

MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

March 29, 2021

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

Nebraska State Office Building

301 Centennial Mall

Lincoln, NE 68501

Zoom Link Available for Virtual Participants

Members in Attendance:

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

Staff:

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

Guests:

[Kelly Mand](#) – A Time to Health Cancer Foundation
Gary George – Hospice House, NHPCA
Tamara Robinson
Matt Prokop

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">Todd Sauer called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 1:00 p.m. He referenced the NE Open Meetings Act, which was posted where everyone attending in-person could read:<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 on the counter near the door.</i>	<ul style="list-style-type: none">N/A
Council Member Check-Ins	<ul style="list-style-type: none">Council members provided 2-3 minute updates regarding COVID-19’s impact over the last several months	<ul style="list-style-type: none">N/A
Council Report to the Governor and Legislature	<ul style="list-style-type: none">At the February 2020 meeting, Council members agreed the time was right to draft a (concise) progress report outlining the Council’s progress and recommendations. At the March 2021 meeting, all agreed that it was still a worthwhile project	<ul style="list-style-type: none">Stacie Sinclair to resend outline with assignments, and any completed sections filled in

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	<ul style="list-style-type: none"> ○ Andrew Macfadyen noted the outline was ambitious, but good ○ Julie Masters volunteered to continue the discussion about how to access demographic data, and also provide writing support for the discussion on COVID-19 and aging adults 	<ul style="list-style-type: none"> ● Council members to submit drafted sections 2-3 weeks before next meeting (Stacie Sinclair to send out reminder 3-4 weeks beforehand)
Council Workgroup – Website <i>(Andrew Macfadyen)</i>	<ul style="list-style-type: none"> ● There were no new updates. Any changes should be emailed to Shirley Pickens-White ● The Council would welcome suggestions on how to disseminate the website more widely 	<ul style="list-style-type: none"> ● Council members to periodically review website, submit any changes to Shirley Pickens-White
Council Workgroup – Regulatory <i>(Marcia Cederdahl, Stacie Sinclair)</i>	<ul style="list-style-type: none"> ● Presentations to State Licensure Boards. Council members reiterated that it made sense to proceed with virtual presentations (Andrew Macfadyen noted that the Council’s delay was probably appropriate, since the Physician Board had only just started renewing licenses again). Members were interested in participating in these presentations as they are scheduled ● Palliative Care Definition. The Council continues to think it is worthwhile to pursue slight changes to the palliative care definition to ensure that it can be available across settings, and that the expectation is that it will be a complete service. Marcia Cederdahl will follow-up with Becky Wisell at DHHS 	<ul style="list-style-type: none"> ● Marcia Cederdahl to coordinate with Becky Wisell re: timing of BOH presentations, progress on palliative care definition
Council Workgroup – Public Awareness and Education <i>(Sabrina Schalley)</i>	<ul style="list-style-type: none"> ● The goal of this workgroup is to identify opportunities to promote public awareness of and education on palliative care (TBD: whether the Council’s role is to make recommendations on those opportunities, pursue them directly, or a mix of the two) ● Sabrina Schalley and past Council member Holly Adams met with NHPA (pre-pandemic) to discuss past survey results, ask about any efforts to raise community awareness. Sabrina is happy to move awareness forward, but don’t want to duplicate effort. Some proposed ideas included a speakers bureau, webinars, awareness campaign; Stacie Sinclair suggested it would be best to partner with other groups, rather than doing things in a solitary manner 	<ul style="list-style-type: none"> ● Council members (and public) to reach out to Sabrina Schalley if they would like to participate on this workgroup
Tracking Palliative Care Initiatives In Nebraska	<ul style="list-style-type: none"> ● Stacie Sinclair suggested that the Council could be a good centralized place to track and promote existing palliative care initiatives in Nebraska. Andrew Macfadyen thought this could be appropriate, since the Council’s authorizing legislation is provides a lot of latitude; Sabrina Schalley and Marcia Cederdahl concurred. Several members though the Council report should be the first priority, since it could provide a road map for action ● Todd Sauer suggested that another place in which the Council might want to focus is getting a better sense from payers in the state how they are funding palliative care. Financing is the missing piece – 	<ul style="list-style-type: none"> ● N/A

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	<p>there are a lot of programs and providers who want to deliver palliative care, but there isn't sufficient payment to get them off the ground</p> <ul style="list-style-type: none"> ○ Angela Mortensen suggested that, in the current landscape, it might make sense to prioritize raising palliative care awareness, starting with the medical board, while continuing to look into in-home payment for palliative care ● Sabrina Schalley suggested that, moving forward, the Council identify more specific tasks for members to take on in between meetings so it can make more progress 	
Open Discussion	<ul style="list-style-type: none"> ● Andrew Macfadyen observed that COVID-19 and the proliferation of telehealth have transformed pediatric palliative care practice. Prior to the pandemic, almost no patients and families wanted it; in the pandemic, have seen a huge embrace – greater visit efficiency (can see more patients), reduced no show rate, less burden on patients and families. It remains to be seen how many of the flexibilities in telehealth policy will carry over after the end of the public health emergency ● Stacie Sinclair noted that there is still one slot on the Council to be filled. Those who are interested should complete the application 	<ul style="list-style-type: none"> ● N/A
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 was TBD. Stacie Sinclair will proactively set up a Zoom link; as the date nears, Council members will discuss whether it makes sense to meet in person. ● Agenda items: <ul style="list-style-type: none"> ○ Council Report to the Governor and Legislature ○ Council workgroups report outs <ul style="list-style-type: none"> ▪ Website ▪ Regulatory ▪ Public Awareness and Education ○ <i>Please submit additional agenda items to Todd Sauer and Stacie Sinclair</i> 	<ul style="list-style-type: none"> ● Council members to submit requests for reimbursement to Christine Esch ● Council members to submit additional agenda items ● Stacie Sinclair to send out meeting appointment

Meeting Adjourned at 2:42 p.m.

Meeting Minutes: Stacie Sinclair