State of Maine Palliative Care Advisory Council

April 27, 2018

Present: Jason Whitney, Dennis Fitzgibbons, Elizabeth Keene, Lauren Michalakes, Bruce Condit, James (Greg) Burns, Peggy Belanger, Steve D'Amato, Kandyce Powell, Bill Primmerman

Scribes: Christine Grundy, Bertha Morin

Guests: Annie Graham, ACS; Aysha Sheikh, Maine Community Foundation; Hilary Schneider, ACS Cancer Action Network (ACS CAN); Tom Winchell, Director Telehealth MMC; Joan Ingram, Program Manager Diabetes, Maine Health; Shelly, Allison, Susan White

Topic	Discussion	Follow up
Welcome and Introductions	Meeting started at 8:10am opening statements by Elizabeth Keene	
Review	**Current status of council appointments** 1. VA appointment, Myra Ross MD, was not approved by the Governor due to the fact she is not a nurse. 2. Steve D'Amato and Bill Primmerman are pending final approvals. **Question:** Is there a time limit for the council? **Discussion:** The council is open ended. There are other states that have councils with different models. The Massachusetts model was discussed. This model has "morphed' over time to become a coalition of member/stakeholder type of organization, including system-wide advocacy organizations. **Question:** Are we mandated to stay in this structure? Can we alter the structure? **Discussion:** There has always been the ability to bring in other stakeholders. It is the basic structure that was legislated. Any changes to that would need to go back to legislation for approval.	Kandyce to seek clarity on the delay. Current plan is to continue moving forward with present structure.

Review of AAHPM Conference (American Academy of Hospice and Palliative Medicine	Lauren Michalakes and Greg Burns presented highlights. Discussion ensued to determine what aligns with the council's mission. The AAHPM is an organization that providers look to as a resource for clinicians about trends and best practices. Education is key. Evidence-based data helps add credibility to the work. Over time the groups have helped define standards for quality palliative care programs. New guidelines are in progress and are expected to be released in November 2018. **Question:** What is our role as a group? Would we use this structure as an endorsement for programs in Maine? **Discussion:** Yes we need to endorse this structure and use it in any work we do. Concern that our health care structure would present barriers to this work. The National Consensus Project has developed best practice standards for Palliative Care. **Question:** How do we coordinate care to get resources incorporated and face the reality that money for programs is not readily available? **Discussion:** The value of palliative care needs to be brought to the insurance companiess. Anthem Blue Cross is rolling out coverage for palliative care and home based coverage for palliative care this year. Community palliative care programs, in collaboration with payers will, hopefully, create a collaborative program that works. CMS – Alternative Payment Models that align payments with quality outcomes are being proposed; one by AAHPM, one by C-TAC. Both have apparently been approved and might be ready for pilot later this year. They create payment tiers that provide palliative care utilizing a team approach. Payment level will be based on outcomes and quality.	

Advocacy and Legislative report	Kandyce Powell & Hilary Schneider **Kandyce** – Senator King is supporting S2260, "Opioids and STOP Pain Initiative Act". - Ask NIH to get more involved in researching alternatives to opioids and corresponding reimbursement for those alternatives. Senator Brian Shatz also working on this bill. - Senator Collins has introduced a bill to allow Hospice Nurses to dispose of opioids in the home. Prior attempts to discuss policies/standards for the disposal of medications in Maine over the past 15 years have not been successful due to disagreements between agencies and law enforcement. A highly successful "Mail-back" program, developed by the Center for Aging and other partners was discontinued due to lack of State funding. **Hillary –** Palliative Care and Hospice Education and Training Act (PCHETA) HR 1676 S693 opioid prescribing bill. Utilizing palliative care as leverage for changes in opioid usage. Introducing holistic measures to deal with pain. Sen Collins part of new health care committee. Focus on thanking Senator Collins for including PCHETA on the opioid bill. Having access to opioids is a critical part of palliative care to control pain. Some of the proposed restrictions will create a barrier for these patients. It is challenging to bring patient voice to the discussion due to fear of repercussions and potential for safety of their home. What are we doing about education at the point of prescribing the opioids and other pain medications? **Jackman bill** – The FQHC in Jackman recently received support from the	

	Appropriations Committee to fund a shortfall for its emergency services. Some prescribers are refusing to prescribe opioids out of fear for their licenses.	
Project ECHO	**Tom Winchell, Director Telehealth MMC, Joan Ingram, Diabetes Program Manager, Maine Health** Care focused model for sharing knowledge. Started in 2003 by Sanjeev Arora, MD. Provide training and knowledge to direct care via a teleconference model. Central hub of specialists that conduct virtual "grand rounds" with remote service providers. The goal is to create a learning loop that moves knowledge not people. Off the hub are "spokes" of providers presenting cases and getting feedback. The end result is getting the best care to patients. This is a model that has improved patient access to healthcare. The program spans across health care specialties and builds relationships between providers. **Discussion:** Project structure, benefits to providers and patients, and how this information relates to the councils work. Evidence based value of the program and what data points are being tracked. Cost and possible funding sources. What are the resources that will assist in the initiation of an ECHO Hub and /or service provider participation? Super hubs, ECHO Institute trainings. How is this program being communicated to providers? Newsletters, magazines, word of mouth, Providers who have an interest in the program start with a basic structure and then approach a primary funder to start a hub. Maine Quality Counts is working on starting an ECHO hub related to palliative care. What types of specialty hubs are using this model? Drug addiction, Palliative Care, Oncology, and many more.	
Large Group Discussion: Focus on Education	**Review:** What is happening in individual regions and who will we focus on. Identify care providers, payer sources, health care students, and general public. What are our short and long term goals? What is a reasonable and achievable goal to be set for this year? **Discussion:** What resources are already available to start getting the word out? What conferences are happening around the state that we can tap into? Maine Geriatrics conference, MHC pain symposium, and other public education avenues. Can the Maine CDC include an education piece, small interview sessions with policy makers, Make small videos of people who have benefited	Identify social media resources Invite Scott Fish to next meeting. Invite groups to return and

	from palliative care and present them to providers and legislators. What group should we start with that could make the most impact. Kandyce – Scott Fish could be a point of contact to create a public campaign. AARP has been doing work in this area and perhaps a representative could present to the council. What evidence-based education models are already available? Nursing module, HPNA has a module. Getting the general public to understand the meaning of palliative care. Part of this education must explain the difference between palliative care and Hospice care. There are differences as well as common threads. Identify organizations that would collaborate with the council to create an education program. Identify social media resources Invite interns to invest in an education project. Create videos of people telling their story. Approach it from a personal narrative. Any social media Initiative should include personal stories. Kandyce – suggested contacting Scott Fish to consult on a media campaign. Concern about a media campaign would be the issue of demand verses supply. How will the education campaign continue the work of expanding palliative care? How do we create a cohesive bond between the projects that already exist? This council needs to be involved in these efforts. Need further discussion of inviting organizations to collaborate on the council's efforts.	speak on the progression of their work and building further relations. Identify and approach organizations that will align with the education piece Kandyce to contact and formally invite Scott Fish to July meeting.
Topic	Discussion	Follow up
Subcommittee Reports	**Pediatric** – 1. Education – Utilize the Hub and Spoke ECHO project model. 2. Provision for an Annual Pediatric Palliative Care Training. Invite sponsors to provide financial support. 3. Clinical availability – Southern portion of the state has resources. Getting those southern agencies connecting to northern providers and have an advisory council. Create a specific tab on the website that has links to pediatric resources. 4. Discussion – Kandyce will e-mail everyone with Scott Fish's contact info.	Pediatric Plan – Group will meet monthly as a subcommittee.

	Rural – 1. Relationship with AARP and their resources. – Bill has been in contact with Laura from AARP. 2. Maine Council of Churches – Some of their programs are intended to reach. 3. Social determinants that affect rural access - Recommend that our Legislators form regional forums to connect with the people in rural areas. The rural infrastructure and public health system are good talking points with candidates in 2018 elections. 5. Maine Health Care Access Foundation – MHC pursuing a grant from MeHAF to support a project the Rural Access committee has identified. **Payer/Provider** 1. There is disconnect between the concept of palliative care and how it is reimbursed. Lauren will meet with Harvard pilgrim, and Anthem to discuss a pilot program. Possibly the program would be in the coastal area. (Knox, Lincoln, and Waldo counties). 2. Connect pediatric efforts to create a full coverage palliative care pilot program.	Rural Plan - Bill to formally invite Laura to July meeting to discuss AARP collaboration
Debrief	Next meeting - July 20, 2018 Location to be determined. Invite to next meeting: Joanna Buzzle, Laura – AARP, Scott Fish	Kandyce to check on The Vile's Estate in Augusta as a possible venue
Public Comments	Ms. Grundy commented on the council's discussion of people's reactions to the words "palliative" and "hospice". There needs to be an effort to change the narrative that goes along with those words. There was agreement with the use of "stories" told by individuals that have received both kinds of services. How do we get the conversation going with service providers and the public? There was discussion of current programs being utilized by various hospices in the	

	state. Lauren felt this was something that would potentially tie in well with any media conversations with Scott Fish. Kandyce commented there are a lot of resources that might be helpful.	
Closing	Meeting adjourned @3pm	Respectfully submitted by Christine Grundy and Bertha Morin