

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

January 9, 2024

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

Zoom

Members in Attendance:

Theresa Jizba
Brenda Kastens
Julie Masters
Stacie Sinclair

Staff:

Shirley Pickens-White
Leah Snyder

Guests:

Melissa Johnson (Bryan Health)
Marilee Malcom (Nebraska Hospice and Palliative Care Association)
Kathleen McKillip (Nebraska Cancer Specialists)
Laura Schabloske (Nebraska Cancer Coalition)
Megan Word (American Cancer Society Cancer Action Network, NE Chapter)

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 10:03 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>The Council did not vote on the meeting minutes from October 2023, so will need to vote to approve at the next scheduled meeting	<ul style="list-style-type: none">N/A
Nebraska Hospice and Palliative Care Association Update <i>(Marilee Malcom)</i>	<ul style="list-style-type: none">NHPCA is hosting a virtual Alzheimer’s Disease and Dementia Care Seminar on January 17-18, 2024. More details can be found here.NHPCA and the Nebraska Home Care Association (NHCA) are jointly hosting a legislative luncheon day on February 7, 2024. More details, including the registration link, can be found here.Registration is open for NHPCA’s Annual Conference (March 19-20, 2024 at the Embassy Suites by Hilton). Keynote speakers include Dr. Timothy Ihrig, Dr. Cordt Kassner, and Judi Lund Person.NHPCA is partnering with Creighton University to offer a virtual Advance Care Planning Symposium on April 4 from 9:00am-12:30pm, which will also be keynoted by Dr. Ihrig.	<ul style="list-style-type: none">N/A

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	<ul style="list-style-type: none"> NHPCA continues to host 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. NHPCA has received a conditional commitment from the Gadfly Project for an in-kind technical support grant, valued at \$300,000, to develop a state ePOLST registry. Proposed conditions include NHPCA raising \$52,000 in matching funds, and securing participating from at least four other states to create a pathway for funding sustainability. While representatives from the National POLST Paradigm were initially enthusiastic about the work, the Board did not vote to officially endorse the project; therefore, NHPCA will need to identify potential state partners on an individual basis. If this project proceeds, NE would be the primary administrator. See “End of Life Treatment Orders (POLST/NETO) and EMTs” section of minutes for additional updates. 	
NE Council Policy Work	<ul style="list-style-type: none"> The Nebraska Unicameral Legislature began the second session of the 108th Legislature on Wednesday, January 3, 2024. It will be working through the rules process until January 19, which will determine a great deal of how this session will proceed. In the meantime, the Legislature has 10 days to file all new bills; any bill filed before this deadline will receive a hearing. This is a 60-day session, so no real budget work will happen beyond tweaking what has been passed. <ul style="list-style-type: none"> Some bills/issues that may pertain to the Council include colorectal, lung, access, biomarkers. Senator Bostar filed LB 937 to adopt the Caregiver Tax Credit Act, which is written broadly enough that it may be applicable to the caregivers of patients living with serious illness. Given the Council’s reduced capacity pending Governor’s appointments, the Council cannot directly track legislation. DHHS will not forward any relevant legislation unless it specifically mentions palliative care. Given this, Stacie Sinclair will work with identified partners to learn about relevant bills, and use the Council’s communication channels to disseminate information. ACS CAN NE, NHPCA, and NC2 all volunteered to send relevant bills; Stacie will also reach out to AARP, AAA, and/or the Alzheimer’s Association (Nick Faustman) to see if they will direct relevant bills towards the Council (Stacie will also monitor NASW-NE’s tracker) [Post-meeting] Stacie has created a tracker for the NE Palliative Care Advisory Council so that interested members and friends can input and/or review relevant legislation in real time Melissa Johnson highlighted a discussion from the July 2023 Council meeting regarding a regulatory push to ensure the palliative care definition passed in the first session of the 108th Legislature is supported by proper standards. Megan Word suggested that the current session provides a good opportunity to socialize this work. Brenda Kastens provided an overview of the regulatory process 	<ul style="list-style-type: none"> Stacie Sinclair to contact identified partners to request relevant legislation be directed our way Stacie Sinclair to disseminate relevant legislation to Council members and the broader listserv as appropriate

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	<p>based on her experience the Medicaid office, giving the caveats that this is likely a 2-3 year process, and can be challenging – particularly in election years. Proposed steps:</p> <ul style="list-style-type: none"> ○ Our group(s) begin drafting the language that we would want to see (lay the groundwork) ○ Our group(s) update interested Senators on implementation; ask them to reach out to DHHS to ask, “What have you done since the bill advanced?” and/or “Are there other people you would like us to contact?” ○ Begin working with the DHHS Policy Department as requested; after this point, it will largely be out of our hands 	
Communications Strategy (<i>Julie Masters</i>)	<ul style="list-style-type: none"> • Leah Snyder posted the last new article that Sabrina Schalley wrote on the website in December. The communications workgroup will take a pause until we learn more about Governor appointments. 	<ul style="list-style-type: none"> • N/A
End of Life Treatment Orders (POLST/NETO) and EMTs <i>(Theresa Jizba)</i>	<ul style="list-style-type: none"> • Serious illness champions on Nebraska are now largely coalescing around POLST as the primary form to support end of life decision-making. The Nebraska Emergency Treatment Orders (NETO) website has been taken down; people can make copies of them, but there will be no further updates. The Veterans Administration (VA) has indicated that it will be moving over to POLST as well. • Following up on the NE Board of Emergency Medical Services on September 11, 2023, there continues to be inconsistent understanding about EMS’s legal obligations and/or liabilities regarding adherence to end-of-life wishes. Everyone wants a consistent form and a clear understanding of legal obligations; however, there is some resistance to an internet-based registry due to technology limitations. The Committee is going to review the language. • There continues to be some low-level resistance among rural providers that implementation of an internet-based form will be feasible. More education will be needed if/when the ePOLST registry goes live. • Again, clear education and messaging on POLST is needed. Specific tensions discussed at this meeting included misperceptions about not intubating; the harms of using hospital-specific forms (tremendous variation); how to navigate when a form says one thing and a family member says another; and working against EMS/ER foundation training oriented towards life saving measures. “It’s the people who are sitting with the patient downstream that see firsthand the consequences of missed opportunities to make decisions upstream.” 	<ul style="list-style-type: none"> • (From October 2023 meeting) Stacie Sinclair to draft a high-level statement on the Council’s position re: EOL treatment orders
Strategic Plan Review (<i>Stacie Sinclair</i>)	<ul style="list-style-type: none"> • Overall, Council members and public attendees thought the draft Strategic Plan developed by the UNO School of Public Administration was well-done. Council members did a high-level review of the 	<ul style="list-style-type: none"> • Stacie Sinclair to explore establishing a Facebook page for the NE Palliative

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	<p>process/methods sections, and then reviewed and prioritized the near-term strategies (in order of priority):</p> <ul style="list-style-type: none"> ○ Better Utilize Digital Tools for Outreach and Education – all agreed this was the most feasible initial strategy, Stacie volunteered to explore the idea of setting up a Facebook page for the Council. Additionally, discussed doing a website clean-up ○ Improve and Develop Stakeholder Relationships – Theresa would be willing to do more one-on-one work, such as cultivating relationships with Methodist, Nebraska Health System, CHI, etc.) ○ Establish a Dedicated Government Affairs Councilmember ○ Establish Applicable Working Groups ○ Increase Outreach and Visibility through Face-to-Face Meetings with Stakeholders – all agreed that this was worthwhile, but likely a Year 2 effort given the Council’s reduced capacity <ul style="list-style-type: none"> ● Rather than posting the complete Strategic Plan on the website, Laura Schabloske suggested distilling it into more of an executive summary document and creating an action plan that includes primary owners and timelines. Stacie volunteered to take the first pass. 	<p>Care and Quality of Life Advisory Council</p> <ul style="list-style-type: none"> ● Stacie Sinclair to draft an action plan of near-term strategies including owners and timelines
Open Discussion and Public Comments	<ul style="list-style-type: none"> ● Council members discussed the challenge of continuing to operate with limited capacity, as we are still waiting on Governor Pillen to appoint new members to the Council. If we do not hear any news by the next Council meeting, members will discuss developing a more assertive approach to get appointees. ● No public comments. 	<ul style="list-style-type: none"> ● N/A
Planning for the Next Palliative Care Meeting	<ul style="list-style-type: none"> ● Stacie Sinclair or Leah Snyder will send out an email to schedule the next Nebraska Palliative Care and Quality of Life Advisory Council meeting. ● Agenda items: <ul style="list-style-type: none"> ○ Council Strategic Plan review (cont’d) ○ NHPCA update ○ Legislative session review ○ <i>Please submit additional agenda items to Stacie Sinclair</i> 	<ul style="list-style-type: none"> ● Stacie Sinclair or Leah Snyder to schedule the next NE Council Meeting ● Council members to submit requests for reimbursement to Shirley Pickens-White

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		<ul style="list-style-type: none"><li data-bbox="1640 175 1990 272">• Council members to submit additional agenda items

Meeting Adjourned at 11:47am CT
Meeting Minutes: Stacie Sinclair

DRAFT