

Palliative Care and Quality of Life Interdisciplinary Advisory Council

Meeting Minutes

April 14, 2016, 8 am – 4 pm (Cross State Office Building, Room 206)

Attendees:	
Discussion:	<p>Welcome and Introductions – In Attendance: Council Members: Jim VanKirk, Elizabeth Keene, Kandyce Powell, Bruce Condit, Debra O’Neil, Greg Burns, Kolawole Bankole, Lauren Michalakes, Denise Needham, Jason Whitney, Kevin Lewis, Dennis Fitzgibbons, Peggy Belanger, Roland Joy.</p> <p>Members of the Public: Matt Caston, ACS CAN</p> <p>The meeting was audio streamed via the legislature’s audio streaming system.</p> <p>The committee has done great work! Kandyce provided an update on LD1646 - a bill that would have set comprehensive limits on prescribing of pain medications – original bill had no exemptions for chronic/terminal illness patients. Cancer, palliative care and end of life populations were quickly exempted. People around the country are paying attention to our work.</p> <p>Definition of Palliative Care</p> <ul style="list-style-type: none">• Kandyce Powell –Proposed to add to the definition to include both present populations and coming trends in population.• All voted in favor of keeping definition as it was drafted as a result of the last meeting.
Action Items:	None
Discussion:	<p>Vision Statement</p> <ul style="list-style-type: none">• It was decided that given that the committee will be addressing the current state of palliative care, it would be best to table this discussion until the end of the council meeting. A motion was made to table this discussion and passed.
Action Items:	None
Presentation/ Discussion:	<p>The State of Hospice in Maine (Kandyce Powell)</p> <ul style="list-style-type: none">• Kandyce Powell delivered a presentation reviewing the state of hospice care in Maine – Cordt Kassner from Hospital Analytics was commissioned to do a post-data analysis primarily utilizing Medicare claims data between 2013 and 2014.• The report found that over 10 years, we have seen an overall increase on 23.8 % in Medicare patient usage of hospice care. Hospice is increasingly utilized in Maine at a faster rate than at a national level, but access and utilization varies by state region. The national rate of utilization is plateauing as it follows palliative care use increases. Hospice utilization by county varies widely with rural Maine seeing less

utilization. Washington and Aroostook Counties are 19% and below in utilization.

- 2013 Hospice Utilization – Maine Ranked 33rd at 42.6% Nat'l 45.4% - 2014 Hospice Utilization – Maine ranked 27th in percentage of Hospice Medicare deaths 44.6 % Nat'l 45.9
- Change in Hospice Utilization '13-'14 – Maine is 4th at a 2% increase compared to the Nat'l average of 0.5% (Up from 0% in Maine '12-13)
- 2014 Utilization by County – Washington and Aroostook are at 18% and 19% respectively. Androscoggin highest at 59%
 - When EMHS had the acquisition of Mercy Hospital, their CEO Kline Hilton restored a renewed interest in Aroostook County. They have had a difficult time in getting staff of all types, but have placed an emphasis on Palliative/Hospice care. Palliative Care physician, Dr. O'Neill with a PA at EMHS – also involved with the community of Presque Isle to open a comfort house in Spring of 2017. Aroostook Medical Center has a Palliative Care room.
- Overall, it was reported that Maine is behind on mean days of Hospice Care/Beneficiary – Long term care is not very robust in Maine, however it depends by state and how early patients are admitted into programs (e.g. Debility Unspecified crackdown).
- When going by racial division of Medicare Hospice Admissions, usage of Medicare Hospice in Maine is disproportionately white. This seems to stem from a lack of education on hospice benefits to these target populations. Hospice often viewed as a white, middle-class service.
 - The Advisory Council discussed ways in which to reach out to these communities. It was suggested that targeting of spiritual leaders, as well as utilizing simple non-clinical messaging would be effective tactics. Death and dying is a very important and intimate issue for many; being able to link home hospice care education to keeping these people within their community – perhaps even stepping away from the term 'Hospice' and focusing on quality of care– would be integral in outreach.
 - It was felt by the Council that cultural humility trumps cultural competence. The question at hand isn't how can we get more people in to hospice, but rather how can we help people through hospice into end of life care.
- Levels of Care in days in 2014 – Maine is far below the national average for continuous home care and respite care. Some programs are working hard to provide this form of service – people are saying they want to stay home and remain home for end of life care, but there are issues due to reimbursement and transportation costs.
 - Example: Jackman – area the size of RI, has no access to hospice/palliative medicine.
- When Hospital Analytics looked at Somerset, Jackman, and Aroostook Counties, it was found that travel expenses were a huge issue as were resources when it came to providing adequate hospice access. Institutions have felt that there is no affordability to implement more

	<p>hospice and palliative care, and there is no standard model for implementation best practices in rural areas, despite these areas having the highest usage rates of ER visits.</p> <ul style="list-style-type: none"> ○ There is a huge unidentified need for proper hospice care – patients are dying in venues where they should not/do not want to be. ● The Advisory Council discussed a lack of proper Medicare reimbursement at \$60 per patient/day. This equates to a need of roughly 40 patients per day to just break even. There was a consensus that the current model of Medicare hospice needs to be revised to address current realities. ● Questions raised were: <ul style="list-style-type: none"> ○ Are any of these discussions moving forward to push lobbying either toward reimbursement issues or revising the entire Medicare Hospice model. ○ In the scope of what the Committee is setting out to do – is there an opportunity to present a report to recommend cost savings of increased Medicare Hospice access in Maine’s rural areas. ● One solution raised was the use of ACOs – Accountable Care Organizations: Thought is that regions or populations are provided a pool of money that they collaborate to provide adequate care. Incentive tied to health deliverable metrics. ● In looking ahead, the Council felt that Maine has the opportunity to be a unique test case – We have an aging population and caregivers who will be utilizing these services to a greater and greater extent as the years progress. This is also an underpaid workforce providing these services.
Action Items:	None at this time.
Presentation/ Discussion:	<p>The State of Palliative Care in Maine (Lauren Michalakes, MD)</p> <ul style="list-style-type: none"> ● Dr. Lauren Michalakes was tasked with exploring and presenting the state of Palliative Care in Maine. ● What was found was that nearly all of New England received an A from the Center to Advance Palliative Care (CAPC) Maine got a B. However, Maine raised itself from a D previously. 11 out of 14 hospitals in Maine now have palliative care programs. While this is certainly an improvement, Maine can do better. It was also noted, however, that the CAPC evaluation does not take into account VA or other programs despite having a national registry of hospice/palliative care programs. ● Likewise, as CAPC invites programs to enter their data manually into their registry, or gathers data from captured surveys answered from the American Hospital Association, the difficulty in accurately mapping the state of palliative care in Maine quickly becomes apparent. ● Palliative Care according to CAPC is “specialized care for people with serious illness that focuses on improving quality of life for patients and their families. It provides patients of any age with relief from the symptoms, pain and stress of a serious illness – whatever the diagnosis.” ● As of 2012, 1,734 out of 2,844 hospitals nationwide with 50 beds or more reported that they had a Palliative Care team.

	<ul style="list-style-type: none"> • Palliative Care is now a key standard of practice in US Honor Roll hospitals – both Children’s and General Hospitals that made the Honor Roll for ’14-’15 had 100% participation with Palliative Care Teams. However, the 355 palliative care teams participating in the CAPC Registry only reached a 4% average, with high performing teams reaching an average of 7% penetration. Higher staffing levels are a key determinant of higher penetration rates. • What does this mean for Maine and where do we go from here? • Kandyce Powell spoke that the Council is looking to get funding to have a study to comprehensively evaluate the state of Palliative Care in Maine backed by hard data – Hospice Analytics would potentially handle this report beginning in July, and would likely have the study report completed by December 2016 <ul style="list-style-type: none"> ○ Hospice Analytics has a survey to input and grind through data – phone survey. Peggy suggested if this was an opportunity to engage graduate students, but Kandyce answered that Cordt’s staff would likely handle this instead. • The ICER (sic) draft report came around and presents compelling findings 20% PMPM. The report looks at appropriate organizations and expenditures, and focusing on where we put this money and how effectively it is being used. The answer from the report is that currently, funding is not be used as effectively as it could be. ICER (sic) invited to present at next meeting when we do finalize the date. • Kandyce Powell is working with the Critical Care Roundtable – Transform Advanced Care, CTAC is working with them.
Action Items:	<ul style="list-style-type: none"> • There was a suggestion by the Council to engage Marilyn Collucci at UNE given her involvement with geriatric care.
Presentation/ Discussion:	<p>Palliative Care in the VA System (Jim Schneid, MD)</p> <ul style="list-style-type: none"> • Dr. Schneid has a background as a primary care physician and nurse educator, eventually coming to the VA in 2012. • In Dr. Schneid’s presentation, he discussed how many Palliative Care specialists are skeptical of PCPs to provide such care. However, because of residential curriculum and that residents are being exposed to Palliative Care consultations with patients, physicians and other clinicians, more are graduating from residencies with the skill necessary to educate and implement Palliative Care services throughout the state. However, they are being put on the spot to see as many patients as possible. On average, PCP’s are seeing patients every 15-20 minutes – they are allowed 40 minutes to an hour to spend with bereaved patient, but then are tasked with adjusting accordingly with subsequent patients. • One of the problems in getting outpatient consultations – PCPs don’t see why they would necessarily need to refer to a Palliative Care outpatient consultation. • Dr. Schneid concluded that much of the PCP System is overburdened– they have the skills to provide compassion and care, but they need the time given and the pressure needs to be let up. Many practices that are developing an interdisciplinary approach, but unless you change the lifestyle of the nurse practitioner or PA, nothing will change.

Model of Palliative Care Consultation

- It was found that patients say routinely in the healthcare system that no one ever asks them if they were a veteran. Personal questions are just never asked and these things show that you are actually personally interested in the patient and their individual care.
- 8.4 million veterans are enrolled for healthcare, yet there are 24 million total veterans nationwide – this is because most veterans are eligible for healthcare if they have a service connected disability. They are evaluated for a percentage disability that is related to service. Most veterans are eligible for VA healthcare via – service connected disability, meet income guidelines, post-service in Iraq or Afghanistan for five years, or are Hospice Eligible and catastrophically disabled.
- Though all veterans are Hospice Eligible, regardless of presence or lack of preexisting service connected disability. Many turn it down out of a feeling of being undeserving.
- Veteran Integrated Service Networks – Maine is in VISN 1 and our VA systems including Togus rise to the top of access to hospice and palliative care. There is a concerted effort to move toward a seamless, ongoing continuity of care system.
- In Maine, VA/Togus physicians are able to do home visits and see people in nursing home. Normally VA cannot do this, but the administration is now allowing this on the basis of accreditation requirement through Dr. Schneid's efforts.
- It was mentioned that there are concerns that Palliative Care will become the next pain clinic due to ongoing opioid restrictions and exemptions to those with chronic/terminal illnesses.
- VA's Palliative Care Team has a full range of support roles – Neural Psych and Psychology residents for outpatient and inpatient consultations for mental health along with Pastoral Care. This also includes an active inpatient consultation service with includes 67 bed Dementia unit. 12 bed inpatient hospice unit. Serving approx. 70 patients statewide through Veteran hospice agency partnership on Home Hospice. Approx. 150 patients through ongoing Palliative care appointments or home visits.
- There has been a more liberal approach to contract out chemotherapy to other orgs when it used to be restricted to within 40 miles of VA location. NECC can now provide cancer care through the VA to VA patients where 4 months ago, this was not available.
- Tensions between PCPs and Palliative Care – It is pushing the envelope. Robust Palliative Care Team, results in ability to cut through VA bureaucracy and provide care through access. Oncology and other departments beginning to utilize Palliative Care Team.
- VA Challenges in Maine
 - Geographic Distance from either VA Togus or one of the CBOCs for telehealth communications.
 - Lack of education around the role of Palliative Care versus Hospice Care – It is an effort to cut through the perception that the team is end-of-life care focused

	<ul style="list-style-type: none"> ○ Lack of appropriate home based support for critically ill patients, particularly within rural areas – Resistance to admitting a patient to Hospice care due to a belief that inpatient care is adequate/no place to admit them ○ When asked whether there was one thing Dr. Schneid would suggest to improve Palliative Care in Maine, Dr. Schneid responded that Palliative Care is an incredible care and navigation agent. He elaborated that Palliative Care is the role of care and navigation – patients never see their PCP after a cancer diagnosis, rather they are referred to specialists. Palliative care should remain a specialty service. He went on to state that Primary Care should be able to handle this issue and that he was confident that Primary Care can do the job with enough work.
Action Items:	None
Presentation/Discussion:	Open Session with the Governor’s Office <ul style="list-style-type: none"> ● Due to legislative activities, David Sorenson was unable to attend the meeting.
Action Items:	N/A
Presentation/Discussion:	Maine Hospital Association (Jeff Austin) <ul style="list-style-type: none"> ● Jeff Austin, the principle lobbyist with MHA gave a report on the state of palliative care in Maine. The report card only included hospitals with 50 or more beds in their results, hence why Maine showed only 14 hospitals. Report Card based on AHA from 2014. Took AHA data from ’15 to figure out and try to find hospitals below 50 beds. ● Results – 5 Maine hospitals responded to AHA that they have inpatient Palliative Care Units 3 Critical access hospitals, 1 sole community provider. 14 say they have palliative care programs. 17 hospitals have neither. ● The report did not go deeper than this including what defines/constitutes palliative care. The easiest way to survey items is through coding; billing codes are consistent among all hospitals. Jeff stated that he was happy to do a deeper data dive for the Council. ● Jeff’s questions to Council – What would you like to see in terms of definite activity? What specific items are missing in Maine? Wants us to bring the payer community into this discussion - how can Palliative Care help with the cost of care savings side – Jeff’s members. ● It was noted that Jeff will be available at the behest of the Council after the end of session.
Action Items:	None.
Public Comment:	
Discussion:	Open Forum and Next Steps <p>The Council began discussing groups and organizations to reach out to regarding the Open Forum and next steps ahead of the Palliative Care Advisory Council’s next meeting. The following groups and organizations were brought up by members of the Council:</p> <ul style="list-style-type: none"> ● Quality Counts

- Hospice and Palliative Nurses Assoc. – Maine
- Organization of Maine Nursing Executives (OMNE)
- Maine Hospital Association
- Maine Health & Eastern Maine Health
- Maine General and Central Maine Health
- Maine Council of Churches
- Interfaith Council of Maine
- Maine Healthcare Association
- Greater Portland Refugee and Immigrant Healthcare Collaborative
- New Mainers Public Health Partnership
- Healthy Androscoggin
- Healthy Acadia
- Maine Association of Area Agencies on Aging
- Wabanaki Health and Wellness
- Maine Immigrant and Health Coalition (MIHC)
- City of Portland’s Minority Health Program
- National Association of Social Workers (NASW) Maine
- New England Rural Health Table
- Beth C Wright Cancer Center
- Cancer Community Center of South Portland
- Maine Associate Immigrant Network
- Cancer Support Center of Maine
- Cancer Care Center of York County
- Maine Healthcare Association

Discussion of Vision

The Council then held a discussion on the Council’s vision for this next year and on into 2017, given the goals outlined during the previous meeting.

- It was felt by the Council that they should target low-hanging fruit that the Council can address. During this, the question of identifying some concrete goals that could be accomplished was brought up.
- The Council concluded that the goal of this first year was to establish a comprehensive picture of the state of palliative care in Maine, which included hearing from groups, organizations, and hospital systems as to the challenges that our state faces in further implementing care.
- Going forward, with the open forum, general invitation to chosen organizations would be sent out, asking them to present issues to the Council. The panel discussed making the Open Forum a panel discussion rather than individual presentations.
- The panels decided on will be: Geriatric, long-term care. Caregiver panel. Underserved panel.
- Looking at October 8am to 9pm.

Outreach Action

The following were assignments and actions to be taken by members of the Council in reaching out to and setting up open forum participants for October.

- Dr. Allan Teal – Kandyce Powell to reach out to
- **MCHA**– Kandyce Powell to reach out to

	<ul style="list-style-type: none"> • Long-term Care Organizations – Maine Healthcare Association – Bonney Small. Kevin recommends finding an organization or facility that does an exceptional job of providing access to long-term Palliative Care. • Dr. Nate Harmon, Maine Gen – Lauren Michalakes will reach out to • Greg Burns – Unassigned outreach • James Donoghue - Unassigned outreach • NAMI Maine – Unassigned • Preble Street – Unassigned • John Hennessey of SAGE Maine - Unassigned • Native American Communities - Jason • Wabanaki Health – James to reach out • Underserved Communities – Dr. Bankole • Wabanacki Health – Jason • Martins Point - Kevin <p>Panels and Working Schedule for the Open Forum/Panel Discussion –</p> <ul style="list-style-type: none"> • Long-term Care – Morning 8:30 – 10:30 (Lauren Michalakes and Deb O’Neil to facilitate) • Dementia – Mid-Morning 10:30 – 12:30 (Jim VanKirk to facilitate) • Underserved – After Lunch 1:30pm to 4pm (Dr. Bankole to facilitate) • Possible panel for Insurers – Are we hearing from them on their recommendations, or are we giving recommendations to them? • Insurers would be next April – The was a discussion to possibly bring in Medicaid/CMS • It was noted that the Council decided caregivers will be incorporated into each panel discussion <p>Questions for each panel to consider:</p> <ul style="list-style-type: none"> • What are palliative care needs for each group/subject? • Challenges, needs, barriers, and recommendations. • What is currently offered? • What do they need to have? • Recommendations on how they can help. • It was noted that it will be important to explain why we are inviting these groups, and what we need from there; What goals the Council has in mind.
Action Items:	<ul style="list-style-type: none"> • Long Term Care group – Going to be organized by Lauren and Deb • Dementia Group – Will include Alzheimer’s Organization Kandyce – Southern Maine Agency on Aging – Jill Croll will be reached out to • Underserved Group – Dr. Bankole will search immigrant and racial minority groups/refugee groups. • Wabanaki Health will be reached out to by Jason. NAMI Maine. Robin Wright – growth for social workers to come to this as well. • Preble St. Native Am, Refugee, Pediatric, Mentally Disabled, NAMI (Kandyce), Prison Population (Kandyce), Disabled (Dennis) • The Panel Forum/Next Meeting was set for Thursday, Oct 20 • Maine CDC to be added to Distribution List – Kandyce to reach out to them. • Elizabeth Keene to reach out to Ken Albert with Maine CDC to possibly ask to join next meeting.
Next Meeting:	Thursday, October 20, 2016

	Location: ??
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