The Washington Rural Palliative Care Initiative Handbook

July 2020
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Welcome

When rural community members are living with serious illness, it is quite stressful to leave the community, familiar places, and supportive people, to travel to care in a distant city. That distant care may try to fix an illness that will inevitably progress rather than staying focused on quality of life as defined by the patient.

In this exciting work, rural health teams and other members of the community work to improve an approach to serious illness, improve coordination across local care settings, build non-medical supports, 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 community members find out it is possible to stay home with the support of palliative care, there can be tremendous relief.

When you develop a new approach, there are wonderful gifts as well as challenges along the path, and we are so pleased that your community has decided to join us.

Pat Justis
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Executive Director, Rural Health
Office of Community Health Systems
WA State Department of Health

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Mobile 360-338-2875
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 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

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

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


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

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.  
- Data from 2017 show 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 ten rural Washington counties will have greater than 30 percent of the population age 65 and older and 25 percent or more of the population in another 12 rural counties.
- “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.”
- 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 hospitals

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6 Ibid

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WRPCI Structure Diagram

**Palliative Care - Rural Health Integration Advisory Team (PC-RHIAT)**

- **Core Guidance/Steering**
- **Coordination**
- **Cohort selection/ Policy/ Funding/Evaluation/Communication/Research**
- **Centers of Excellence**

**COHORT 1**
- Six rural health organizations
  - Clinical and Culture Work Group (Now ad hoc)

**COHORT 2**
- Nine rural health organizations
  - Telemedicine Work Group (currently active)
  - Community Engagement Group (Now ad hoc)

Community teams for each community
Washington Rural Palliative Care Initiative
Getting Started: A Map to Key Steps

Set the stage

Step 1
Educate leadership

Step 2
Select team leads and champions

Step 3
Integrate activities in team lead calendars

Step 4
Begin to shape a vision for your clinical model

Assess your current state and set a direction

Step 5
Recruit your community team

Step 6
Asset and Gap Analysis in community meeting 1

Step 7
Action Plan and education in DOH-facilitated community meeting 2
Design and test workflows

Step 8
Decide on who will be on the interdisciplinary clinical team

Step 9
Decide on patient population and care setting for first tests of change

Step 10
Define who will screen patients and plan the overall workflow step by step

Step 11
Train the coding and billing teams

Step 12
Design a community education strategy

Step 13
Perform practice screens to profile the needs of the population

Step 14
Design clinical workflow and documentation systems

Step 15
Select measures and set up systems for capturing

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## Washington Rural Palliative Care Initiative

<table>
<thead>
<tr>
<th>Activity Name</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asset and gap analysis</td>
<td>One time</td>
<td>A community team completes the tool using dialogue to develop shared perceptions.</td>
</tr>
<tr>
<td>Community meeting 1 and 2</td>
<td>One time</td>
<td>Meeting 1 completes the asset and gap analysis and is facilitated by the team lead(s). Meeting 2, facilitated by the DOH team, offers palliative care education, and a process to develop the action plan.</td>
</tr>
<tr>
<td>Community meeting 3</td>
<td>One time</td>
<td>These community meetings occur one year after the initial startup and review the action plans and progress made, then decide on plans for the future.</td>
</tr>
<tr>
<td>Action plan development</td>
<td>Initial plan and one update a year later</td>
<td>Occurs in Community Meeting 2 and sets smart objections, action steps and measures of success.</td>
</tr>
<tr>
<td>Mentoring calls</td>
<td>4-6 times per year</td>
<td>One or more members of the cohort team have an opportunity to discuss their action plan, explore needed resources, vent frustrations and explore next step with Pat Justis at DOH and sometimes other DOH team members.</td>
</tr>
<tr>
<td>Telehealth case consults</td>
<td>Once per month</td>
<td>All cohort sites rotate to present clinical cases for an interdisciplinary review and discussion using secure telehealth connections.</td>
</tr>
<tr>
<td>PC-RHIAT meetings</td>
<td>monthly</td>
<td>The advisory team for the WA Rural Palliative Care Initiative guides the planning process, gives 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.</td>
</tr>
<tr>
<td>Cohort Roundtables</td>
<td>4-5 per year</td>
<td>A discussion among Cohort site participants about the challenges, surprises and pleasures of</td>
</tr>
<tr>
<td>Activity Name</td>
<td>Frequency</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------------</td>
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</tr>
<tr>
<td>The PC Lounge Meetups</td>
<td>Ad hoc</td>
<td>An optional idea that can occur if people would like an informal forum for getting to know each other.</td>
</tr>
<tr>
<td>Virtual Education Series</td>
<td>5 sessions per year</td>
<td>Education should not be deadly boring PowerPoints so we hold our webinars talk show style, to offer an interactive, lively method of education. We do slip in a slide or two. Topics alternate between telehealth and the practice of palliative care. Please note: we will be opening all sessions to a wider rural health audience.</td>
</tr>
<tr>
<td>Complex Conversations skill workshops</td>
<td>1-2 times per year</td>
<td>A skill-building day for palliative care.</td>
</tr>
<tr>
<td>Metrics</td>
<td>quarterly</td>
<td>Upload data to a common site for aggregation across the initiative.</td>
</tr>
<tr>
<td>Mini-grants</td>
<td>12 month work plan</td>
<td>Develop a work plan for one of four categories, telemedicine, education, strategies for sustaining, work flow development</td>
</tr>
</tbody>
</table>
Participation levels with expectations

Guiding principles
1. Rural communities can set their own goals and pace for change.
2. Any progress is a success.
3. The initiative is intended to be supportive but not prescriptive.
4. The DOH team needs to assure they use their resources wisely and seeks to invest in rough proportion to the level of community engagement. This drives the participation levels offered.
5. Community engagement can be reassessed at any time.
6. Mini-grants will be available to full participants.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Building a foundation for participation</th>
<th>Moderate participation</th>
<th>Full participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asset and gap analysis</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Community meeting 1 and 2</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Community meeting 3</td>
<td></td>
<td></td>
<td>X</td>
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<tr>
<td>Action plan development</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Mentoring calls</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Telehealth case consults</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Project Echo events with Providence and Four Seasons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PC-RHIAT meetings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Building a foundation for participation</td>
<td>Moderate participation</td>
<td>Full participation</td>
</tr>
<tr>
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</tr>
<tr>
<td>Cohort Roundtables</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The PC Lounge Meet ups</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Virtual Education Series</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>In Person Cohort Plus In Person PC-RHIAT</td>
<td>X</td>
<td></td>
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<tr>
<td>Complex Conversations skill workshops</td>
<td>X</td>
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<td></td>
</tr>
<tr>
<td>Metrics</td>
<td>optional</td>
<td></td>
<td>Completes</td>
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<tr>
<td>Mini-grants</td>
<td>optional</td>
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<tr>
<td>Asset and gap analysis</td>
<td>optional</td>
<td></td>
<td>Completes</td>
</tr>
<tr>
<td>Community meeting 1 and 2</td>
<td>optional</td>
<td></td>
<td>Completes</td>
</tr>
<tr>
<td>Community meeting 3</td>
<td>optional</td>
<td></td>
<td>Completes</td>
</tr>
<tr>
<td>Action plan development</td>
<td>optional</td>
<td></td>
<td>Completes</td>
</tr>
<tr>
<td>Mentoring calls</td>
<td>Optional, if scheduled notifies DOH if unable to attend</td>
<td></td>
<td></td>
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<tr>
<td>Telehealth case consults</td>
<td>May arrange to observe</td>
<td>Attends at least four</td>
<td>Attends at least 50% of scheduled calls and notifies DOH when unable to attend, presents case at least once during the year</td>
</tr>
<tr>
<td>Project Echo events with Providence and Four Seasons</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Building a foundation for participation</td>
<td>Moderate participation</td>
<td>Full participation</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-----------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>PC-RHIAT meetings</td>
<td>Leads attend at least 50 %</td>
<td>Attends 70% of meetings and notify DOH when unable to attend</td>
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</tr>
<tr>
<td>Cohort Roundtables</td>
<td>Leads attend at least 50 %</td>
<td>Attends 70% of meetings and notify DOH when unable to attend</td>
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</tr>
<tr>
<td>The PC Lounge Meet ups</td>
<td>optional</td>
<td>optional</td>
<td>optional</td>
</tr>
<tr>
<td>Virtual Education Series</td>
<td>optional</td>
<td>Attends at least 3 of 5 events</td>
<td>Attends at least 3 of 5 events</td>
</tr>
<tr>
<td>In Person Cohort Plus In Person PC-RHIAT</td>
<td>optional</td>
<td>optional</td>
<td>Attends</td>
</tr>
<tr>
<td>Complex Conversations skill workshops</td>
<td>optional</td>
<td>Sends at least one person</td>
<td>Attends and or recruits colleagues to attend</td>
</tr>
<tr>
<td>Metrics</td>
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<td></td>
<td>Selects at least 2 measures to contribute</td>
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<tr>
<td>Mini-grants</td>
<td></td>
<td></td>
<td>Participates</td>
</tr>
</tbody>
</table>

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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.

Participants in WRPCI also have access to password protected team spaces.

The WRPCI Portal holds an ever growing set of resources on palliative care in one place and easily accessed.

Visit

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

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Rural Palliative Care: Community Team Development

Building

- 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.

Evolving

- 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.

- 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.

Thriving

- 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.

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.

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What is a Rural Palliative Care Community Team?

May be formed with existing Rural Health Councils or other current group or newly gathered.

- Critical Access Hospital (CAH) champions
- Rural Health Clinic (RHC) champions
- Home Health & Hospice, Home Care
- Key community organizations
- Long term care
- Patient, family, care partners

Community work plan

Community education forums
Using media and a trained facilitator to provide both information and support dialogue

Clinical approaches, culture change and training within healthcare organizations

Health setting work plan

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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 Councils or other existing groups can be considered.

Potential participants in a community meeting about rural palliative care

Hospital – Including discharge planners, physicians/providers, hospital leaders, nursing, care coordinators, pharmacists, chaplains if on staff
Skilled nursing facilities
Long-term care
Home health/hospice agencies
Hospice medical directors
EMS
Health Home Care Managers
Community pharmacies
Private nursing and home care agencies
Area Council on Aging and their case managers
Parish nurses and cross-denominational chaplains
Senior centers and senior services
Community Action Councils
Assisted Living directors
Senior Housing
Adult Family Home operators
Primary care providers
Behavioral health providers
City / county government
Civic leaders and service clubs
Accountable Communities of Health representatives
Housing Authority
Patient and family perspectives (please see team role descriptions for screening tips)
Nursing schools
Medical Schools
Osteopathic schools
Social work association or other professional associations
Oncologists
Pulmonologists
Sample invites

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

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, and 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, long-term care facilities, or people’s homes. For more information on palliative care, go to [www.getpalliativecare.org](http://www.getpalliativecare.org).

Washington State Office of Rural Health, at Washington State Department of Health, facilitates the Learning Action Network (LAN) 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 participating to 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 develop our community action plan and assure we build a common understanding of palliative care..

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>
Top leadership  Palliative Care day to day lead
Sample Agenda for Meeting 1 with guidance

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.


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 is one of seven communities in rural Washington State invited to participate in this 24-month visioning and planning program to develop or strengthen palliative care services in our communities. The goal of this process will be to identify and develop an action plan to develop or enhance palliative care services. Washington Department of Health (DOH) State Office of Rural Health (SORH) is supporting the program.

3. **Review/Discuss definition of Palliative Care vs. Hospice to help ensure team has a shared understanding:**
   - **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. 8

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8 Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care.
• **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.9

**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 have in place?
   - What aspects of palliative care would you prioritize as most important for our team to focus on?

**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 on-going team communication (e-mail, calls)?
     - What roles do we need have in place to operate as a team and what organizations/people can take on those roles (i.e., organizer, facilitator, note taker, time keeper, 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**

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Sample agenda

{Name of Palliative Care Community}

ACTION Planning Session

Date XX, 2020

AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 minutes</td>
<td>Welcome and Introductions</td>
</tr>
<tr>
<td>60 minutes</td>
<td>Palliative Care and Community Capacity Building</td>
</tr>
<tr>
<td>45 minutes</td>
<td>Lunch</td>
</tr>
<tr>
<td>75 minutes</td>
<td>Case Studies - Clarify community focus area(s)</td>
</tr>
<tr>
<td>30 minutes</td>
<td>Model for Improvement and Action Plan Basics</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Break</td>
</tr>
<tr>
<td>90 minutes</td>
<td>Community Action Plan Development</td>
</tr>
<tr>
<td></td>
<td>• Goals and aim</td>
</tr>
<tr>
<td></td>
<td>• Measures</td>
</tr>
<tr>
<td></td>
<td>• Work plan (timeline, responsibilities...)</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Wrap-up</td>
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<tr>
<td></td>
<td>Identify additional resources needed</td>
</tr>
<tr>
<td></td>
<td>Next steps for team and initiative</td>
</tr>
</tbody>
</table>

Objectives:
As a result of this session, the participant will be able to:

- Describe desired clinical outcomes and processes of palliative care
- Recognize the importance of developing relationships across the continuum to improve transitions of care and care coordination for patients and families
- Develop an initial goal and action plan for palliative care in your community
- Identify resources available to support palliative care

Washington State Office of Rural Health

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Rural Community-Based Palliative Care

Asset and Gap Analysis

Each Community Team participating in the Rural Community-Based Palliative Care Project is required to complete this Asset and Gap Analysis aimed at identifying the resources, needs, and opportunities in your community to develop, implement, and sustain successful palliative care services.

Please work with your Community Team to gather the below information, and either return completed form to Washington State Department of Health-State Office of Rural Health by Month Day 2020

Send completed forms to: Pat Justis
Email: patricia.justis@doh.wa.gov
Or mail to:
Washington State Department of Health-State Office of Rural Health
Attn: Pat Justis
Mail: PO Box 47853,
Olympia WA 98504-7853

Feel free to contact Pat Justis at patricia.justis@doh.wa.gov or 360-236-2805 with any questions.

Definitions

- Community Team refers to the organizations and individuals working together on this project.
• **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. **

• **Hospice care** is a service that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual 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 care further addresses the bereavement needs of the family following the death of the patient.*

**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.**

Services and Processes

The following questions are helpful in assessing the current level of services in your community and prioritization of improvement opportunities.

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

<table>
<thead>
<tr>
<th>Services</th>
<th>Currently available in our community?</th>
<th>Provided by an organization on our Community Team?</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Yes  No</td>
<td>Yes  No</td>
</tr>
<tr>
<td>Adult/geriatric nurse practitioner</td>
<td>☐  ☐</td>
<td>☐  ☐</td>
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<tr>
<td>Bereavement care (apart from hospice)</td>
<td>☐  ☐</td>
<td>☐  ☐</td>
</tr>
<tr>
<td>Case management for chronic disease</td>
<td>☐  ☐</td>
<td>☐  ☐</td>
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<tr>
<td>Community health workers</td>
<td>☐  ☐</td>
<td>☐  ☐</td>
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<tr>
<td>Home care (supportive care)</td>
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<td>---------------------------</td>
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<tr>
<td>Home health services (medical care)</td>
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<tr>
<td>Hospice care</td>
<td></td>
<td></td>
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<tr>
<td>Medical social worker</td>
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<td></td>
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<tr>
<td>Pain management consultation</td>
<td></td>
<td></td>
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<tr>
<td>Parish nursing</td>
<td></td>
<td></td>
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<tr>
<td>Pastoral care/chaplaincy</td>
<td></td>
<td></td>
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<tr>
<td>Respite care for family caregivers apart from hospice</td>
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<td></td>
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<tr>
<td>Support groups, such as caregiver support groups or grief support groups</td>
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<td></td>
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<tr>
<td>Transportation</td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify):</td>
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</tbody>
</table>

Comments:

2. On a scale of 0 to 4, with 4 being the highest, rate your overall health care community’s current level of experience/expertise in the following areas.

<table>
<thead>
<tr>
<th>Palliative Care Core Processes</th>
<th>Rate level of expertise</th>
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<tbody>
<tr>
<td></td>
<td>None</td>
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<tr>
<td>Bereavement care (apart from hospice)</td>
<td>0</td>
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<tr>
<td>Continuity of care/care management</td>
<td>0</td>
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<tr>
<td>Family conferencing with goals of care discussions</td>
<td>0</td>
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<tr>
<td>Hospice</td>
<td>0</td>
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<tr>
<td>Interdisciplinary team care</td>
<td>0</td>
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<tr>
<td>Pain management consultation</td>
<td>0</td>
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<tr>
<td>Staff education on palliative care</td>
<td>0</td>
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<tr>
<td>Symptom management (other than pain)</td>
<td>0</td>
</tr>
</tbody>
</table>

3. Do members of your health care community work in more than one setting? For example, the hospital social worker also sees patients in the nursing home.

☐ Yes     ☐ No
If yes, list which disciplines and their settings:

4. 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.

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<tr>
<th>Opportunities for improving care</th>
<th>Rate level of opportunity to improve care</th>
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<tr>
<td></td>
<td>None</td>
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<tr>
<td>Advance directives assistance</td>
<td>0</td>
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<tr>
<td>Alternatives to hospital admission at end of life</td>
<td>0</td>
</tr>
<tr>
<td>Chronic disease case management</td>
<td>0</td>
</tr>
<tr>
<td>Comprehensive care plan for those requiring comfort care</td>
<td>0</td>
</tr>
<tr>
<td>Home visits as part of care coordination (not part of home health services or home care)</td>
<td>0</td>
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<tr>
<td>Pain management consultation</td>
<td>0</td>
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<tr>
<td>Providing education to families/caregivers about caring for people with advanced illness</td>
<td>0</td>
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<tr>
<td>Providing education to staff about caring for people with advanced illness</td>
<td>0</td>
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<tr>
<td>Psychosocial support for patient/family</td>
<td>0</td>
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<tr>
<td>Referrals to hospice, home health services, home care, or other placements</td>
<td>0</td>
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<tr>
<td>Spiritual care</td>
<td>0</td>
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<tr>
<td>Symptom management consultation</td>
<td>0</td>
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<tr>
<td>Transitioning the plan of care between hospital, nursing home, home care, etc.</td>
<td>0</td>
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<tr>
<td>Other (please specify):</td>
<td>0</td>
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</tbody>
</table>
5. On a scale of 0 to 4, with 4 being the highest, rate how well you believe that pain and symptom management needs are being met in your community?

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<tr>
<th>Not met</th>
<th>Moderately met</th>
<th>Fully</th>
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<tr>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>3</td>
<td>4</td>
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</tbody>
</table>

6. On a scale of 0 to 4, with 4 being the highest, rate how well you believe that current care transition processes meet the needs of patients in your community?

<table>
<thead>
<tr>
<th>Not met</th>
<th>Moderately met</th>
<th>Fully</th>
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<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td></td>
<td>3</td>
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</table>

Population Served by Your Community Team
The following information will be valuable in determining the need for palliative care services and the potential patient volume in your community, as well as helping plan and identify resources.

7. In which of these specific health care settings do you want to focus your 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):

8. Would you like to target your palliative care services in these specific patient populations?

☐ Yes ☐ No Chronically ill patients with multiple, complex problems and dependency
☐ Yes ☐ No Critically ill/ICU patients
☐ Yes ☐ No Frail elderly patients
☐ Yes ☐ No Oncology
☐ Other (please specify):
Background in Palliative Care
This section focuses on the background and experience of health care professionals in your community related to palliative care.

9. Do any physicians, nurses, nursing assistants, or other clinicians on your Community Team organizations have certification in palliative care/hospice?
   - Yes  
   - No

10. 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:

<table>
<thead>
<tr>
<th>Profession</th>
<th>Palliative care/hospice board certification (physicians &amp; nursing)</th>
<th>EPEC trained (Education in Palliative and End of Life Care) – for physicians</th>
<th>ELNEC trained (End of Life Nursing Education Consortium)</th>
<th>Other palliative care/hospice training or education e.g., PCLC (Palliative Care Leadership Center) or clinical training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chaplain</td>
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<tr>
<td>Nurse</td>
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<tr>
<td>Nursing assistant</td>
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<tr>
<td>Nurse practitioner</td>
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<tr>
<td>Pharmacist</td>
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<tr>
<td>Physician</td>
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<tr>
<td>Physician’s assistant</td>
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<tr>
<td>Social Worker</td>
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<tr>
<td>Other (please specify):</td>
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</tbody>
</table>
11. 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.

<table>
<thead>
<tr>
<th>Professional</th>
<th>Rate perceived level of knowledge</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
</tr>
<tr>
<td>Administration</td>
<td>0</td>
</tr>
<tr>
<td>Chaplain</td>
<td>0</td>
</tr>
<tr>
<td>Medical (MD, PA, NP)</td>
<td>0</td>
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<tr>
<td>Nursing</td>
<td>0</td>
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<tr>
<td>Pharmacy</td>
<td>0</td>
</tr>
<tr>
<td>Social work</td>
<td>0</td>
</tr>
<tr>
<td>Other clinical (PT, OT, SLP, etc.)</td>
<td>0</td>
</tr>
</tbody>
</table>

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

12. 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.

13. 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?

14. 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.

<table>
<thead>
<tr>
<th>Educational need areas</th>
<th>Rate need for Community Team</th>
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<tbody>
<tr>
<td></td>
<td>None</td>
</tr>
<tr>
<td>Advanced care planning</td>
<td>0</td>
</tr>
<tr>
<td>Ethical dilemmas in palliative care</td>
<td>0</td>
</tr>
<tr>
<td>Educational need areas</td>
<td>Rate need for Community Team</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td></td>
<td>None</td>
</tr>
<tr>
<td>Grief counseling</td>
<td>0</td>
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<tr>
<td>Health insurance literacy (e.g., understanding coverage and costs to help patients and families with decision making)</td>
<td>0</td>
</tr>
<tr>
<td>Interdisciplinary teamwork (e.g., care coordination)</td>
<td>0</td>
</tr>
<tr>
<td>Involving patients/families in care decisions</td>
<td>0</td>
</tr>
<tr>
<td>Pain assessment and management</td>
<td>0</td>
</tr>
<tr>
<td>Providing emotional support to patients/families</td>
<td>0</td>
</tr>
<tr>
<td>Strategies to inform patient/family of diagnosis/prognosis</td>
<td>0</td>
</tr>
<tr>
<td>Symptom management (other than pain management)</td>
<td>0</td>
</tr>
<tr>
<td>Understanding cultural beliefs/values</td>
<td>0</td>
</tr>
<tr>
<td>Understanding family dynamics/support systems</td>
<td>0</td>
</tr>
<tr>
<td>Understanding local community resources</td>
<td>0</td>
</tr>
<tr>
<td>Understanding philosophy of palliative care</td>
<td>0</td>
</tr>
<tr>
<td>Understanding spiritual needs of patients/families</td>
<td>0</td>
</tr>
<tr>
<td>Other (please specify):</td>
<td>0</td>
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</tbody>
</table>

14. 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
Quality Mechanisms and Measures

This section provides information on how the organizations on your Community Team may use quality measures related to palliative care.

15. What data do the organizations on your community team currently collect that may relate to palliative care needs/management? For example, hospital readmissions, emergency department utilization, pain scores, etc.

16. Are there other quality/performance improvement initiatives in your community or organizations that may relate to palliative care services (e.g., chronic disease management, medical home, reducing hospital readmission, Advance Care Planning)? Please describe:

17. What does success mean to your community, with regard to implementing a rural community-based palliative care program?

18. Upon completion of planning for palliative care services within your community, what indicators to measure your success are you considering?

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.

19. 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.

<table>
<thead>
<tr>
<th>Potential barrier</th>
<th>Rate ability to affect your community</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
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<tr>
<td></td>
<td>Moderate</td>
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<td></td>
<td>High</td>
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<td></td>
<td>0</td>
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<td>--------------------------------</td>
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</tr>
<tr>
<td>Community awareness of palliative care</td>
<td></td>
</tr>
<tr>
<td>Human resources to provide services</td>
<td></td>
</tr>
<tr>
<td>Lack of clinician knowledge and experience about palliative care</td>
<td></td>
</tr>
<tr>
<td>Coordination of care between providers/settings</td>
<td></td>
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<tr>
<td>Medical staff commitment/buy-in to palliative care</td>
<td></td>
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<tr>
<td>Reimbursement</td>
<td></td>
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<tr>
<td>Other (please specify):</td>
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**Comments:**

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

1.

2.

3.

21. Other information you would like to share:

**Community Information**

22. Name of Community (if applicable):
23. Location (City, State):

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
</tr>
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Thank you for your time and participation.

Return to Table of Contents
(Use SMART* criteria):

<table>
<thead>
<tr>
<th>Process Steps</th>
<th>Responsible Person</th>
<th>Date/Timeline</th>
<th>Measurement</th>
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|               |                    |               |             |</p>
<table>
<thead>
<tr>
<th>(Use SMART* criteria):</th>
<th>Process Steps</th>
<th>Responsible Person</th>
<th>Date/Timeline</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

* SMART: specific, measurable, achievable, relevant, and time bound objectives

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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.
### Palliative Care

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.

### Eligibility

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.

### Timing

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.

### Payment

It is most common to receive palliative care through your healthcare provider’s office, home care services, hospitals, nursing homes or the patient home.

### Location

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.

### Treatment

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.

### Hospice

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.

### Primary Care

Everyone is eligible for primary care, throughout the lifespan. Primary care focuses on preventative care, care for acute illnesses, and management of chronic conditions.

### Location

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.

<table>
<thead>
<tr>
<th><strong>Palliative Care</strong></th>
<th><strong>Hospice</strong></th>
<th><strong>Primary Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>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.</td>
<td>Everyone is eligible for primary care, throughout the lifespan. Primary care focuses on preventative care, care for acute illnesses, and management of chronic conditions.</td>
</tr>
<tr>
<td>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.</td>
<td>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.</td>
<td>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.</td>
</tr>
<tr>
<td>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.</td>
<td>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.</td>
<td>Most insurance covers primary care. If you are unsure of coverage, contact your insurance company.</td>
</tr>
<tr>
<td>It is most common to receive palliative care through your healthcare provider’s office, home care services, hospitals, nursing homes or the patient home.</td>
<td>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.</td>
<td>Primary care is delivered most commonly in clinics. Primary care providers also travel to nursing homes and sometimes make home visits.</td>
</tr>
<tr>
<td>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.</td>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>
## Updated 2020
Washington Rural Palliative Care Initiative

All Activities Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Meeting type and location</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 14</td>
<td>12-1:00 pm</td>
<td>Telehealth Case Consultation</td>
</tr>
<tr>
<td>July 28</td>
<td>12-1:00 pm</td>
<td>Zoom Cohort Roundtable</td>
</tr>
<tr>
<td>August 5</td>
<td>1-2:30 pm</td>
<td>PC-RHIAT Zoom only</td>
</tr>
<tr>
<td>August 10</td>
<td>9-10:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>August 10</td>
<td>10-11:00 am</td>
<td>Mentoring calls Newport</td>
</tr>
<tr>
<td>August 10</td>
<td>1-2:00 pm</td>
<td>Mentoring calls Port Townsend</td>
</tr>
<tr>
<td>August 11</td>
<td>12-1:00 pm</td>
<td>Telehealth Case Consultation</td>
</tr>
<tr>
<td>August 13</td>
<td>9-10:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>August 13</td>
<td>10-11:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>August 13</td>
<td>1-2:00 pm</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>Date</td>
<td>Time</td>
<td>Event Description</td>
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<td>------------</td>
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<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>August 25</td>
<td>12-1:00 pm</td>
<td>Rural Health Telehealth and Palliative Care Education</td>
</tr>
<tr>
<td>August 27</td>
<td>8-5:00</td>
<td>Complex conversation workshop two days if live and one day if virtual</td>
</tr>
<tr>
<td>September 2</td>
<td>1-2:30 pm</td>
<td>PC-RHIAT Zoom only</td>
</tr>
<tr>
<td>September 8</td>
<td>12-1:00 pm</td>
<td>Telehealth Case Consultation</td>
</tr>
<tr>
<td>September 16</td>
<td>TBD</td>
<td>Outcomes Congress</td>
</tr>
<tr>
<td>September 22</td>
<td>12-1:00 pm</td>
<td>Rural Health Telehealth and Palliative Care Education</td>
</tr>
<tr>
<td>October 7</td>
<td>1-2:30 pm</td>
<td>PC-RHIAT Zoom only</td>
</tr>
<tr>
<td>October 12</td>
<td>9:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>October 12</td>
<td>10:00 am</td>
<td>Mentoring calls Newport</td>
</tr>
<tr>
<td>October 12</td>
<td>11:00 am</td>
<td>Colfax</td>
</tr>
<tr>
<td>October 12</td>
<td>1:00 pm</td>
<td>Port Townsend</td>
</tr>
<tr>
<td>October 13</td>
<td>12-1:00 pm</td>
<td>Telehealth Case Consultation</td>
</tr>
<tr>
<td>October 15</td>
<td>9-10:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
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<tr>
<td>October 15</td>
<td>10-11:00 am</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>October 15</td>
<td>1-2:00 pm</td>
<td>Mentoring calls-COHORT 2 TBD</td>
</tr>
<tr>
<td>November 4</td>
<td>1-2:30 pm</td>
<td>PC-RHIAT Zoom only</td>
</tr>
<tr>
<td>Date</td>
<td>Day</td>
<td>Time</td>
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<tr>
<td>November 10</td>
<td>Tuesday</td>
<td>12-1:00 pm</td>
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<tr>
<td>November 24</td>
<td>Tuesday</td>
<td>12-1:00 pm</td>
</tr>
<tr>
<td>December 2</td>
<td>Wednesday</td>
<td>1-2:30 pm</td>
</tr>
<tr>
<td>December 8</td>
<td>Tuesday</td>
<td>12-1:00 pm</td>
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<tr>
<td>December 14</td>
<td>Monday</td>
<td>9-10:00 am</td>
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<tr>
<td>December 14</td>
<td>Monday</td>
<td>10-11:00 am</td>
</tr>
<tr>
<td>December 14</td>
<td>Monday</td>
<td>11-12:00 pm</td>
</tr>
<tr>
<td>December 14</td>
<td>Monday</td>
<td>1-2:00 pm</td>
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<tr>
<td>December 17</td>
<td>Thursday</td>
<td>9-10:00 am</td>
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<tr>
<td>December 17</td>
<td>Thursday</td>
<td>10-11:00 am</td>
</tr>
<tr>
<td>December 17</td>
<td>Thursday</td>
<td>1-2:00 pm</td>
</tr>
<tr>
<td>December 24</td>
<td>Tuesday</td>
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Training Strategies for the WA Rural Palliative Care Initiative

Training master plan with learning objectives in developmental phases, by audience, with linked resources

Mini-grant funding to drive a local training plan

Annotated catalogue of training resources

Basic PC overview in community meeting #2

Communication skills and other subjects arranged by DOH

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Washington Rural Palliative Care Sustainability Model: Tell the Story

- Increase revenue generating skills across the team
- Negotiate contracts for value
- Contribute to policy change in WA and nationally
- Build volunteer contributions
- Build philanthropic community support
- Seek grant funding
- Tell the story with human stories and data
- Build links to Accountable Communities of Health
- Metrics demonstrate the business case

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Measures

From 2017-2020 this initiative had the honor to have an evaluation sponsored by NORC Walsh Center for Rural Health Analysis. In 2021 the Department of Health will take on support for the measures sites which to adopt. The following chart shows all the measures under consideration and you will see that one column lets you know which measures were part of the NORC Walsh measures. These measures were collected only by those actively see patients.

Moving forward, participants will be asked to reach consensus on a small set of shared measures, allowing all sites to roll up numbers and make site to site comparisons.

**Metrics Quick Reference Chart**

<table>
<thead>
<tr>
<th>Measure number</th>
<th>Measure domain and topic</th>
<th>Measure statement</th>
<th>Included in NORC WALSH multi-state?</th>
<th>Optional or Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>CLINICAL Well-Being</td>
<td>Average first, 30-day, and final ESAS-r$^{10}$ score for wellbeing</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>2</td>
<td>CLINICAL Pain</td>
<td>Average first, 30-day, and final ESAS-r score for pain</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>3</td>
<td>CLINICAL Dyspnea</td>
<td>Average first, 30-day, and final ESAS-r score for shortness of breath</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>4</td>
<td>CLINICAL Pain screening</td>
<td>Percentage of palliative care patients who were screened for pain during the palliative care initial encounter.</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>5</td>
<td>CLINICAL Dyspnea screening</td>
<td>Percentage palliative care patients who were screened for dyspnea during the palliative care initial encounter.</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>6</td>
<td>CLINICAL Advanced Care Planning</td>
<td>Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>7</td>
<td>CLINICAL</td>
<td>Percentage of palliative care patients with documentation in</td>
<td>yes</td>
<td>Required</td>
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$^{10}$ Edmonton Symptom Assessment System, revised
<table>
<thead>
<tr>
<th>Measure number</th>
<th>Measure domain and topic</th>
<th>Measure statement</th>
<th>Included in NORC WALSH multi-state?</th>
<th>Optional or Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Spiritual concerns aka Beliefs and Values</td>
<td>the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss</td>
<td>no</td>
<td>Optional</td>
</tr>
<tr>
<td>8</td>
<td>CLINICAL Emotional or psychological needs</td>
<td>Percentage of seriously ill patients receiving palliative care with chart documentation of a discussion regarding emotional or psychological needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>PATIENT EXPERIENCE Satisfaction or experience survey</td>
<td>Percentage of patients who rate their satisfaction as X.</td>
<td>yes</td>
<td>Required</td>
</tr>
<tr>
<td>10</td>
<td>UTILIZATION Inpatient Days</td>
<td>Percentage of patients with decrease in hospital days using a one year look back.</td>
<td>no</td>
<td>Yes-claims data</td>
</tr>
<tr>
<td>11</td>
<td>UTILIZATION Readmissions within 30 days-all cause</td>
<td>The 30-day All-Cause Hospital Readmission measure is a risk-standardized readmission rate for beneficiaries age 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.</td>
<td>no</td>
<td>Yes-claims data</td>
</tr>
<tr>
<td>12</td>
<td>UTILIZATION Emergency department visits not leading to an inpatient stay</td>
<td>Percentage of patients with decrease in ED visits using a one year look back.</td>
<td>no</td>
<td>Yes-claims data</td>
</tr>
<tr>
<td>13</td>
<td>UTILIZATION Transfers to tertiary hospitals</td>
<td>Percentage of patients with decrease in transfers to hospitals outside the</td>
<td>no</td>
<td>Yes-claims data</td>
</tr>
<tr>
<td>Measure number</td>
<td>Measure domain and topic</td>
<td>Measure statement</td>
<td>Included in NORC WALSH multi-state?</td>
<td>Optional or Required</td>
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<tr>
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<tr>
<td></td>
<td></td>
<td>community using a one year look back.</td>
<td>no</td>
<td>Yes-claims data</td>
</tr>
<tr>
<td>14</td>
<td>UTILIZATION Total cost of care</td>
<td>Percentage of patients with decrease in total cost of care using a one year look back.</td>
<td>no</td>
<td>Yes</td>
</tr>
<tr>
<td>15</td>
<td>UTILIZATION Total cost of care Case Study</td>
<td>Total reduction in inpatient, ED and 911 utilization or Total reduction cost of all care For an individual patient using a one year look back.</td>
<td>no</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>TELEHEALTH CONSULTATION- Screening tool</td>
<td>Counts of patients who meet denominator criteria who are screened for palliative care using the standardized tool adopted by the cohort.</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>17</td>
<td>TELEHEALTH CONSULTATION- Clinical team participation</td>
<td>Number of rural clinical team members who participate in telehealth case consultation</td>
<td>no</td>
<td>DOH collects</td>
</tr>
<tr>
<td>18</td>
<td>TELEHEALTH CONSULTATION- Telehealth case consultation participant satisfaction</td>
<td>Number of rural clinical team members who rate their experience with telehealth case consultation as very good or excellent.</td>
<td>no</td>
<td>Required for participants</td>
</tr>
<tr>
<td>19</td>
<td>TELEHEALTH CONSULTATION-</td>
<td>Number of rural clinical team members who rate their confidence to provide palliative</td>
<td>no</td>
<td>optional</td>
</tr>
<tr>
<td>Measure number</td>
<td>Measure domain and topic</td>
<td>Measure statement</td>
<td>Included in NORC WALSH multi-state?</td>
<td>Optional or Required</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>-------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>20</td>
<td>OPERATIONAL Patient demographics</td>
<td>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.</td>
<td>yes</td>
<td>required</td>
</tr>
<tr>
<td>21</td>
<td>UTILIZATION</td>
<td>Average number of ED visits per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care</td>
<td>yes</td>
<td>Optional</td>
</tr>
<tr>
<td>22</td>
<td>UTILIZATION</td>
<td>Average number of inpatient stays per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care</td>
<td>yes</td>
<td>Optional</td>
</tr>
<tr>
<td>23</td>
<td>UTILIZATION</td>
<td>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</td>
<td>yes</td>
<td>Optional</td>
</tr>
</tbody>
</table>

Please note the following utilization measures were just released from NORC Walsh and do not match our suggested metrics. They are optional measures and are listed for reference until the discrepancy is worked through.

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**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.


**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/](https://wshpco.org/)

**Cambia Palliative Care Center of Excellence -University of Washington**

The 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 through key activities such as development and implementation of standards, program evaluation, and program development support.

The Center offers education and training in palliative care across the UW Health Science Schools focusing on interprofessional education and developing programs. The Center’s nationally recognized experts will partner and collaborate with nationally recognized palliative care
experts from other institutions. The Center offers a nine month certificate program and has recently begun to offer shorter courses to health professionals across the state.  
http://depts.washington.edu/pallcntr/

**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.wwu.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, palliative care, clinician training, financial sustainability, and community culture, the Task 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](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 uses a variety of approaches, such as an advance care planning program, community engagement, physician education, advocacy, and a central repository.

**Honoring Choices Pacific Northwest** help 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.

[https://www.honoringchoicespnw.org](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 of the resources listed here.

[http://www.stratishealth.org/palcare](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/PalliativeCare/index.htm](http://www.fairview.org/Services/PalliativeCare/index.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/

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/

Palliative Care Guideline
Institute for Clinical Systems Improvement (ICSI)
This guideline assists primary and specialty care providers in identifying and caring for adult patients with a potentially life-limiting, life-threatening or chronic, progressive illness who may benefit from palliative care. It outlines key considerations for creating a plan of care to meet patient, family, and other caregivers’ needs throughout the continuum of care. A palliative care order set is also available.

https://www.icsi.org/guidelines_more/catalog_guidelines_and_more/catalog_guidelines/catalog_palliative_care_guidelines/palliative_care/National Quality Forum

The NQF has 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.

National Consensus Project for Quality Palliative Care

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

These areas are delineated and the elements of best practice are described. 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

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. http://www.aacn.nche.edu/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. http://hpna.advancingexpertcare.org/

Physicians

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/

**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:

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
http://www.growthhouse.org/stanford/modules.html

**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**
This online resource 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:** [https://www.healthcarechaplaincy.org/](https://www.healthcarechaplaincy.org/)

**Social workers:** [http://www.swhpn.org/](http://www.swhpn.org/)
Rural Resources

- The Rural Health Research Gateway - [www.ruralhealthresearch.org](http://www.ruralhealthresearch.org)
- Agency for Health Care Research and Quality - [www.ahrq.gov](http://www.ahrq.gov)
- National Rural Health Association - [www.ruralhealthweb.org](http://www.ruralhealthweb.org)

References


Return to Table of Contents
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  Christine Opiela
Addendum

A. Standard Screening Tool
B. Communication talking points
C. Evidence
D. Video with discussion guides

Addendum A

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 are going to 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 the 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 nor does not access services.

If you are like our other communities, you may be surprised at how many community members might benefit from services. Because active curative treatments can occur concurrently, this is often more preferred than hospice but 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.

You can also find this tool on the portal as well as a short YouTube sort of video to discuss how to use the tool.
## Washington State Rural Palliative Care Initiative
### Palliative Care Screening Tool

<table>
<thead>
<tr>
<th>Patient Name: ____________________________</th>
<th>Date: ____________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Not a permanent part of the medical record)</td>
<td></td>
</tr>
</tbody>
</table>

### Criteria – Please consider the following criteria when determining the palliative care score of this patient

#### SECTION 1 - BASIC CONDITION

- Cancer (Metastatic/Recurrent)
- Advanced COPD (SOB in conversation or at rest/continuous O₂)
- Stroke (with decreased function by at least 50%)
- End stage renal disease (Stage 4)
- Late stage dementia (decreased verbalization/ambulation)
- Advanced cardiac disease – i.e. CHF severe CED, CM (LVEF < 25%)
- 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

- Liver disease
- Moderate renal disease
- Moderate COPD
- Moderate congestive heart failure
- Other condition complicating cure
- Early to mid-stage dementia

**Score 1 Point Overall**

#### SECTION 3 - FUNCTIONAL STATUS OF PATIENT

Using ECOG Performance Status (Eastern Cooperative Oncology Group)

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

**Score as specified below**

#### SECTION 4 - OTHER CRITERIA TO INCLUDE IN SCREENING

- 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

**Score 1 point EACH**

**TOTAL SCORE**

### SCORING GUIDELINES

Scoring schema inserted by organization

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Addendum B
Talking Points

Washington Rural Palliative Care Initiative

Talking points

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. 11

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

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

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. 12

• 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. 13

• 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.

13 ibid
• 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.14

• 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 and so the health systems will face an even greater influx of patients with needs.
• Data from 2017 show 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. 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.”

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 support from family and other loved ones at the time it is most needed.

• Studies show that people facing serious illness prefer to be in their own environment.15

• Because of work force recruitment challenges, low patient volumes and lean and 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 and so 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 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

“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


15 https://www.capc.org/topics/palliative-care-community/?gclid=EAIaIQobChMIpKn7j6L2QIVBCIpCh2gZAhYeEAYAyACeJEK_D_BwE accessed 3/11/2018
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.

**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).

<table>
<thead>
<tr>
<th>Aetna Medicare Advantage Compassionate Care Program</th>
<th>ProHealth Accountable Care Organization Supportive Care Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 81% decrease in acute care days</td>
<td>• 37% decrease in hospital admission rate</td>
</tr>
<tr>
<td>• 86% decrease in ICU days</td>
<td>• 20% decrease in ED visit rate</td>
</tr>
<tr>
<td>• High member satisfaction</td>
<td>• High patient satisfaction</td>
</tr>
<tr>
<td>• 82% hospice election rate</td>
<td>• 34% increase in hospice enrollment, with a 240% increase in hospice length of stay</td>
</tr>
<tr>
<td>• $12,600 in savings per person</td>
<td>• $12,000 in savings per person</td>
</tr>
<tr>
<td>• No patient complaints in 10 years</td>
<td></td>
</tr>
</tbody>
</table>

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 a number of 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.”

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

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 also 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 care 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:
  i. Facilitates transfer of practices and peer consultation
  ii. 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 similar to 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:
  o Reduced hospital days
  o Reduced ED visits
  o Reduced readmissions
  o Reduced tertiary transfers
• Process measures
  o Increased number/percentage of patients identified by standardized palliative care triggers/decision aids.
  o 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.

Roster of Contributing Organizations:

Washington State Department of Health, State Office of Rural Health
Northwest Rural Health Network
Providence Health and Services
Heartlinks Hospice and Palliative Care,
Home Care Association of Washington
Washington Hospice and Palliative Care Organization
Northwest Telehealth / Inland Northwest Health Services (INHS)
Washington State Hospital Association
Newport Hospital and Health Services
Whitman Hospital and Medical Center
Pullman Regional Medical Center
Columbia Basin Hospital
The Lookout Coalition
Jefferson Healthcare
Columbia County Health System
Ferndale Family Medicine, Family Care Network
Northwest Regional Telehealth Resource Center
University of Washington, Department of Family Medicine
University of Washington, Cambia Center for Palliative Care Excellence
Washington State University Elson S. Floyd College of Medicine
Amerigroup
Qualis Health
Stratis Health
Molina Healthcare
The Health Care Authority of WA
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-cute 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 but 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 and 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 and smoked for 30 years, he quite 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 if his medications are secure enough and to 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 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 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 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 and 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 family/friends.”


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:
    o 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)
    o 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
    o 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).
    o 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.

- Print

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 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 hospital 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 in order 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 (assuming that 2 percent and 6 percent of Medicaid patients discharged from the hospital received palliative care, respectively), if very hospital with 150 or more beds had a fully operational palliative care consultation team.

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- 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 results 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.**

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

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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%) \( \text{Tangeman et al., 2014} \).

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

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).

- 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 a number of 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, in particular 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 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’s (2015) 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). The papers listed below provide a survey of key ideas in palliative care, authored by leading researchers in the field. These papers comprise a short list of essential reading, exploring palliative care principles, the conceptual framework that guides palliative care service delivery, and directions for future program development and research.


Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. Milbank Q. 2011; 89(3):343-380.  


• Some of the papers cited remain the most compelling studies on the topic concerned. Other studies have informed more recent palliative care initiatives and research cited in the palliative care literature review.


• Citations


Lustbader D, Mudra M, Romano C, Lukoski E, Chang A, Mittelberger J, Scherr T, Cooper D. The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. J


National Quality Forum. National voluntary consensus standards: Palliative care and end-of-life care – A consensus report. April 2012. Available at:


National Palliative Care Registry™ Center to Advance Palliative Care

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A project of the Center to Advance Palliative Care and the National Palliative Care Research Center

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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

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.

<table>
<thead>
<tr>
<th>Community audience</th>
<th>Healthcare audience</th>
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<tbody>
<tr>
<td>How has serious illness touched your lives?</td>
<td>How has serious illness touched your lives?</td>
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<tr>
<td>Why do you think palliative care is important? What did you think before seeing the video?</td>
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<td>Question</td>
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<tr>
<td>What opportunities are there for care for serious illness in your community?</td>
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<td>If you could add services in your community, what would you add?</td>
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<tr>
<td>Would you want palliative care for yourself or a loved one? Why or why not?</td>
<td>How would you envision an ideal community system of palliative care?</td>
</tr>
<tr>
<td>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?</td>
<td>How can your health care team work in closer coordination with human service agencies that might provide non-medical supports to community members with serious illness?</td>
</tr>
<tr>
<td>What might community organizations contribute?</td>
<td>Who is most likely to identify opportunities to serve people with serious illness, which teams or settings?</td>
</tr>
<tr>
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**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.  

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

“"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  

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.  

Addendum for clinical audience

Discussion Guide for Offering Palliative Care in Rural Communities  
(5 min 29 sec)

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

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

17 https://www.capc.org/topics/palliative-care-community/?gclid=EAIaIQobChMlpKn7j6L2QIVBClpCh2g2AhyEAAYAaAEgJEK_D_BwE  accessed 3/11/2018
**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).

<table>
<thead>
<tr>
<th>Aetna Medicare Advantage Compassionate Care Program</th>
<th>ProHealth Accountable Care Organization Supportive Care Program</th>
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<tbody>
<tr>
<td>• 81% decrease in acute care days</td>
<td>• 37% decrease in hospital admission rate</td>
</tr>
<tr>
<td>• 86% decrease in ICU days</td>
<td>• 20% decrease in ED visit rate</td>
</tr>
<tr>
<td>• High member satisfaction</td>
<td>• High patient satisfaction</td>
</tr>
<tr>
<td>• 82% hospice election rate</td>
<td>• 34% increase in hospice enrollment, with a 240% increase in hospice length of stay</td>
</tr>
<tr>
<td>• $12,600 in savings per person</td>
<td>• $12,000 in savings per person</td>
</tr>
<tr>
<td>• No patient complaints in 10 years</td>
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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 a number of 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.”

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 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 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 also build rapport with the palliative care team, leading to earlier and more frequent hospice referrals when and if the time is right.