

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

July 7, 2023

10:00 a.m. to 12:00 p.m.

In-Person and Zoom

Members in Attendance:

Marcia Cederdahl
Theresa Jizba (via Zoom)
Brenda Kastens (via Zoom)
Andrew Macfadyen (via Zoom)
Julie Masters (via Zoom)
Angela Mortenson (via Zoom)
Todd Sauer (via Zoom)
Sabrina Schalley (via Zoom)
Stacie Sinclair

Staff:

Shirley Pickens-White
Leah Snyder

Guests:

Melissa Johnson (Bryan Health)
Marilee Malcom (Nebraska Hospice and Palliative Care Association)
Oscar Sinclair

In accordance with Section 84-1411 of the [Open Meetings Act](#), advanced publicized notice of the time and place of this meeting was posted on the [Nebraska Public Meeting Calendar](#).

Agenda Topic	Key Points	Action Items (if any)
Call to Order, Introduction, Meeting Minutes	<ul style="list-style-type: none">Stacie Sinclair called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 10:00 am CT and read the NE Open Meetings Act:<ul style="list-style-type: none"><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 [available online].</i>It was determined that since the Council did not have an in-person quorum, this meeting would be considered a “Virtual Meeting;” i.e., no formal public votes could be taken, and this does not count towards the statutory requirement that the Council meet in person at least 2x per year.There was no feedback or corrections on the meeting minutes for December 5, 2022 and March 28, 2023. The vote to approve these minutes will take place at the September meeting, pending an in-person quorum.	<ul style="list-style-type: none">N/A
Virtual Council Participation	<ul style="list-style-type: none">Julie Masters asked about the possibility of making Council meetings wholly virtual to better accommodate geographic spread and busy schedules. Stacie agreed with the need to continuing providing a virtual option to promote participation (affirmed by Council vote in February 2020);	<ul style="list-style-type: none">Stacie Sinclair to emphasize “in-person”

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<p><i>(Stacie Sinclair, Julie Masters)</i></p>	<p>however, she acknowledged that the Council operates under the Open Meetings Act, which requires an in-person quorum (> 50% of appointed members) to count towards the statutory requirement for two in-person meetings annually.</p> <ul style="list-style-type: none"> • Since the Council decided to conduct full meetings quarterly, members discussed making every other meeting “virtual only;” and then emphasizing which meetings were important to attend in-person (while continuing to make a virtual option available for those who need it). Since the March meeting met quorum requirements, only one additional in-person meeting is needed in 2023. 	<p>meeting in September meeting notice</p>
<p>Nebraska Hospice and Palliative Care Association Update <i>(Marilee Malcom)</i></p>	<ul style="list-style-type: none"> • Congratulations on the passage of LB 227, which includes a definition of palliative care! Many thanks to ACS CAN, the Council, and all the stakeholders who attended action days, conducted outreach, submitted testimony, etc. • The Key Findings and the Full Report for the 2022 Nebraska End-of-Life Survey are now posted on the Council’s website, and champions are encouraged to distribute widely. • Planning for next year’s NHPCA’s Annual Conference (March 19-20, 2024) has begun, and the Call for Presentations is now open. All are encouraged to submit. • NHPCA has decided to endorse POLST as the state form to collect and share end-of-life wishes. To support this effort, it will be hosting free educational webinars with Jacob Dahlke (ethicist for NE Medicine, state POLST leader) on the first Friday (Zoom link here) and third Wednesday (Zoom link here) of each month from 12:00-1:00pm CT. The goal is to get all providers engaged. Moving forward, NHPCA will be looking for grant funding to establish a state registry. Marilee is talking to leaders from other states – particularly those for which POLST did not go through the legislature – about how they have made this work (see next agenda item re: POLST and NETO follow-up). • Save-the-Date: October 19, 2023 from 9:00am-4:00pm. NHPCA and LeadingAge will be teaming up to host a Fall Symposium at Firespring in Lincoln. There will be 7 CEUs available. 	<ul style="list-style-type: none"> • Council Members and other interested parties to submit abstracts for NHPCA Conference
<p>End of Life Treatment Orders (POLST/NETO) and EMTs <i>(Theresa Jizba)</i></p>	<ul style="list-style-type: none"> • Following NHPCA’s presentation, Council members discussed that there was general movement towards POLST among Nebraska palliative care and hospice champions (with some exceptions such as pediatrics, certain health systems). Melissa Johnson suggested that there could be a path for connecting with CHI; she is willing to help, and had suggestions re: timing. • Both Theresa Jizba and Marilee Malcom have been trying to get on the agenda for the NE Board of Emergency Medical Services, with minimal luck. The next step is to contact Tonja Bohling, as well as the Board Chair, to explore options. Stacie suggested that they could potential explore reaching out to other agency contacts or legislative champions. 	<ul style="list-style-type: none"> • Stacie Sinclair to connect Theresa Jizba and Melissa Johnson

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	<ul style="list-style-type: none"> • Council members and attendees discussed that benefits of not pursuing a legislative strategy for POLST outweigh the drawbacks. • Council members and attendees also discussed the importance of clear education and messaging on POLST. Julie explained that POLST is intended for sick patients who are likely in the last year of life, and perhaps better communication could help alleviate confusion. Theresa observed that, too often, providers do not recommend POLST completion because prognostication is difficult and/or they “don’t want to scare the patient.” This leads to patients dying without a plan, under circumstances that they wouldn’t have chosen. Stacie also highlighted that providers (particularly organizations) can go too far in the other direction, having seen instances in which nursing facilities include POLST as part of the admission package, regardless of resident’s trajectory, which is immensely harmful. • Theresa shared that Meghan Potthoff and Mandy Kirkpatrick have a large grant to create an Advance Care Planning clinic targeting the elderly in NE; it is good that there is growing consistency around POLST is increasing as this project operationalized. 	
<p>Legislative Session Wrap-Up, PCHETA <i>(Marcia Cederdahl, Stacie Sinclair)</i></p>	<ul style="list-style-type: none"> • Stacie reiterated congratulations regarding the passage of LB 227, thanking the Council, NHPCA, and ACS CAN for their efforts; Andrew Macfadyen expressed additional gratitude for Julie Erickson, ACS CAN’s lobbyist. The repository to house all definition effort materials including meeting recordings, leave behinds, FAQs, etc., will remain live. • Following the passage of the definition, the Council, NHPCA, and other palliative care stakeholders must be proactive in helping develop the regulations. Absent this, there is a chance that the work with either stall, or DHHS may proceed without input from the palliative care community. <ul style="list-style-type: none"> ○ Stacie and Andrew observed that this part of the process may be more difficult than the definition, because the former was relatively high-level and didn’t involve any money. Developing regulations involves a much deeper dive into standards for palliative care and will require greater input and communication with stakeholders. ○ Marcia Cederdahl suggested asking Dan at DHHS about a workgroup process. Brenda Kastens clarified that stakeholders are not involved in drafting process of regulations. With other Chapters, once the Policy and Internal teams have drafted the regulations, they are opened up for public comment. She suggested that the Council use the hospice regulations as a template for palliative care, and then submit prior to or during the internal drafting process. She also clarified that this process can take years, so the Council should be prepared. ○ Andrew observed that work on regulations should be informed by the Council’s vision and goals, which should be articulated through the Strategic Planning process. 	<ul style="list-style-type: none"> • Stacie Sinclair to send out more information on outreach to Senators Fischer and Ricketts

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	<ul style="list-style-type: none"> The Palliative Care and Hospice Education and Training Act (PCHETA) is set to be reintroduced on July 11, 2023. Advocates from Nebraska met with Senators Fischer and Ricketts on June 22, 2023 as part of the Patient Quality of Life Coalition’s Lobby Day. Senator Fischer is well-positioned to champion, having co-sponsored in the past, but needs to hear that this bill continues to be a priority. Senator Ricketts’ office needs additional education, as some of his staff are newer and unaware of his previous support for palliative care. Andrew suggested inviting Senator Ricketts to join a future Council call. 	
Council Strategic Planning <i>(Julie Masters)</i>	<ul style="list-style-type: none"> Following up on the Council’s need to conduct a strategic planning process, Julie connected with Dr. Tara Bryan at the UNL School of Public Administration. Dr. Bryan will be teaching a virtual course on strategic planning in the fall, and proposed that the Council could be the class project. Of the two options available, the Council determined that the more in-depth “client-based” option would be more appropriate. Stacie volunteered to serve as primary contact along with Julie. Council members cycling off said they would be willing to participate in this process. 	<ul style="list-style-type: none"> Julie Masters to confirm with Dr. Tara Bryan Stacie Sinclair to serve as co-primary contact
Council Workgroup – Public Awareness <i>(Marcia Cederdahl, Julie Masters, Sabrina Schalley)</i>	<ul style="list-style-type: none"> The Public Awareness workgroup has worked diligently to increase the library of materials on the palliative care website. Newly published and upcoming pieces include a series of perspectives on palliative care from the interdisciplinary care team, patients, and caregivers; how to navigate differences in care preferences between the patient and family; and the difference between home- and hospital-based palliative care services. These pieces can be used in any request for information or promotional efforts moving forward. The workgroup is still looking for a piece written from the chaplaincy perspective. Angela Mortenson suggested contacts at Nebraska Medicine; if those people are unavailable, Theresa has a contact at Methodist/CHI. 	<ul style="list-style-type: none"> Angela Mortenson and Theresa Jizba to share chaplaincy contacts with Sabrina Schalley
Council Workgroup – Website <i>(Andrew Macfadyen)</i>	<ul style="list-style-type: none"> Andrew shared that website traffic is down a little bit this year, but bounce rate (leaving without any additional clicks) is lower. Julie asked if there is a way to drill down further on where people are going/spending time so that the Council can better understand which resources are resonating; it is possible, but the numbers get too small to be particularly useful. 	<ul style="list-style-type: none"> Council members to share website feedback and items for posting to Stacie Sinclair until new workgroup lead is identified
Acknowledgement of Board Members Cycling Off, Reflection	<ul style="list-style-type: none"> This was the final meeting for four Council members – Dr. Todd Sauer, Dr. Andrew Macfadyen, Sabrina Schalley, and Marcia Cederdahl. These members have been with the Council since it began in 	<ul style="list-style-type: none"> Council members to recruit new candidates for the Council

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(All)	<p>2017, and their contributions have been invaluable to getting the Council up and running. Members expressed gratitude for these individuals' service.</p> <ul style="list-style-type: none"> Stacie asked that attendees proactively recruit candidates to fill the upcoming vacancies. Shirley Pickens-White said that it would be helpful for Council members to share the names of anyone we know applied so that she can follow up with the Governor's office. 	<ul style="list-style-type: none"> Council members to share the names of confirmed applicants with Shirley Pickens-White
Open Discussion and Public Comments	<ul style="list-style-type: none"> Marilee Malcom expressed pride and gratitude for the Council's work. 	<ul style="list-style-type: none"> N/A
Planning for the Next Palliative Care Meeting	<ul style="list-style-type: none"> The next Nebraska Palliative Care and Quality of Life Advisory Council meeting was scheduled for September 11, 2023 from 1:00-3:00pm CT in Omaha, NE; however, this may need to be rescheduled to later. Stacie Sinclair will update the calendar appointments with a Zoom link and location once the meeting is confirmed. Subsequent Council meetings are set for: <ul style="list-style-type: none"> December 4, 2023 Agenda items: <ul style="list-style-type: none"> Council Strategic Planning NHPCA update Palliative care definition campaign Council workgroup report outs <i>Please submit additional agenda items to Stacie Sinclair</i> 	<ul style="list-style-type: none"> Council members to submit requests for reimbursement to Shirley Pickens-White Council members to submit additional agenda items

Meeting Adjourned at 12:00pm CT
Meeting Minutes: Stacie Sinclair