

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

February 4, 2019

1:00 p.m. to 3:00 p.m.

Lincoln, NE

Members in Attendance:

Holly Adams
 Marcia Cederdahl
 Andrew Macfadyen
 Linda Rock (via Zoom)
 Sabrina Schalley
 Stacie Sinclair

Staff:

Christine Esch
 Shirley Pickens-White
 Andrea Wenke

Guests:

Becky Wisell

| Agenda Topic | Key Points | Action Items (if any) |
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| Call to Order and Approval of Minutes | <ul style="list-style-type: none"> • The Council voted for Stacie Sinclair to serve as acting Chair for the February 4 meeting. • Stacie Sinclair called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council meeting to order at 1:07 p.m. She referenced the Open Meeting Act, which was posted where everyone could read: <i>Open Meeting Act Location Announcement: In accordance with Section 84-1412 of the Nebraska Revised Statutes, a copy of the Nebraska Open Meetings Act is located on the counter near the door.</i> • There are currently two vacancies – one for DHHS and one for Dr. Lazoritz. The Governor must appoint replacements. It is likely these will come from the previous pool of applicants; however, Council members voiced a strong preference that Dr. Lazoritz’s replacement come from the payer/health plan perspective. • Stacie reviewed the meeting minutes. Holly Adams saw a reference to reaching out to Lincoln Journal Star which she did not commit to; moved to strike from the minutes. • The Council discussed including the use of Zoom to allow for better remote participation | <ul style="list-style-type: none"> • Todd Sauer to confirm whether he will serve as Chair; depending on outcome, Full Council vote on Stacie Sinclair for Vice Chair or Chair position at next Council meeting • Stacie Sinclair to provide DHHS staff with Zoom credentials for upcoming meeting |
| Review of Palliative Care Council Webpage | <ul style="list-style-type: none"> • Andrea Wenke reviewed the test site, which rearranges the Palliative Care resources and includes new images and features (e.g., social media, palliative care FAQs). The deadline to submit any new materials to the state is 2/8; the go live date is planned for mid-March. • Council members requested new images that include greater diversity in regards to age, race, and ethnicity. Andrea said that she could replace images as long as they are free, publicly available, and maintain a specific aspect ratio. | <ul style="list-style-type: none"> • Full Council to submit additional changes to Andrea Wenke in writing, with the understanding that these might not be incorporated until revisions to the DHHS website are completed |

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| | <ul style="list-style-type: none"> Stacie Sinclair and Marcia Cederdahl asked if Andrea could create sub-lists to better organize the “Provider” resources; Andrea asked for a list so that she could follow-up. Stacie suggested that the Navigation options be revised to specify “Resources for ____”. Stacie asked whether Andrea could a LISTSERV function, Andrea said this is possible through GovUpdate; she is waiting on the webmaster for instructions on how to set up. Council members suggested that Andrea add Association of Oncology Social Work and Association of Pediatric Oncology Social Workers, and re-add NHPCO to “National Resources.” Council members suggested that Andrea incorporate “any age” in the first reference of the FAQs. Council members discussed posting meeting agendas and minutes to the Council within a certain timeframe, and sending these out through the LISTSERV automatically. | <ul style="list-style-type: none"> Stacie Sinclair and Marcia Cederdahl to send categories to Andrea on the Provider Resources Andrea Wenke to make changes discussed DHHS Staff to post agenda and minutes 2-4 weeks after each meeting; post agenda for upcoming meetings 4 weeks before each meeting (as available) |
| Opioid Policy Paper Follow-Up | <ul style="list-style-type: none"> Stacie Sinclair is still working on finalizing the paper. Meanwhile, Marcia Cederdahl reported that she is hearing from the field that patients are reluctant to ask for opioids and providers are reluctant to prescribe. Given this, Sabrina Schalley voiced that finishing the position statement is still a worthwhile activity. <ul style="list-style-type: none"> If the Council posts the paper on its website, it is likely that the DHHS Communications department will need to review and possibly provide feedback. Shirley Pickens-White will research the process, including whether the Council should insert a disclaimer. Andrew Macfadyen noted that a bill introduced in the current legislature, LB 557, addresses some of these concerns by including a provision that the bill does not apply cancer and palliative care. The challenge is that it does not specify any other conditions, and there is still no clarity on how the palliative care exemption would be applied. Andrew noted that there is a hearing (February 13), providing an opportunity to submit written or oral testimony. <ul style="list-style-type: none"> Council members discussed whether it could submit official testimony as a body. Decided this was unlikely because it is classified as an “Advisory” council. That said, individual members (including the Nebraska Hospice and Palliative Care Association) have the right to testify (e.g., Andrew testified on last year’s opioid bill). Council members noted that it would be helpful to develop a system for vetting legislation in future sessions. | <ul style="list-style-type: none"> Stacie Sinclair to finalize Opioid Position Statement Shirley Pickens-White to research process for posting a position statement online, including whether we must insert a disclaimer Marcia Cederdahl to contact Ashlee Fish about process for disseminating Opioid Position Statement to key stakeholders Full Council to develop process for reviewing and vetting relevant legislation in future sessions |
| Palliative Care Best Practices (NETO) | <ul style="list-style-type: none"> The goal of the Nebraska Emergency Treatment Orders (NETO) Project is to improve advance care planning in the state with a simple, standardized form. NETO 2.0 is a two-sided form; the first page is a “Declaration” page describing the patient’s wishes to accept, limit, or refuse treatment. The second is an “Orders” page that provides instructions for Emergency Medical Services (EMS) and is signed by the patient’s provider. | <ul style="list-style-type: none"> Council Members to review NETO materials and provide feedback to the NETO team as desired |

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| | <ul style="list-style-type: none"> • The NETO team did not introduce legislation this session. Rather, they are asking that Council members review the revised NETO form and provide feedback. <ul style="list-style-type: none"> ○ Note – LB 365, “Adopt the Health Care Directives Registry Act,” addresses a similar topic of communicating wishes, but is not directly relevant to what the NETO team is working on (i.e., improving how advance directives are <i>written</i>, rather than where to store them). ○ All Council members present acknowledged the value of having a standardized form. Andrew Macfadyen liked that it was straightforward and would support discussions with all counties and EMS directors. • Regarding implementation, the NETO team sounds more inclined to pursue a grassroots adoption approach, since history with legislation and POLST has been difficult. Looking ahead, if a policy strategy is necessary, the NETO team is more likely to modify the Rights of the Terminally Ill Act, rather than introducing new legislation. | |
| <p>Policy Barrier “Bucket #1” – Continued Discussion</p> | <ul style="list-style-type: none"> • Continuing the discussion from the November 2018 Council meeting on updating the definition of palliative care, Council members discussed that there are almost no community-based palliative care services in Nebraska, making it difficult for patients once they leave the hospital. There is also no mechanism to ensure that facilities and/or providers claiming to deliver palliative care are doing so in accordance with what the Council considers high-quality care. Finally, palliative care is not defined in the Nebraska Health Care Facility Licensure Act (§§ 71-401 to 71-475), and the definition in the Hospice Regulations (Title 175) needs updating. <ul style="list-style-type: none"> ○ Given this, Council members decided it is important to achieve consensus on a good regulatory definition for palliative care, and that this should happen between meetings so that we can use in-person time to approve. The Council should then update the definition of palliative care in the Hospice regulations and adopt for other regulations (focus on <u>facilities</u>, not clinicians). There is a window of opportunity, because DHHS is in the process of updating ALL regulations as part of the Executive Review of Regulations called for in 2017. • Continuing the discussion on a potential landscape study, Stacie Sinclair shared that there is a legislative process to support an “Interim Study” that the Council might be able to pursue. Council members in attendance were interested, and wanted to know what other Nebraska Governor-appointed Councils do (to inform whether this is an appropriate activity). Sabrina Schalley volunteered to contact other Councils; Shirley Pickens-White volunteered to provide contact information. <ul style="list-style-type: none"> ○ As a process note, meeting guest Becky Wisell shared information on NE Boards of Health, which are similar to the Council in that they are Governor-appointed. If | <ul style="list-style-type: none"> • Stacie Sinclair to recirculate sample definitions and standards from other states • Stacie Sinclair to circulate capacity assessments from other states • Stacie Sinclair to update policy options slide deck, and develop outline plan for education State Health Professional Boards • Shirley Pickens-White to provide contact information for other NE Councils; Sabrina Schalley to contact these Councils to learn more about their work |

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| | <p>these Boards decided to take a position on any legislation or regulation, they must represent these opinions as their own; DHHS provides guidance only.</p> <ul style="list-style-type: none"> • The Council also discussed adding NETO to its list of general policy options (bucket #4), and updating proposed collaboration activities to include educating State Professional Boards on palliative care | |
| Legislative Bills | <ul style="list-style-type: none"> • The Council discussed three bills introduced in the 2019 Nebraska Legislature that could be relevant to our work. As discussed in the opioid item, the Council will not take action as a full body on these bills, although individual members may act on their own accord • LB 557 – An Act Relating to Controlled Substances <ul style="list-style-type: none"> ○ This bill, among other things, would change the first and third prescription to a 60-day look back, and add an exemption for hospice and palliative care or a cancer diagnosis • LB 365 – Adopt the Health Care Directives Registry Act <ul style="list-style-type: none"> ○ This bill, among other things, would direct the Department of Health and Human Services to create and administer a “Health Care Directives Registry,” which would store written advance health care directives submitted by eligible adults and make them available electronically upon request • LB 488 – An Act Relating to Schools <ul style="list-style-type: none"> ○ This bill, among other things, would require school districts beginning with school year 2020-21 to incorporate age appropriate mental health education and age appropriate comprehensive drug awareness and prevention education for students | <ul style="list-style-type: none"> • N/A |
| Next Committee Meeting | <ul style="list-style-type: none"> • TBC in Omaha, NE • Proposed Agenda Items <ul style="list-style-type: none"> ○ Voting on Regulatory Definition ○ NE Palliative Care Landscape Study ○ Opioid Position Statement Debrief ○ Planning for Palliative Care Month ○ Education strategy for State Boards of Health | <ul style="list-style-type: none"> • Marcia Cederdahl to confirm if NHCA is willing to host • Full Council to suggest any additional agenda items |
| Public Comments | <ul style="list-style-type: none"> • N/A | <ul style="list-style-type: none"> • N/A |

Meeting Adjourned at 2:59 p.m.

Meeting Minutes: Stacie Sinclair