State of Maine Palliative Care Advisory Council

July 20, 2018

Present: Dennis Fitzgibbons, Elizabeth Keene, Lauren Michalakes, James (Greg) Burns, Steve D'Amato, Kandyce Powell, Bill Primmerman, Jim Vankirk, Hilary Schneider

Scribe: Bertha Morin

Guests: Aysha Sheikh, Maine Cancer Foundation; Joan Ingram, Program Manager Diabetes; Maine Health, Lori Parham, AARP; Scott Fish, Maine Seacoast Mission; Deb Silberstein, MaineHealth Palliative Care

| Topic | Discussion | Follow up |
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| Welcome and Introductions | Meeting started at 8:10am opening statements by Elizabeth Keene | |
| Approval of minutes from last meeting | | |
| F/U from the 21st Annual Pain Symposium<br><br>(8:15-8:45) | **Kandyce Powell** shared highlights from the patient panels regarding pain in a nonterminal disabling disease<br><br>Code B-prescribing exception for opioids. Providers not willing to use exception out of fear.<br><br>Abandonment issues that chronic opioid patients are feeling with physicians not wanting to prescribe opioids. Dr. Vankirk stated this behavior has not been seen since the AIDS first started.<br><br>Discussed the Prescription Monitoring Program (PMP)-They are not a punitive organization—currently data gathering and the reports sent out comparing them to "peer" group—but not much information of what "peers" consist of. Some physicians will not use the exemption B code for any patient since they are not Board Certified Palliative physicians. We asked if any quality metrics and outcome measures being kept to monitor if these changes are affecting patient outcomes. None are currently being kept. One metric is overdose deaths.<br><br>Other highlights were from presentations from integrated pain clinics in the Portland and Lewiston area. All different modalities of pain control with varying levels of reimbursement. Rural areas have little or no access to resources except | |

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| | medication.<br><br>Gubernatorial candidates invited for panel discussion. All agreed that opioid crisis is not going to be solved by regulating prescribing. They all felt that the healthcare system is broken not only in Maine, but nationally. There must be work done on the social determinants that are driving opioid use/ crisis. All in support of one payer health coverage. Current system is not working. | |
| (8:45-10:00)<br><br>Subcommittee Reports from the Rural Access/Payer Pilot Pediatric Palliative Care | **Payer Pilot**—Lauren—CMO meeting with Anthem and Harvard Pilgrim.<br><br>Anthem does have palliative care on its radar. Aspire health care—home based palliative care program; currently in 20 states; NP driven with physician support and other discipline; 24/7 t/c support is contracted with providers to provide this. Currently not established in Maine. Aspire –CMO wants to learn more about Maine—Lauren will meet with him. Anthem has purchased Aspire—see article.<br><br>Pilot program with a Payer would be option to explore. Steve D'Amato has appointment with them next week; contract renewal.<br><br>Important to keep abreast of national trends. | Lauren will continue to explore opportunities, meet with CMO of Aspire<br><br>Report back to the group |
| | **Pediatric Palliative**<br><br>**Greg and Elizabeth**<br><br>Have had 2 meetings. Well attended—Androscoggin, CORE Health, and Maine Health.<br><br>How to utilize project ECHO. How to provide standardized education throughout the state.<br><br>Plan to meet once a month.<br><br>Representation from Northern Maine—<br><br>Utilizing technology. | Greg and Elizabeth will keep the group updated |

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| | The number of pediatric patients is quite small. The referrals are declining. One of the causes could be not enough knowledge about the resource. Scott states that once the program is underway and it is communicated the numbers grow. Never been able to roll out a pediatric palliative program. Jason program was doing well until the funding ran out.<br><br>**Rural Access**<br><br>**Jim-**Improve outreach; broadband access; forming alliance with state council of churches; AARP; telehealth.<br><br>The area is so big that causes a challenge.<br><br>**Bill**—MeHAF grant is on-going. Anthem is major insurer in Jackman. Maybe through the Aspire program, the FQHC could get more funding.<br><br>Hospice volunteers of Somerset County have been getting less referrals.<br><br>There is a grant available for communities who are working together (RWJ site) to get more information and promote our Age Friendly communities.<br><br>Bill, Jim and Kandyce working on additional discretionary funding. | |
| 10:00<br><br>**AARP Rural Access Presentation by Lori Parham** | Lori State Director of AARP in Maine—Age Friendly Communities.<br><br>Over-view of work AARP does: offices in every state—office in Portland; non-profit, non-partisan. Founded 60 years ago this month. Focus on health and retirement security of people over 50-but take an inter-generational interest.<br><br>AARP loves to work with partners—AARP Maine has few members and resources—they are only 6 staff in Maine—that is why developing partnerships are so worthwhile. AARP does biweekly TV spots in Bangor—they also have radio in | |

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| | L/A—they can enhance our communication to reach more listeners. AARP holds monthly coffees in different areas where speakers are invited to provide information. There are times the coffees are simply discussions on topics that members maybe interested in getting more information. There are also times that folks simple come together. Event schedules are on the AARP website. AARP also has monthly and quarterly columns in some periodicals—those can also be shared with partners. There are e newsletters. AARP has supported telehealth nationally; they also have done a poll in Maine regarding telehealth and are willing to share those findings. Part of the broadband coalition—not available in Jackman and other areas in Rural Maine.<br><br>Lori was in Jackman yesterday—AARP working nationally with folks >50 and who are working on creating Age Friendly Communities—there are 8 domains: housing; transportation; health; civic; outdoor areas/ parks; connectivity/informatics; social inclusion. Working in 56 communities in Maine. Second year of holding county panels regarding access to healthcare.<br><br>Community Health Needs Assessment (Hilary Schneider)—Maine CDC contracts to accumulate this data—tied to the work with ACA.<br><br>Each community has so many ties and work with various non-profits—hopefully not all these repeat work. Good to collaborate—not redo or repeat work.<br><br>There are Community Health Needs Assessment are being held and released to the public this fall.<br><br>Current work being done for continuum of healthcare: acute, palliative, then Hospice. Versus the current acute care—then hospice.<br><br>Education and public awareness are the best ways to reach the general public.<br><br>**Bill**—What can we do for you (AARP)? Lori states simply to share information with AARP.<br><br>$2 billion saved / yr. by MCD—by caregivers who provide unpaid care to family/friends. Legislation few years ago that would provide tax breaks for unpaid caregivers. Also attempted paid leave for be caregivers. | |

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| | November in Maine is State Caregiver month. Working with chambers of commerce to convince companies in Maine to supporting family caregiver in the work place—"react" is name of the program being used by Phiser and other companies. | |
| 1:00<br><br>**Using Social Media as an Educational Vehicle to Promote Education about Advance Care Planning and Palliative Care by Scott Fish** | **Scott**<br><br>Has done the Palliative Care Website.<br><br>Lived 30 yr. in Dixmont has worked in legislature for years.<br><br>When internet and e mail came out—opportunity to get information out vs. relying on TV and radio only,<br><br>Ways council could use social media. Educate what the council does; find supporters.<br><br>Law that set up council—provide public/ professional links to information regarding palliative care.<br><br>-be pro-active; use social media to keep folks up to date on what council is doing—use layman's terms. Term "palliative" is not well understood by the general public. How would you do that?—face book; twitter; u-tube; instagram; lynked in.<br><br>Example: Pain Symposium—if we had videotaped that—could have posted it. If tape—edit it—most people won't sit through 90 min.<br><br>Social media is not expensive.<br><br>Social media caters to larger audience.<br><br>Could "live feed" in order for an absent member could watch from anywhere.<br><br>People go more frequently to social media than web sites.<br><br>The council has a face book page. There are settings that you can bar others from | Lots of information here. Discussion will be taken back to full Advisory Council for discussion of further steps |

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| | posting on it. Be consistent—with frequency of posting.<br><br>**Dennis**—Need to set policy on use of social media re access, frequency and content.<br><br>If there is a specific topic/ event of particular interest to the council to get information out to the general public, "a call to action."<br><br>**Kandyce**-wonders if getting a grant for such a position is a possibility. Possibly post council meetings, issues, important facts for 1 year then review and assess the pros/ cons—if want to continue.<br><br>**Hilary**—great tool to share information. At times may be able to find a student who will take on such a program and develop. There are analytics that can be connected to various social media—how many times have you been viewed etc. There is a staffing issue that may arise from a project such as this.<br><br>When the council is ready to take a on the role of providing education via social media—that would require a multi-model effort and possibly require a grant for the funding.<br><br>**Kandyce**—would PSA be useful? A short PSA on TV is very brief—if you miss it, it's gone. Discussion regarding expense and time used for PSA—need to know the target audience—then develop—then focus group, there is time and expense.<br><br>If use social media—it is quicker, more cost effective, know the tools of the trade, to watch a broader audience, takes time and capacity. You R Target.<br><br>**Aysha**—"You are the targent.com"—mentioned. | |
| **1:00-3:00**<br><br>**Project ECHO brainstorming and work session** | **Joan Ingram**—since there has been so much interest in the ECHO; MaineHealth has agreed to expand their ECHO (extension for Community Health Outcomes) program—now Joan is doing this only. MaineHealth is going to expand to 4 specialties.<br><br>Our council has shown appreciation so Maine Med has agreed work with the | MaineHealth will continue to develop infrastructure for new ECHOs, including Palliative Care. |

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| | palliative council.<br><br>Diabetes is 1 hr. month.<br><br>**Lauren** is going to training in August 2018.<br><br>ECHO-would met goals of the council for education, consultation, reaching out to other parts of the state that don't have access to palliative care and/or little understanding.<br><br>There are no MaineHealth boundaries. Maine Cancer Foundation, Maine Quality Counts are also partners with the ECHO program.<br><br>Reimbursement for these services.<br><br>How CME awards—will be linked out of the New Mexico—will be given a link to go and fill out a survey, then get the CMEs. This is done on an honor system.<br><br>Clinical note taker would be beneficial—during the case presentation. There will not be recording—due to various privacy and confidentiality concerns.<br><br>Where the spokes—currently not limited to in patient—palliative care is provided everywhere. The HUB is usually team approach.<br><br>Who should attend? Palliative care is a team approach—there should be different disciplines. There is discussion that some of the spokes limit to peers—different disciplines may not participate; ask questions if there are other disciplines in the conversation. There are pros and cons to both views. If the HUB is interdisciplinary—they should be the example—so the spokes should be team.<br><br>**Aysha** states she was part of an ECHO this morning that was national—there were peers involved that did not feel comfortable asking questions in the presence of peers from other states.<br><br>Mostly use video—helps with the team building. Some participants black out their screens, and some simply call into the clinic. The video is always preferred—but if only way one can attend—that is one of the options.<br><br>Goal would be to build a state wide community among palliative providers and the | Lauren will attend Immersion in Houston in early August<br><br>Joan will attend Immersion in New Mexico in September |

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| | people who do the care.<br><br>**Kandyce**—questions if project ECHO could serve as an informational site—such as a patient navigator that is present for cancer patient. Are there consumer based project related with ECHO? Joan states that she is not aware if ECHO has consumer based informational site---Maine Health does not.<br><br>**Hilary** states more of a "tele-medicine" model. Basically there is no reimbursement for that service. This is a service that the population would benefit from a service like this.<br><br>There are people who will provide services for free, not always looking for reimbursement.<br><br>**Bill**-there are many consumers looking for information; searching but, some areas are not trustworthy. Providing information that is accurate and trusted is important.<br><br>What outcomes are we looking for?<br><br>How many miles saved from travel to get the care provided? Pre-Post care survey? Do you feel more comfortable providing this care?<br><br>Benchmarks for inpatient palliative care consults.<br><br>**Jim** has reviewed the above measured benchmarks. The study also reviewed the availability of palliative care providers—that doesn't consider outpatient palliative. States that not all chronically ill patient needs and/or warrants a palliative care consult. Would possibly increase the knowledge, and capabilities of primary physician's confidence and ability to provide palliative end of life care.<br><br>**Joan** will contact the other Hubs that are working with palliative care—discuss the curriculum, metrics, and what outcomes are they measuring.<br><br>Would a needs assessment and survey would be helpful to develop a curriculum.<br><br>Next steps:<br><br>Joan will invite those who want to be involved with the planning. They will decide as a group to decide how to move forward with curriculum. | |

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| | Faculty—those are members for the Hub—can be a virtual HUB-to have one moderator who is present at the site of HUB. Faculty would be presenter. Will need to decide who will assist with preparing slides; presentations. See handouts.<br><br>Participants—who would want to be a spoke site—many of the hospitals are now equipped with the materials. One person is a spoke then there is also one site is a spoke—explanations vary. It's the number of cameras. Goal for 10 spoke sites consistently—would need 15 spokes. Members of the different health systems involved will contact possible spoke sites and if they are interested send the name and contact to Deb Silberstein or Joan.<br><br>Would be nice to meet monthly for 1 year—then possibly have a day-long event in person. Some meet in person first then start with the ECHO. If did meet annually that would probably cost money; that being said if the ECHO for palliative care is successful-then maybe the participants would not mind paying a fee.<br><br>Discussion regarding how to get the information out to providers. Hilary will provide Joan with the list of contacts she and Kandyce had when first assembling the council.<br><br>January 2019 tentative initial start.<br><br>Physicians present state that first thing in the morning is usually best time to meet; before their patient case load.<br><br>Lauren will attend her ECHO training in a few weeks, then reach out and assemble the planning committee and tasks that different folks can assist with.<br><br>Things can evolve, change and adapt. Planning committee should be interdisciplinary.<br><br>Possibly have a patient voice to get their understanding, experience with palliative care.<br><br>Length should be 1 hr. maximum length. | Lauren and Elizabeth will prepare a letter to the members of the council who |

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| | | are not here today.<br><br>Lauren will send out e-mail to see who wants to be on the planning committee. |
| **Adjournment** | **Motion made by Greg and 2nd by Jim.** | |
| Next Meeting: | | To be scheduled. |