

## MEETING MINUTES

Nebraska Palliative Care and Quality of Life Advisory Council

November 4, 2019

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

Omaha, NE

**Members in Attendance:**

Holly Adams  
 Marcia Cederdahl  
 Andrew Macfadyen  
 Todd Sauer  
 Stacie Sinclair  
 Sabrina Schalley  
 Denise Woolman

**Staff:**

Andrea Wenke

**Guests:**

Tamara Robinson (NC2)  
 Heather Sorello (student)  
 Lindsay Adams (student)  
 Brittany Johnson (student)  
 Additional Student #1  
 Additional Student #2

Agenda Topic	Key Points	Action Items (if any)
<b>Call to Order and Approval of Minutes</b>	<ul style="list-style-type: none"> <li>• Todd Sauer called the Nebraska (NE) Palliative Care and Quality of Life Advisory Council (“Council”) meeting to order at 1:06 p.m. He referenced the Nebraska Open Meetings Act, which was posted where everyone could read:                             <p style="margin-left: 40px;"><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></p> </li> <li>• Council members voted to approve the August 12, 2019 meeting minutes.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Andrea Wenke</b> to post August 12 meeting minutes on the website</li> </ul>
<b>Developing Council Workgroups</b>	<ul style="list-style-type: none"> <li>• Stacie Sinclair reiterated concerns with the current interpretation of the Open Meetings Act which is preventing remote participation for non-Council members. She and Denise Woolman will work with NE DHHS to clarify.</li> <li>• In the meantime, the Council decided at the August 12 meeting that establishing smaller workgroups would be an effective way to 1) engage non-Council members in palliative care initiatives; and 2) complete work in between quarterly Council meetings. The Council established the following initial workgroups, which will report their progress at each meeting:                             <ul style="list-style-type: none"> <li>○ <b>Regulatory Workgroup</b> (Marcia Cederdahl, Stacie Sinclair, Denise Woolman) – this workgroup will continue working on codifying a definition of palliative care, and address other policy issues as they arise</li> <li>○ <b>Public Awareness/Education Workgroup</b> (Holly Adams, Sabrina Schalley) – this workgroup will continue working on strategies to increase public/provider awareness of palliative care</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Stacie Sinclair</b> and <b>Denise Woolman</b> to share clarifying questions on Open Meetings Act with <b>Andrea Wenke</b>, follow-up</li> <li>• <b>Council members</b> to contact named workgroup members if they want to join</li> <li>• <b>Workgroups</b> to begin their activities; reach out to non-Council members</li> </ul>

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	<ul style="list-style-type: none"> <li>○ <b>Website Monitoring Workgroup</b> (Andrew Macfadyen) – this workgroup will monitor the website and contact Andrea Wenke with any needed changes</li> <li>○ <b>Survey Workgroup</b> (Stacie Sinclair) – this workgroup will develop a work plan to conduct a statewide survey on the availability of palliative care in Nebraska, and how this matches up with the current need</li> <li>● While attendees thought it best to start with a few workgroups and see how that goes, Council members may establish additional workgroups as desired (e.g., Billing, Workforce, and Program Support).</li> <li>● Holly Adams noted that the Council has been charged with surveying “palliative care providers regarding best practices and recommendations” and questioned whether the Council was in compliance with that provision. Several Council members observed that existing resources fill that purpose, and thus this requirement has been met: <ul style="list-style-type: none"> <li>○ The <a href="#">National Consensus Project</a> (NCP) Clinical Practice Guidelines for Quality Palliative Care are best practices that have been endorsed by the palliative care field writ large, and that Council endorsement (which is comprised of palliative care providers ) of the NCP could suffice</li> <li>○ The <a href="#">Nebraska Cancer Coalition</a> (NC2) surveyed Commission on Cancer (CoC)-accredited programs in Nebraska to learn what palliative care services/programs look like for oncology patients, published June 2019</li> <li>○ <a href="#">GetPalliativeCare.org</a> has a Provider Directory that lists all the known hospital- and community-based palliative care programs in Nebraska. This directory is subject to the limitations of self-report, but provides a starting place for Nebraskans with serious illness to identify where services exist</li> <li>○ NE DHHS operates the <a href="#">Nebraska Network of Care</a>, a directory of licensed services for aging and disabled persons. This directory <i>could</i> contain palliative care, but that is contingent on the establishment of formal licensure for palliative care</li> </ul> </li> <li>● Sabrina Schalley observed that Council members are term-limited (each member can serve up to two consecutive 3-year terms), and original members are now entering the third year of their first term. Council members agreed that the next meeting should include a discussion on how to stagger Council terms to preserve continuity.</li> </ul>	<p>for engagement and support</p>
<p><b>NC2 Report on Palliative Care</b></p>	<ul style="list-style-type: none"> <li>● Guest speaker Tamara Robinson provided an overview of NC2’s new report, which surveyed features of inpatient palliative care in Nebraska’s 13 CoC-accredited programs (<i>see attached report and slide deck</i>). This work was done using the National Palliative Care Registry™ survey (six programs participated) and program interviews.</li> <li>● The report includes national trends and research on palliative care. Findings from the CoC hospitals included that staffing varied by location and system; most utilize NCP Guidelines; only one program had</li> </ul>	<ul style="list-style-type: none"> <li>● <b>Council members</b> should review the report/ slides and connect with Tamara Robinson if they want to participate in CoC planning discussions</li> </ul>

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	<p>standardized trigger or screening criteria, although 66% have a standardized consult note; top reasons for palliative care referral include symptom management and goals of care discussions; and top funding sources are hospitals and FFS billing.</p> <ul style="list-style-type: none"> <li>At a follow-up meeting with all 13 CoC and private oncology practices in the state, participants raised several palliative care-related challenges, including a lack of outpatient palliative care; an insufficient number of palliative care providers; and a lack of palliative care knowledge in the medical and patient community.</li> <li>The findings from this survey, as well as the retention of palliative care in the <a href="#">2020 CoC Standards</a> (Standard 4.5), present a significant opportunity for Council partnership. The Standards clearly state that palliative care must be integrated into the continuum of care and available onsite or through referral. CoC-accredited centers must update their policies and procedures on the structure of palliative care offerings annually, and palliative care providers are encouraged to join these efforts. The Council should consider how to leverage these opportunities, since this is where palliative care is <b>definitely</b> available in NE; NC2 also stands ready to partner with the Council.</li> </ul>	<ul style="list-style-type: none"> <li><b>Andrea Wenke</b> to post NC2 report and slides on the Council website (meeting materials)</li> </ul>
<p><b>National Hospice and Palliative Care Month</b></p>	<ul style="list-style-type: none"> <li>The newly formed Public Awareness Workgroup (Sabrina Schalley and Holly Adams) shared a draft press release for Hospice and Palliative Care Month. Council members are asked to review and provide their feedback (including a quote by Dr. Sauer) by November 11 so that it can be sent to Nebraska media outlets. Dissemination for this year will rely on earned media, and could take the place of a Governor’s proclamation (since it’s likely the window has passed for 2019). Holly and Sabrina shared that this was a first step, and anticipate that the awareness activities will grow incrementally in the coming years.</li> <li>Additional resources for public awareness: <ul style="list-style-type: none"> <li><a href="#">George Washington Cancer Center Palliative Care Awareness Social Media Toolkit</a></li> <li><a href="#">CAPC Marketing and Messaging Palliative Care Toolkit</a></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li><b>Council members</b> to review the press release and provide feedback to <b>Sabrina Schalley</b> and <b>Holly Adams</b> by 11/11</li> <li><b>Marcia Cederdahl</b> to confirm whether the proclamation window has passed</li> </ul>
<p><b>Updated NETO Form</b></p>	<ul style="list-style-type: none"> <li>Andrew Macfadyen and Sabrina Schalley shared the history of the <a href="#">Nebraska Emergency Treatment Orders</a> (NETO) Project; namely, that in the absence of a successful <a href="#">POLST</a> initiative, Dr. Lou Lukas spearheaded an effort to develop a standardized (voluntary) form that would support emergency and other health care professionals in delivering goal-concordant care. This form has been revised over time, and NETO recently released a <a href="#">2.0 version</a> for adults and a new form for pediatrics (see <a href="#">Council minutes</a> from <a href="#">November 2018</a> and <a href="#">February 2019</a> for more details on NETO).</li> <li>Todd Sauer shared that there has been a resurgence in the Nebraska POLST movement recently, as the form has also improved over time, and the benefit of a “conforming” treatment order is that it is more easily recognized and honored across state lines.</li> </ul>	<ul style="list-style-type: none"> <li><b>Andrea Wenke</b> to post a link to Nebraska NETO on the Council website</li> </ul>

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	<ul style="list-style-type: none"> <li>• Council members discussed that it was not necessarily a problem to have two standardized forms in NE – particularly because these forms have become increasingly synchronized over time and neither movement is pursuing a legislative mandate. The main challenge is ensuring that EMS professionals and other providers are trained to recognize the forms and act on the information contained therein. A secondary challenge is programming the information in the EMR in a way that is usable and also reflects changes in real time.</li> <li>• After much discussion, Council members decided against officially endorsing either form for multiple reasons; however, they thought it appropriate to make this information available to consumers by posting a link to NETO on the Council website (and eventually POLST, if/when that form becomes available). Stacie Sinclair suggested the Council consider developing a brief position statement on care planning, but Council members did not think it was necessary at this time.</li> </ul>	
CAPC 2019 SxS Report Card	<ul style="list-style-type: none"> <li>• Stacie Sinclair shared that CAPC recently released its <a href="#">2019 State-by-State Report Card</a> on palliative care. Nebraska was one of the few states whose grade dropped, due to the increase in the number of hospitals in the state. Several Council members asked questions about how the grade was derived. Stacie also shared that the Report Card contains a menu of policy- and policy-adjacent recommendations that the Council could anchor its work to, if so inclined.</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
Updated Palliative Care Definition	<ul style="list-style-type: none"> <li>• The newly formed Regulatory Workgroup (Marcia Cederdahl, Stacie Sinclair, and Denise Woolman) reported meeting with Becky Wisell and Pamela Kerns at the NE DHHS Licensure Unit to discuss next steps for expanding a definition of palliative care to apply across care settings. This work is important because the Council wants to make sure that: <ul style="list-style-type: none"> <li>○ Palliative care is <i>legally</i> available across care settings – particularly to facilitate RN and social work services in the home (increase access)</li> <li>○ If a provider or organization says they are delivering palliative care, there is some element of quality and oversight (patient protection)</li> </ul> </li> <li>• Currently, palliative care is only mentioned under the <a href="#">Health Care Facility Licensure Act</a> under hospice; it is not specifically mentioned under hospital, but yet that’s where it’s primarily available in Nebraska. The Regulatory Workgroup will continue working with the state to identify if a legislative or regulatory approach is needed, as well as if there are any unintended consequences of proceeding with this effort (e.g., creating a new, unfunded mandate).</li> <li>• Connected to the work with the Licensure Unit, Marcia Cederdahl and Stacie Sinclair will develop a presentation on palliative care to deliver to key Nebraska health care professional boards, e.g., Board of Medicine and Surgery, Board of Nursing, Board of Mental Health Practice (including Social Work), Board of Audiology and Speech-Language Pathology/OT/PT, and pharmacy. They might reach out to additional Council members for the presentations based on discipline.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Regulatory Workgroup</b> to continue working with the NE DHHS Licensure Unit</li> <li>• <b>Marcia Cederdahl</b> and <b>Stacie Sinclair</b> to develop draft presentation, begin scheduling with boards, reach out to additional Council members as needed</li> </ul>

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NE Palliative Care Landscape Study	<ul style="list-style-type: none"> <li>• Stacie Sinclair discussed that she thought a study on the current availability of palliative care in Nebraska and how it compares to patient need is still a necessary activity for the Council to better inform future efforts and recommendations. Council members provided several recommendations for university research programs and analysts who might be able to support this work:               <ul style="list-style-type: none"> <li>○ UNO Public Administration Program</li> <li>○ <a href="#">UNO STEPS Group</a> – Center for Community Engagement</li> <li>○ Children’s Hospital – evaluation research study</li> <li>○ Julie Masters</li> <li>○ UNMC School of Public Health</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <b>Stacie Sinclair</b> to write up a project description</li> <li>• <b>Marcia Cederdahl, Andrea Wenke, Sabrina Schalley</b> to provide contacts</li> </ul>
Public Comments	<ul style="list-style-type: none"> <li>• N/A</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
Planning for the Next Palliative Care Meeting	<ul style="list-style-type: none"> <li>• Reimbursement forms are available for Council members’ travel.</li> <li>• The next Nebraska Palliative Care and Quality of Life Advisory Council meeting will take place on February 3, 2020 from 1:00-3:00pm in Lincoln, NE (location TBC)</li> <li>• Potential discussion items:               <ul style="list-style-type: none"> <li>○ Council workgroups report outs                   <ul style="list-style-type: none"> <li>▪ Regulatory</li> <li>▪ Public Awareness and Education</li> <li>▪ Website</li> <li>▪ Survey</li> </ul> </li> <li>○ Strategy for Council membership terms</li> <li>○ Council Report to the Governor and Legislature</li> </ul> </li> <li>• Stacie Sinclair to send out calendar appointment</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Council members</b> to submit requests for reimbursement to Christine Esch</li> <li>• <b>Council members</b> to submit additional agenda items</li> <li>• <b>Stacie Sinclair</b> to send out meeting appointment</li> </ul>

Meeting Adjourned at 2:58 p.m.  
Meeting Minutes: Stacie Sinclair