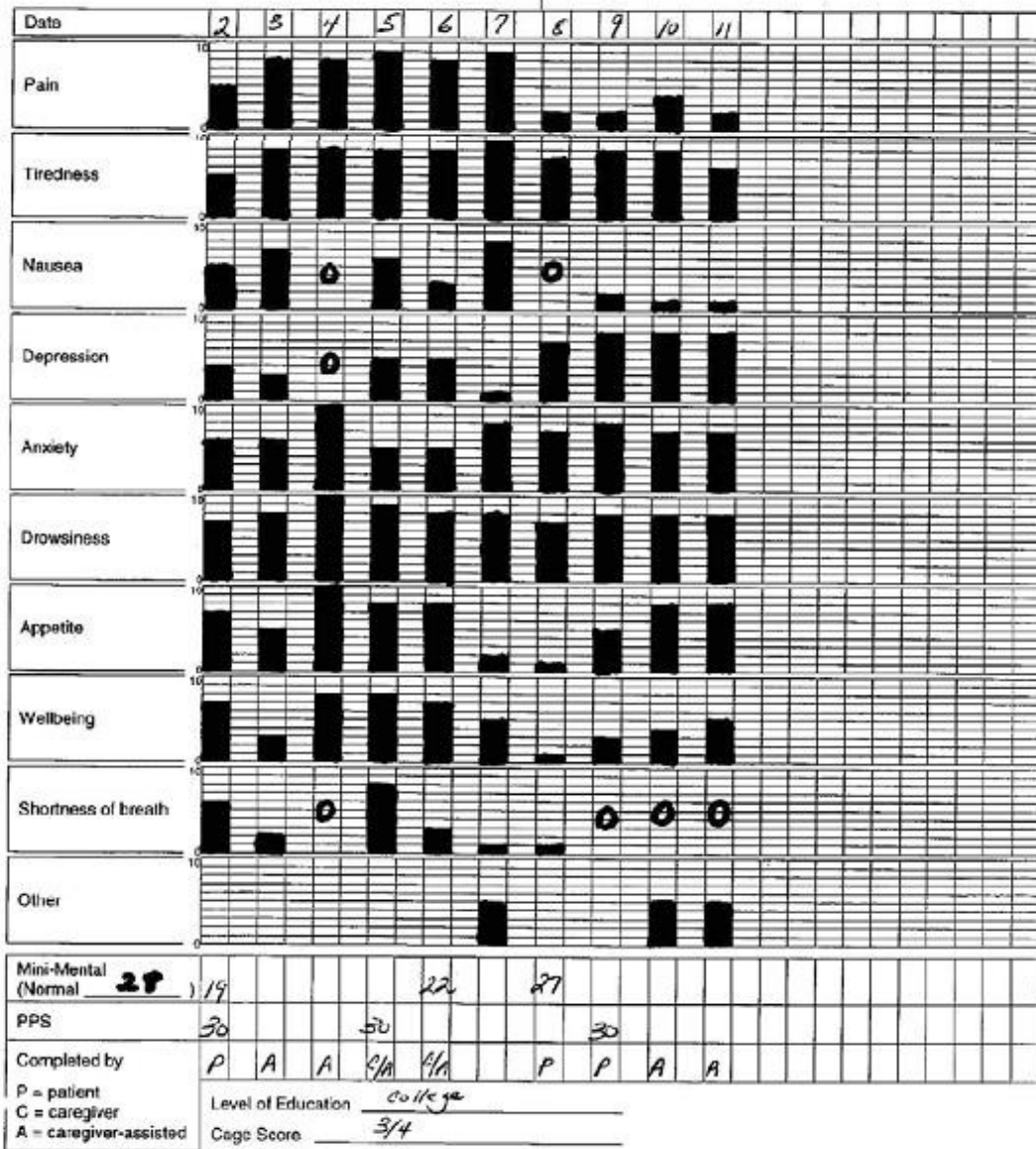
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Edmonton Symptom Assessment System Graph (ESAS)



CH-0208 Jun 2001

Appendix B

Titles of Validation Studies

1. Watanabe S, Nekolaichuk C, Beaumont C, Mawani A. The Edmonton Symptom Assessment System (ESAS): what do patients think? [abstract]. *Palliative Medicine* 2008; 22(4): 456. Support Care Cancer. 2009 Jun;17(6):675-83. doi: 10.1007/s00520-008-0522-1. [Poster No. 187, 5th Research Forum of the European Association of Palliative Care, Trondheim, Norway, May 28-31, 2008].
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7. Nekolaichuk C, Watanabe S, Mawani A. What is the most appropriate time frame for assessing symptoms? A validation study of the Edmonton Symptom Assessment System-Revised (ESAS-r) in advanced cancer patients [abstract]. *European Journal of Palliative Care* (in press). [Poster No. 216, 8th World Research Congress of the European Association of Palliative Care, Lleida, Spain, June 5-7 2014 & Society of Palliative Care Physicians Annual Meeting, Toronto, ON, May 29-31, 2014]. doi: 10.1177/0269216314532748



Appendix C

Guidelines for Administration of the ESAS-r (Clinical Assessment Guide)

Purpose

The *ESAS* is a tool that was developed to assist in the assessment of nine symptoms that are common in palliative care patients: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing (1). There is also a blank scale for patient-specific symptoms.

The *ESAS* has been revised to improve ease of understanding and completion for patients (2). The revised version of the tool is known as the *ESAS-r*. Changes include specifying a timeframe of “now”, adding definitions for potentially confusing symptoms, modifying the order of symptoms, adding an example for “other symptom”, and altering the format for improved readability.

The *ESAS-r* is intended to capture the *patient’s perspective* on symptoms. However, in some situations it may be necessary to obtain a caregiver’s perspective. The *ESAS-r* provides a profile of symptom severity *at a point in time*. Repeated assessments may help to track changes in symptom severity over time. The *ESAS-r* is *only one part of a holistic clinical assessment*. It is not a complete symptom assessment in itself.

General Information - How to administer the ESAS-r

- It is recommended that the patient complete the *ESAS-r* *with guidance from a health care professional*, especially on the first occasion.
- The patient should be instructed to rate the severity of each symptom on a *0 to 10 scale*, where 0 represents absence of the symptom and 10 represents the worst possible severity. The number should be circled on the scale.
- The patient should be instructed to rate each symptom according to how he or she feels *now*. The health care professional may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.
- **Definitions** have been added to items that have been found to be more problematic for patients to understand or rate (3); it is recommended to review these with the patient:
 - Tiredness - lack of energy
 - Drowsiness - feeling sleepy
 - Depression - feeling sad
 - Anxiety - feeling nervous
 - Wellbeing - how you feel overall
- With the previous version of the *ESAS*, patients often *reversed the scale for appetite* i.e. they considered “0” as “no appetite” and “10” as “best appetite”. The scale has now been re-labeled as “lack of appetite”. Coaching patients on the correct direction of the scale is still recommended.
- The *body diagram* on the reverse side of the *ESAS-r* can be used to indicate sites of pain.
- The circled numbers can be transcribed onto the *ESAS-r graph*.

When to do the ESAS-r

- In palliative home care, it is a good practice to complete and graph the ESAS-r during each telephone or personal contact. If symptoms are in good control, and there are no predominant psychosocial issues, then the ESAS-r can be completed weekly for patients in the home.
- In hospice and tertiary palliative care units, the ESAS-r should be completed daily.
- In other settings, palliative care consultants will utilize this tool upon initial assessment and at each follow-up visit.

Who should do the ESAS-r

- It is preferable for the patient to provide ratings of symptom severity by himself/herself.
- If the patient cannot independently provide ratings of symptom severity but can still provide input (e.g. when the patient is mildly cognitively impaired), then the ESAS-r is completed with the assistance of a caregiver (a family member, friend, or health professional closely involved in the patient's care).
- If the patient cannot participate in the symptom assessment at all, or refuses to do so, the ESAS-r is completed by the caregiver alone. The caregiver assesses the remaining symptoms as objectively as possible. The following are examples of objective indicators:

Pain – grimacing, guarding against painful maneuvers

Tiredness – increased amount of time spent resting

Drowsiness – decreased level of alertness

Nausea – retching or vomiting

Appetite – quantity of food intake

Shortness of breath – increased respiratory rate or effort that appears to be causing distress to the patient

Depression – tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern

Anxiety – agitation, flushing, restlessness, sweating, increased heart rate (intermittent), shortness of breath

Wellbeing – how the patient appears overall

If it is not possible to rate a symptom, the caregiver may indicate “U” for “Unable to assess” on the ESAS-r and ESAS-r Graph.

The method of completion of the ESAS-r must be indicated in the space provided at the bottom of the ESAS-r and the ESAS-r Graph as follows:

Bottom of ESAS-r Numerical Scale

Completed by (*check one*):

- Patient
- Family caregiver
- Health care professional caregiver
- Caregiver-assisted

Bottom of ESAS-r Graph

Insert letter from key in date column (date indicated at the top of form)

Completed by □□□□□□

Key:

- P = Patient
- F = Family caregiver
- H = Health care professional caregiver
- A = Caregiver-assisted

Where to document the ESAS-r

- *The ESAS-r is always done on the ESAS-r numerical scale and the results later transferred to the ESAS-r Graph. Graphing symptom severity directly onto the ESAS-r Graph without the use of the numerical scale is not a valid use of the ESAS-r, nor a reliable method of symptom assessment (attention to the graphed historical trend may affect the current scores and thus undermine one of the main purposes of the ESAS, i.e. to assess the current symptom profile as accurately as possible).*

Other information about the ESAS-r

- The ESAS-r Graph contains space to add the patient's Folstein Mini-Mental State Examination score. The "normal" box refers to the cutoff for a normal score for the patient, based on age and education level (see Instructions for MMSE).
- A space for the Palliative Performance Scale (PPS) is also provided.
- The ESAS-r is available in other languages, although most translations have not been validated (4).

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3. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multi-centre study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage* 2011;41: 456-468.
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ACCESS to FORMS

<https://www.albertahealthservices.ca/info/page14546.aspx> - (Assessment approaches tab)

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University of WA Palliative Care Training Center

University of Washington School of Medicine

Palliative Care Institute-Western Washington University

Washington State Hospice and Palliative Care Organization

Providence St. Joseph Health Services

Providence Northwest Telehealth

Northwest Regional Telehealth Resource Center

The Lookout Coalition

