

State of Maine Palliative Care and Quality of Life Advisory Council Meeting Minutes January 26, 2018

State of Maine Palliative Care Advisory Council January 26, 2018

Present: James VanKirk, Lauren Michalakes, Kandyce Powell, Dennis Fitzgibbons, James(Greg)Burns, Kolawole Bankole, Elizabeth Keene, Kevin Lewis Scribe: Elizabeth Keene
 Guests: Christine Grundy, UNE intern at CHANS and Maine Hospice Council, Steve D’Amato, New England Cancer Specialists, Ken Albert, Androscoggin Home Care and Hospice, Annie Graham, ACS, Liza Eager, Hospice Volunteers of Waldo County, Kathryn Randall, Maine Hospice Council, Hilary Schneider, American Cancer Society Cancer Action Network (ACS CAN)

Topic	Discussion	Follow up
Welcome and Introductions 8:20 am	Lauren welcomed the council and introduced guests.	
Approval of minutes from last meeting	No comments	Minutes approved
Review	<p>Lauren reviewed the statute for this council and the definition of palliative care from the initial statute and the revised definition developed by the council in January 2016. Discussed whether palliative care is a philosophy or type of medical care. Kandyce noted that when reimbursement is then factored in, it is even more complicated and parallels the same issues that hospice care faced when it shifted from a philosophy of care to being a defined Medicare benefit.</p> <p>Discussed implications of the definition, especially for the new opioid rules which in some areas has resulted in primary care providers requesting that palliative care providers follow their patients addicted to narcotics. Debated the possibility of adding “life-threatening” or “life-limiting” to the definition but ultimately decided to keep the definition as written: <i>Palliative care' means interdisciplinary, evidence-based, person-centered and family-focused medical care that optimizes quality of life by anticipating, preventing and treating suffering caused by a</i></p>	

	<p><i>serious illness. This extra layer of support includes, but is not limited to, addressing physical, emotional, social and spiritual needs; facilitating and empowering individual autonomy and choice of care; honoring an individual's wishes; providing access to information; discussing the individual's goals for treatment and treatment options, including, when appropriate, hospice care; and managing pain and symptoms comprehensively. This is care provided and supported across the entire age spectrum.</i></p> <p>A question arose about who reviews the “palliative care exclusions” in the state opioid rules. The state has this responsibility and the intent is to provide technical assistance, rather than being punitive to providers. Discussed how to educate providers about the appropriate use of the palliative care exemption. It was noted that all prescribers need 3 hours of education every 2 years. Ideas generated for education:</p> <ul style="list-style-type: none"> -Offer it at the Maine Medical Association (MMA) conference every other year (this has been developed-is it available online?) -Offer it at the DO conference <p>Action items:</p> <ul style="list-style-type: none"> -Invite Gordon Smith from the MMA to attend a council meeting after June (which will be one year after the rules went into effect) -Ask the CDC for a report on the Prescription Monitoring Program (PMP) use of palliative care exclusions <p>Also raised more questions:</p> <ul style="list-style-type: none"> -How can we tell who is falling by the wayside in these opioid rules? -Who gets to decide on what constitutes a person's quality of life? -How can we determine cost savings in palliative care? (CAPC has a calculator for this online: https://www.capc.org/impact-calculator/) 	<p>-Hilary Schneider will invite Gordon Smith to the July meeting.</p> <p>-Will request PMP statistics from Maine CDC.</p>
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<p>Review of council work 2016-2017</p>	<p>Lauren led a review of this council’s work in 2016-2017. The council reviewed hospice statistics (Maine is currently #1 in the country for hospice utilization growth but there are still large regions of the state with no access to hospice care.) The council also reviewed the CAPC palliative care report card which only counted hospitals that have greater than 50 beds (only 14 of the 39 hospitals in Maine.) So this council (through a grant) commissioned a study of palliative care in all Maine hospitals. It revealed that the availability and provision of palliative care was much lower than the CAPC report card. Questions that arose: -Should we now survey for qualitative data through regional focus groups? -Should we endorse certain standards for provision of palliative care? -How can we include palliative care into the community forums for the next community health needs assessment (CHNA) work scheduled for fall 2018? (since the CHNAs drive state health plans, funding and policy)</p> <p>Kandyce reported that she completed the required annual report for the work of the council.</p>	<p>Kandyce will distribute the 2017 annual report.</p>
<p>Updates</p>	<p>Council members shared updates from their respective areas: - Jim noted that this is the tenth year of the palliative care program at EMHS and noted a few program challenges. -Annie discussed some of her work with insurance companies to advocate for palliative care coverage -Liza reported on the “palliative care players” who offer role play scenarios for training on palliative care conversations -Dennis discussed his work with the disability community and shared a personal experience of the importance of palliative care -Greg reported on his program (including pediatric palliative care) and noted that they are working on how to incorporate spiritual care</p>	

	<ul style="list-style-type: none"> -Steve spoke of the work of the New England Cancer Specialists and their work to help the uninsured and underinsured, especially through food insecurity programming -Kandyce reported on her trip to Scotland and the presentations she gave about palliative care programs in the prison setting -Bankole discussed his work with helping various ethnic groups understand palliative care and its impact -Ken discussed the work that Androscoggin Home Care and Hospice (AHCH) is doing to develop a palliative care service line and reported on a grant they submitted for rural access to palliative care -Lauren noted that her palliative care program is now aligned with the Cancer Care Center at Pen Bay and Waldo and plans for team expansion. She also discussed the work they have done through the David Family Foundation grant: Educating a Community to Talk about Palliative Care -Hilary reported federal and state legislation. There is continued bipartisan support for the palliative care bill at the federal level. The RAISE family caregivers act was just signed into law. The American Cancer Society Cancer Action Network (ACS CAN) is also focusing on MaineCare expansion and exploring paid family leave. -Kathryn provided dates for the 2018 annual hospice and palliative care retreat in Rangeley-October 12-14, 2018 -Elizabeth reported on regional work being done in Lewiston-Auburn by the two hospitals and AHCH 	
<p>Subcommittee Groups</p>	<p>Four areas have arisen as initial focus areas: education, access to care, pediatric palliative care and finding a way to pay for palliative care. The council focused on education as an entire council, rather than a subcommittee. Need to understand who is making what educational efforts currently statewide in hopes of synergy and collaboration.</p>	

	<ul style="list-style-type: none"> • Maine Quality Counts initiative “What Is Palliative Care” now replaced by education about MIPS and MACRA • MaineHealth ACO has identified palliative care as a priority: <ul style="list-style-type: none"> ○ has adopted Respecting Choices system-wide ○ has adopted Serious Illness Care program ○ has trained some providers at VitalTalk workshops ○ MaineHealth holds annual Palliative Care conference • EMHS has Serious Illness Care program system-wide • EMHS offers advance care planning, but is not using Respecting Choices <ol style="list-style-type: none"> 1. What do we call <i>palliative care</i>? Is it useful to rebrand as “supportive care”? Would this change patient and/or provider perceptions? 2. What audiences would we target with educational efforts? <ul style="list-style-type: none"> • Patients • Providers • Policy makers • Student health care providers (especially through good mentoring) • Social Work and nursing students 3. What is the best content for education about palliative care? <ul style="list-style-type: none"> • Addressing implicit biases • Tools and information about navigating different cultural perspectives on palliative care • Content available in on-going format, always available on demand • Repetitive content 	
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	<p>6. Kandyce Powell will share Ira Byock’s piece “Advocacy and Activism, Missing Pieces in End of Life Care”</p> <p>7. Possible educational goals, short & long term?</p> <ul style="list-style-type: none"> • PSA campaign • User-friendly web-site not tagged “Hospice” • Use materials developed by other organizations? (NHPCO, Conversation Project, et al) • Media outlet support/sponsorship of these initiatives • MMA initiative (corner of newsletter) • Provider-facing brochure from Hillary, brochures from Lauren and Jim • Seek partners to absorb cost of materials and dissemination 	
<p>Subcommittee Reports</p>	<p>Each subcommittee reported on their initial meeting: PEDIATRICS: (Greg, Bankole and Elizabeth) Discussed whether pediatrics should be separate work group or incorporated into other priorities. Decision: continue with separate work group though there will be overlap. Generated ideas for other subcommittee members; Greg will follow-up to invite identified possible members. Generated content for invitation letter. Overall goal: Create a pediatric advisory/resource group to allow access for areas without specific pediatric palliative care specialists</p> <p>Other focus areas: -Access -Resources -Regulatory/payer options (waiver for concurrent care)</p>	<p>Elizabeth will draft letter of invitation and send it to Greg.</p>

	<p>-Education</p> <p>Discussed format for workgroup-meet 3-4 times a year, 2 council meetings and 2 meetings in between council meetings Also discussed importance of website for palliative care access and information and other forms of social media that might be effective</p> <p>RURAL ACCESS (Liza, Dennis, Kandyce, Jim and Hilary) Distinguished between “unserved” and “underserved.” Subcommittee discussed partners for collaboration and upcoming related legislation such as the Jackman bill to support federally qualified health centers (FQHC) and a broadband access bill. Discussed whether or not this council should endorse legislation in general. Decision was that there were not enough council members present to endorse and we need to clarify the structure and function of work groups. The Maine Hospice Council will be supporting the Jackman bill. The group would like to explore if anyone besides the VA is offering palliative care through telehealth (and if anyone is getting paid for offering it through telehealth.)</p> <p>PAYER PILOT (Steve, Annie, Kevin and Lauren) Subcommittee intends to collect data and research current payer pilots and then approach a payer(s). Other members could include Ken Albert from AHCH and MaineHealth.</p>	<p>Council does have a website and facebook page through the Maine Hospice Council grant; send information to populate this to Scott Fish: Scottfish44@gmail.com</p>
Council Membership	Kandyce reported that letters for new council members went to the appointing authorities and the Governor’s Office	Hilary will follow-up with various offices during the week of 1/30/18
2018 meetings	<p>Fourth Fridays: January, April, July and October Next meeting: April 27, 2018 Conflict for July-will send doodle poll</p>	Elizabeth will send doodle poll to council members for July 20 or July 27, 2018

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Meeting adjourned	Lauren adjourned the meeting at 3:30 pm	Respectfully submitted Elizabeth Keene
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