

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

May 21, 2024

9:00 a.m. to 11:00 p.m.

In-Person and Zoom

Members in Attendance:

Theresa Jizba (Zoom)

Brenda Kastens

Julie Masters

Stacie Sinclair

Staff:

Jennifer Severe-Oforah (Administrator of Lifespan Health Services)

Leah Snyder

Guests:

N/A

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 (Stacie Sinclair)	<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 9:04 a.m. 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 voted on the meeting minutes from October 2023 and January 2024:<ul style="list-style-type: none">October 2023: Julie Masters made the motion to approve, Brenda Kastens seconded; motion passed.January 2024: Brenda made the motion, Julie seconded; motion passed.Stacie expressed gratitude for Shirley Pickens-White, who served as the DHHS liaison to the Council for several years.	<ul style="list-style-type: none">Stacie Sinclair to send final versions of October 2023 and January 2024 minutes to Leah Snyder to post on Council website
Nebraska Hospice and Palliative Care Association Update (Marilee Malcom)	<ul style="list-style-type: none">Marilee Malcom provided the following updates in writing:<ul style="list-style-type: none">NHPCA’s Annual Conference on March 19-20, 2024 was a success, with 130 attendees on the first day, and 158 attendees on the second day. Keynote speakers Dr. Timothy Ihrig, Dr. Cordt Kassner, and Judi Lund Person were all big hits.	<ul style="list-style-type: none">N/A

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	<ul style="list-style-type: none"> ○ NHPCA and Children’s Nebraska are hosting a Pediatric Hospice Training in North Platte, NE on June 4, 2024. Funding and venue for this invaluable training is provided by Great Plains Health and Great Plains Health Care Foundation. ○ NHPCA continues to work on POLST and funding for ePOLST through the Gadfly Project (see October 2023 and January 2024 meeting minutes for more details). ○ In the fall, NHPCA will be co-hosting two events (updates will be available via NHPCA’s website at www.nehospice.org): <ul style="list-style-type: none"> ▪ 2024 Fall Symposium with LeadingAge, on September 24 in Omaha, NE ▪ Half-day hospice track at the Nebraska Home Care Association Annual Conference on November 12-13 in Kearney, NE ● Julie asked a question about appropriate messaging for POLST, since: 1. There is conflicting (and sometimes dangerous) misinformation about what should be done and when, and 2. The Council should provide accurate education and public awareness. Theresa Jizba clarified the parameters for when POLST should be offered (see next section on “Goals of Care/End-of-Life Treatment Orders Draft Position Statement”), and expressed the hope that the Gadfly Project will have a messaging component. 	
Goals of Care/End-of-Life Treatment Orders Draft Position Statement <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> ● Stacie reviewed a draft position statement to help clarify the Council’s position on Goals of Care (GoC) discussions, End of Life (EoL) Treatment Orders, and what the public should know. Julie, Theresa, and Brenda agreed that it was worthwhile to continue drafting, incorporating the following highlights from the POLST discussion: <ul style="list-style-type: none"> ○ Provide a curated list of the most common, evidence-based tools for both GoC and EoL discussions; these should include a brief description, when they are indicated, and where readers can go for more information. For example: “The decision to complete a POLST should be based on a discussion between the provider and the patient, in accordance with the patient’s wishes. For more guidance, please see the National POLST website.” ○ Emphasize the role of families/caregivers in the decision-making process. ○ Incorporate findings from an upcoming literature review that will be conducted by Theresa, Dr. Mandy Kirkpatrick, and Dr. Meghan Potthoff on educational materials for advance care planning discussions. <p>Note: this statement will not take an explicit position on the different tools (e.g., recommending one tool over another).</p>	<ul style="list-style-type: none"> ● Stacie Sinclair to revise draft position statement based on discussion; share with Leah Snyder who will shepherd subsequent revisions with the Council

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Council Sustainability <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> • Neither the Council nor DHHS has received communication from the Governor’s office regarding re-appointment for the existing members whose terms have expired or appointment of the ~five applicants who submitted their information in the last year. With Stacie Sinclair stepping down at the end of May 2024, this will leave the Council with three active members. Having so few appointed members greatly diminishes the Council’s capacity to advance palliative care in Nebraska. • Council members discussed potential options to catalyze Governor’s appointments, including outreaching to State Senators and ACS CAN NE’s Government Relations Director. In the meantime: <ul style="list-style-type: none"> ○ The Council will continue to exist under statute and it has fulfilled its meeting mandate for 2024. As long as the Council meets twice in 2025 (at least once with an in-person quorum, per the Open Meetings Act), it will remain in compliance with statute. ○ Council members may work with additional palliative care champions in Nebraska to see if there is an alternative (e.g., a broader-based independent coalition, perhaps with Creighton or UNMC as a backbone organization) to advance the work/create a centralized hub for palliative care activity in the state. • Stacie will share any outstanding documents with Leah Snyder at DHHS, and also prepare a final communication on Council highlights since 2017 and recommendations for future action. 	<ul style="list-style-type: none"> • Stacie Sinclair to follow-up with Senator Cavanaugh’s office and ACS CAN NE • Stacie Sinclair to share final materials with Leah Snyder
Legislative Tracking <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> • The Nebraska Unicameral adjourned on April 18, 2024. There was no pressing legislation this session; the Council is encouraged to monitor legislation in future sessions. 	<ul style="list-style-type: none"> • N/A
Strategic Plan Review <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> • The Council agreed that the Strategic Plan provides an excellent road map for Council work; however, it cannot begin to implement the strategies given its reduced capacity. Leah will post the revised Executive Summary on the Council website, and members will revisit the Strategic Plan if/when new members are appointed. 	<ul style="list-style-type: none"> • Stacie Sinclair to send revised Executive Summary of Strategic Plan for posting on the Council website
Website Update <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> • Stacie conducted a thorough review of the Council website and provided members with a Word document of suggested edits. Council members are to review the document and notify Stacie of any changes by Tuesday, May 28; then Leah will work with the DHHS web team to update. 	<ul style="list-style-type: none"> • Council members to review Word doc with suggested changes to the website by May 28, 2024 • Leah Snyder to incorporate changes into the website

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Open Discussion and Public Comments	<ul style="list-style-type: none"> No public comments. 	<ul style="list-style-type: none"> N/A
Next Meeting	<ul style="list-style-type: none"> Leah Snyder will send out an email to schedule the next Nebraska Palliative Care and Quality of Life Advisory Council meeting. 	<ul style="list-style-type: none"> Leah Snyder to schedule the next NE Council Meeting Council members to submit agenda items

Meeting Adjourned at 10:55am CT
Meeting Minutes: Stacie Sinclair

DRAFT