

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

March 7, 2022

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

Zoom

Members in Attendance:

Marcia Cederdahl (via Zoom)
 Brenda Kastens (Office Bldg.)
 Andrew Macfadyen (via Zoom)
 Julie Masters (via Zoom)
 Angela Mortensen (via Zoom)
 Stacie Sinclair (via Zoom)
 Sabrina Schalley (via Zoom)
 Theresa Jizba (via Zoom)

Staff:

Christine Esch (Office Bldg.)
 Shirley Pickens-White (Office Bldg.)

Guests:

Maryjan Fiala
 Shelby Hopp (UNMC)
 Marilee Malcolm (NHPCA)
 Meghan Potthoff (Creighton University)
 Mel Teply (UNMC, Guest Presentation)

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 1:03 p.m. 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 located [online].</i> • Andrew Macfadyen called the motion to approve the meeting minutes from December 6, 2021; Marcia Cederdahl seconded the motion; all in favor. 	<ul style="list-style-type: none"> • N/A
Council Member Check-Ins Introductions	<ul style="list-style-type: none"> • Council members introduced themselves. 	<ul style="list-style-type: none"> • N/A
Council Report to the Governor and Legislature <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> • Stacie Sinclair reviewed the Council Report in detail. Julie Masters suggested including hyperlinks to citations in the body of the report. Sabrina Schalley called the motion to adopt the final report (pending corrections of typos and addition of hyperlinks); Andrew Macfadyen seconded the motion; all in favor. • Dissemination: 	<ul style="list-style-type: none"> • Stacie Sinclair to revise and finalize report; send to Christine Esch to post on Council website

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	<ul style="list-style-type: none"> ○ Several Council members did not think the benefit of printing the full 43-page report was worth the cost. Recognizing that it could be helpful to have something tangible when meeting with key contacts, Julie Masters suggested creating a one-page flyer/executive summary that could be printed in color and on heavier paper. This would have the benefits of being more cost-effective and driving more traffic to the Council website. ○ Audiences for dissemination include the Unicameral, members of the Governor’s team, representatives from the state health department, providers (e.g., health care organizations and practicing clinicians), state health associations, etc. Stacie Sinclair to create a tracking sheet that Council members can add their contacts to, and then strategize outreach. 	<ul style="list-style-type: none"> ● Stacie Sinclair to draft an executive summary/flyer for Council to review ● Stacie Sinclair to begin a “dissemination tracker” for Council members to add onto ● Stacie Sinclair to set meeting with ACS CAN NE contacts to discuss dissemination
Council Workgroup – Website <i>(Andrew Macfadyen)</i>	<ul style="list-style-type: none"> ● There were no new updates to the website beyond minor technical fixes and a broken link. Any changes should be emailed to Shirley Pickens-White. ● Ongoing request that all Council members (particularly those who are new) review the website to see if the information is clear, anything should be added or changed. 	<ul style="list-style-type: none"> ● Council members to periodically review website, submit any changes to Shirley Pickens-White
Council Workgroup – Public Awareness <i>(Marcia Cederdahl, Julie Masters, Sabrina Schalley)</i>	<ul style="list-style-type: none"> ● The Public Awareness Workgroup is starting a YouTube channel for the Council that will include palliative care content for providers, patients, and families. They are also continuing to draft articles. Meghan Potthoff (Creighton University) reiterated that some students might be willing to help. ● The Council is pursuing a presentation strategy to introduce palliative care to new audiences. There are several planned presentations; Council members are encouraged to identify additional audiences. Marcia Cederdahl and Stacie Sinclair can provide support as needed. <ul style="list-style-type: none"> ○ Several Council members are presenting at the Nebraska Hospice and Palliative Care Association (NHPCA) meeting in May 2022 ○ Presentations to State Licensure Boards continue (sample presentation to be posted on the Council website). Andrew Macfadyen presented to the Board of Health on January 21, 2022; Marcia Cederdahl and Stacie Sinclair presented to the Board of Pharmacy on March 7, 2022. Council members should contact Marcia if they are willing to co-present at any upcoming sessions: <ul style="list-style-type: none"> ▪ Board of Nursing – April 14, 2022 at 8:30am (Lincoln, NE) ▪ Physician Assistant Committee – May 6, 2022 at 2:00pm (Lincoln, NE) ▪ Board of Advanced Practice Registered Nursing – May 20, 2020 at 1:00pm (Lincoln, NE) 	<ul style="list-style-type: none"> ● Council members to contact Marcia Cederdahl if they are willing to co-present to various Boards of Health ● Stacie Sinclair to submit a sample version of the presentation to post on the Council website ● Council members to provide suggestions/lead presentations for additional audiences

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	<ul style="list-style-type: none"> ○ The Nebraska Rural Health Association/Nebraska Hospital Association invited Stacie Sinclair, Marcia Cederdahl, and Marilee Malcolm to present at its upcoming conference in May 2022. 	
Council Workgroup – Regulatory <i>(Marcia Cederdahl)</i>	<ul style="list-style-type: none"> ● The Regulatory Workgroup has been unsuccessful in reaching the key contact at the state to make changes to the palliative care definition. Marcia Cederdahl will follow-up with Pam Kearns; dissemination of the Council report might also be an opportunity to restart discussions. 	<ul style="list-style-type: none"> ● Marcia Cederdahl to contact Pam Kearns
Nebraska Hospice and Palliative Care Association Update <i>(Marilee Malcolm)</i>	<ul style="list-style-type: none"> ● Marilee Malcolm has been the Executive Director for NHPCA since 2020. One of her and NHPCA’s new priorities is supporting hospice providers in delivering non-hospice palliative care, since they are well-equipped to do this work. ● NHPCA will be hosting its annual conference as a hybrid even on March 22-23, 2022; currently at 80 registrations. ● NHPCA has linked to the Council’s website on its website. ● NHPCA will be conducting its 5th Nebraska Hospice and Palliative Care End of Life survey, which will go out to 3,000 Nebraskans. The anticipated kick-off is mid-April/early May. The survey team is currently in the process of question selection and rewrites, as well as fundraising for analysis and publication. The findings of past surveys have been essential in identifying state progress and gaps, and is often shared with physicians, lawmakers, and hospice providers across the state. 	<ul style="list-style-type: none"> ● Council members to contact Marilee Malcolm if they wish to support survey development and/or dissemination
Creighton University Palliative Care Activities <i>(Meghan Potthoff)</i>	<ul style="list-style-type: none"> ● Creighton University continues to build out its palliative care program, including developing interprofessional opportunities to expose all students to palliative care. Recent initiatives include: <ul style="list-style-type: none"> ○ Receiving a \$15,000 internal pilot grant to create a student run/faculty mentored program that will bring together business, law, and social work students to create advance care planning documents. They will be partnering with the UNMC IDEAS network, and are planning to host a small symposium in spring 2023 on aging and palliative care. ○ Offering an interprofessional palliative care course, that includes simulations and robust, standardized conversation prompts. ● Meghan Potthoff recently completed a project to create GoWish cards for parents and caregivers to prioritize wishes in palliative care. These cards can help caregivers identify shared priorities and better communicate with the health care team. She will present on these at the NHPCA conference. <ul style="list-style-type: none"> ○ Mel Teply suggested submitting an abstract to AAHPM and working with Shelby Hopp to disseminate to other pediatric palliative care groups across the country. ○ Marcia Cederdahl will connect Meghan with her contact at Mourning Hope. 	<ul style="list-style-type: none"> ● N/A

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	<ul style="list-style-type: none"> ○ Those interested in getting a deck can contact Meghan directly; they will also eventually be available for purchase on the Coda Alliance website. 	
Council Guidelines <i>(Stacie Sinclair)</i>	<ul style="list-style-type: none"> ● The Council discussed other ways in which it could support palliative care in the state. The current Council guidelines are broadly written and allow for a lot of options. The NE Department of Health and Human Services (DHHS) does not have any guidance/provide governance to the councils it supports, as these councils are independent bodies. ● Potential activities: <ul style="list-style-type: none"> ○ Lending support to NE palliative care activities. This could include: allowing people to present at Council meetings; providing feedback on programs or proposals; posting on Council website; writing or signing on to letters of support (e.g., endorsing projects, recruiting subject matter experts, committing to dissemination, etc.). It is common practice for grantees to draft letters of support that signatories can then tailor and submit. ○ Reviewing legislation and submitting comments for or against. ● Council members generally agreed that these activities are in scope, would be helpful in building collaboration, and may not require revisions to the Guidelines. However, if the Council proceeds, some concerns include: <ul style="list-style-type: none"> ○ The need to develop objective screening criteria for reviewing requests to avoid concerns of favoritism. ○ Disclaimer language – e.g., consider whether a letter of support implicitly endorses a program’s scientific methodology. ○ Council capacity to commit to this work, since all members are volunteers. 	<ul style="list-style-type: none"> ● Stacie Sinclair to reach out to a representative from the Women’s Health Initiative to learn more about its legislative efforts
Public Comments	<ul style="list-style-type: none"> ● N/A 	<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 is on June 6, 2022 from 1:00-3:00pm CT. Stacie Sinclair already sent calendar appointments with a Zoom link; as the date nears, Council members will discuss whether it makes sense to meet in person. Subsequent Council meetings are set for: <ul style="list-style-type: none"> ○ September 5, 2022 ● Agenda items: <ul style="list-style-type: none"> ○ Council Report dissemination ○ Council workgroup report outs 	<ul style="list-style-type: none"> ● Council members to submit requests for reimbursement to Christine Esch ● Council members to submit additional agenda items

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	<ul style="list-style-type: none"> ○ Council Guidelines ○ NHPCA update ○ (TBC) Guest presentation ○ <i>Please submit additional agenda items to Todd Sauer and Stacie Sinclair</i> 	

Meeting Adjourned at 2:55 p.m.
Meeting Minutes: Stacie Sinclair