

## MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

October 18, 2023

8:00 a.m. to 10:00 a.m.

In-Person and Zoom

**Members in Attendance:**

Theresa Jizba  
Julie Masters  
Stacie Sinclair

**Staff:**

Shirley Pickens-White  
Leah Snyder

**Guests:**

Andrew Macfadyen (Children’s Hospital)  
Marilee Malcom (Nebraska Hospice and Palliative Care Association)

*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)
<p><b>Call to Order, Introduction, Meeting Minutes</b></p>	<ul style="list-style-type: none"> <li>• Stacie Sinclair called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 8:11 am CT and read the NE Open Meetings Act:                             <ul style="list-style-type: none"> <li>○ <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></li> </ul> </li> <li>• With a quorum present, the council voted to approve the meeting minutes for December 2022 (Julie Masters moved, Theresa Jizba seconded, unanimous approval); March 2023 (Theresa moved, Julie seconded, unanimous approval); and July 2023 (Julie moved, Theresa seconded, unanimous approval).</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Stacie Sinclair</b> to send final versions of December 2022, March 2023, and July 2023 minutes to <b>Leah Snyder</b> to post on Council website</li> </ul>
<p><b>Nebraska Hospice and Palliative Care Association Update</b> <i>(Marilee Malcom)</i></p>	<ul style="list-style-type: none"> <li>• The Nebraska Hospice and Palliative Care Association (NHPCA) Board is in the process of doing strategic planning.</li> <li>• NHPCA and LeadingAge hosted a Fall Symposium at Firespring in Lincoln on October 19, 2023 from 9:00am-4:00pm.</li> <li>• Planning for next year’s <a href="#">NHPCA’s Annual Conference</a> (March 19-20, 2024) has begun, and the <a href="#">Call for Presentations</a> is now open. All are encouraged to submit. NHPCA is aware that this conference conflicts with the <a href="#">AAHPM and HPNA Annual Assembly</a> (March 20-23, 2024 in Phoenix, AZ) which prevents participation from those wanting to do both. Marilee looked ahead and does not see conflicts in future years.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Council Members</b> and other interested parties to submit abstracts for NHPCA Conference</li> <li>• <b>Marilee Malcom</b> to provide information on upcoming pediatric trainings</li> </ul>

Agenda Topic	Key Points	Action Items (if any)
	<ul style="list-style-type: none"> <li>At the national level, the National Hospice and Palliative Care Organization (NHPCO) and the National Association for Home Care &amp; Hospice (NAHC) are exploring the possibility of <a href="#">combining their organizations</a>. While details are sparse, this could potentially have downstream impacts at the state level.</li> <li>NHPCA conducted a hospice survey in summer 2023. There were a total of 30 respondents (denominator was 40). 17 responded that they currently provided pediatric hospice; of the remaining respondents, 6 said they would provide pediatric care if they received training. Therefore, NHPCA received a grant to provide low-cost, in-person pediatric care trainings in the Lower Platte area and Western Nebraska.</li> <li>NHPCA has endorsed POLST as the state form to collect and share end-of-life wishes, and is continuing to host <a href="#">free educational webinars</a> with Jacob Dahlke (ethicist for NE Medicine, state POLST leader) on the first Friday (<a href="#">Zoom link here</a>) and third Wednesday (<a href="#">Zoom link here</a>) of each month from 12:00-1:00pm CT. NHPCA is still looking for grant funding to establish a state ePOLST registry.</li> </ul>	
<p><b>Council Guidelines, Electing Officers, Open Meetings Act (i.e., Council Administration)</b> (All)</p>	<ul style="list-style-type: none"> <li>Council members reviewed and voted to approve the revised Council Guidelines (Julie moved, Theresa seconded, unanimous approval). Per the Guidelines, Stacie Sinclair assumed the role as Council Chairperson. Theresa Jizba was voted as Vice Chairperson (Stacie moved, Julie seconded, unanimous approval). All agreed that these votes would be re-taken when new Council members are appointed.</li> <li>Approximately five people have submitted executive appointment applications to join the Council, although Governor Pillen has not announced new Council appointments. Council discussed strategies to catalyze appointments, including: 1) Inviting Governor Pillen to an upcoming meeting; 2) Asking Senator Armendariz and/or other members of the Unicameral to submit a letter; and 3) Sending written requests from Council members.</li> <li>Council members decided to temporarily suspend workgroup activity until more members are appointed and/or until further notice; however, it could be helpful to increase engagement among non-members. Stacie will share the informal listserv to see if anyone else should be added, while Shirley would provide the number of subscribers to the official DHHS Palliative Care website.</li> <li>Per the Council <a href="#">statute</a>, the body must meet at least two times per year. Per the <a href="#">Nebraska Open Meetings Act</a>, “no more than one-half of the meetings of the ... advisory committees ... are held by virtual conferencing in a calendar year.” The Council discussed that this inhibits participation among members, particularly since the more meetings held, the more must be done in person (although the Council remains committed to having a virtual option for non-members). Julie offered to research the steps for a possible exemption, Andrew Macfadyen offered to contact Liz Lyons from Children’s</li> </ul>	<ul style="list-style-type: none"> <li><b>Stacie Sinclair</b> to provide informal listserv contacts, <b>Council members</b> to identify additional folks to be added</li> <li><b>Shirley Pickens-White</b> to provide number of official DHHS Palliative Care subscribers</li> <li><b>Julie Masters and Andrew Macfadyen</b> to research possible exemptions to Open Meetings Act</li> <li><b>Stacie Sinclair</b> to propose dates for next Council meeting in January 2024</li> </ul>

Agenda Topic	Key Points	Action Items (if any)
	<p>Hospital government team to see if there is a pathway. In the meantime, the Council discussed setting an in-person meeting in January to meet the initial 2024 quota for in-person meetings early.</p>	
<p><b>End of Life Treatment Orders (POLST/NETO) and EMTs</b> <i>(Theresa Jizba)</i></p>	<ul style="list-style-type: none"> <li>• Theresa provided an overview of work being done on this issue (details in following bullet points). The Council determined that – while this issue is relevant to Nebraskans living with serious illness – it is not the body’s job to develop and implement the work plan. Rather, the Council is a catalyst to highlight the issue and build connections. To that end, members discussed drafting a statement on this topic.</li> <li>• Jacob Dahlke presented to the <a href="#">NE Board of Emergency Medical Services</a> on <a href="#">September 11, 2023</a>. The presentation went well, although there has not yet been any follow-up. There is inconsistent understanding about EMS’s legal obligations and/or liabilities regarding adherence to end-of-life wishes; Jacob to follow up with the relevant Board subcommittee. 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.</li> <li>• Per Marilee’s update, NHPCA is seeking private support for a statewide POLST registry. Marilee, Jacob, and Theresa will be meeting with the <a href="#">Gadfly Project</a> regarding the feasibility of an in-kind, non-competitive grant for tech support; there is also a supposed grant from the Nebraska Medical Association (\$25,000), although that has not yet come to fruition. Leaders on this issue will be meeting with Dr. Pat Bomba for potential fundraising and action strategies.</li> <li>• Jacob is working on draft legislation on medical decisionmaking.</li> <li>• 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.”</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Stacie Sinclair</b> to draft a high-level statement on the Council’s position re: EOL treatment orders</li> </ul>
<p><b>Open Discussion and Public Comments</b></p>	<ul style="list-style-type: none"> <li>• Strategic planning with the UNO Course are ongoing. Stacie delivered a presentation to the class in August, students sent out a survey and have been meeting with past and current Council members to gather information.</li> <li>• Dr. Lou Lukas reached out with a question about rescheduling drugs. Per Andrew and Theresa, DEA regulations supersede state law, unless the state law is more stringent.</li> <li>• No public comments.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>N/A</b></li> </ul>

Agenda Topic	Key Points	Action Items (if any)
<b>Planning for the Next Palliative Care Meeting</b>	<ul style="list-style-type: none"> <li>• The next Nebraska Palliative Care and Quality of Life Advisory Council meeting is tentatively scheduled for January 2024 in Lincoln, NE. Stacie Sinclair will send a calendar appointments with a Zoom link and location once the meeting is confirmed.</li> <li>• Agenda items:               <ul style="list-style-type: none"> <li>○ Council Strategic Planning</li> <li>○ NHPCA update</li> <li>○ <i>Please submit additional agenda items to Stacie Sinclair</i></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Council members</b> to submit requests for reimbursement to Shirley Pickens-White</li> <li>• <b>Council members</b> to submit additional agenda items</li> </ul>

Meeting Adjourned at 9:58am CT  
 Meeting Minutes: Stacie Sinclair

DRAFT