

**Delaware Health Care Commission
End-of-Life Workgroup
February 26, 2016 Meeting Notes**

Attendees: Jill Rogers, John Goodill, Lexie McFassel, Susan Lloyd, Tim Rodden, Tim Gibbs, Keagen Brown, Laura Waterland, Michael Alexander (telephone), Allison Gonzalez

Other Attendees: Laura Howard, Alex Parkowski, Mike Cordrey, Sean Dwyer, Cheyenne Luzader, Jim Luzader, Casey Walsh, Kathy Collison, Pam Price, Cimone Philpotts, Diana Price, Theresa Latorre-Tegtmeier

Agenda

- Recap of February 12 Meeting
- Final Report Draft Review
- Timeline Review
- Public Comment

Summary of Discussion

Recap of February 12 Meeting

- The workgroup briefly recapped the agenda and discussion from the February 12 meeting, which included:
 - An Overview of Listening Sessions and Feedback Received
 - A Review of the Final Report Outline
 - A Review of Recent Publications
 - DE Journal of Public Health Issue
 - JAMA January 19 Issue
 - Timeline Review
 - Public Comment

Final Report Draft Review

- The workgroup spent the majority of the time reviewing the draft of the final report.
- One workgroup member noted that the first bullet in the report is confusing and should be revised. All acronyms also need to be identified, spelled out, and defined.
- The discussion began with an identification of noticeable alterations that were made to the draft report after the workgroup's previous meeting on February 12. The main alteration was moving the table of recommendations towards the beginning of the report in an effort to engage the reader.
- One workgroup member mentioned that there was no mention of pediatrics anywhere in the report and voiced the opinion that the workgroup needs to be sure to include pediatrics in the discussion of population health management. Another workgroup member followed up on this conversation by noting that the Five Wishes has a pediatric document that is helpful. This work is also currently being undertaken at Christiana Care.
- Another workgroup member stated that the health care system in general needs to focus on the patient and the family during the end-of-life stage of care.

- The suggestion was made to look at Maine and Maryland for models of board/advisory council structure regarding end-of-life issues. It was suggested that an ongoing EOL group could interact with the Health Care Commission (HCC) in a similar fashion to the Delaware Center for Health Innovation (DCHI.)
- The workgroup agreed that the introduction of the report needs to be updated to allow for a clear identification and differentiation between end-of-life care, palliative care, and hospice care.
- The formal charge given to the workgroup by the HCC will be pulled from the body of the report and included as a separate appendix.
- The workgroup agreed that the report should have separate recommendations for end-of-life and palliative care.
- The term “owner” in the recommendation tables should be changed to “stakeholder(s)”.
- One workgroup member noted that on page 14 of the report “Honoring Choices” should be changed to “Respecting Choices”.
- The workgroup agreed on the need to properly identify all relevant stakeholders in the report.

Feedback on Recommendations

- One workgroup member noted that the report does a nice job of cataloging the issues at hand but fails to take it a step further and offer recommendations on how to best organize all of the information and data. Having a lot of information without a central clearinghouse will lead the public astray and serve as a barrier to patient and consumer engagement. The workgroup agreed that the report should include a recommendation on how to coordinate all of the relevant information and data the workgroup has been reviewing.
- Following up on the above recommendation, the workgroup agreed there is a need for a more active engagement on end-of-life and palliative care issues from the payer community, as they need to receive this information in a digestible fashion.
- The workgroup agreed that the recommendation regarding the future structure/organizing body for completing future work should be listed at the beginning of the report in order to provide additional context for readers.
- It was suggested that the recommendations will be presented in order of importance. For example, advance planning is a big one and could be implemented statewide.
- On the topic of advance care planning, it was noted that the public may not be familiar with this terminology.
- The workgroup should ensure the report is free of jargon and is as easy to read as possible.
- The DMOST outreach initiative was recognized for including 20+ stakeholders across the state. A similar initiative will need to be undertaken here.
- It was noted that the recommendation(s) regarding data need to reference what is available and where, as well as where and how to obtain the information needed
- The workgroup then began discussing metrics that could be looked at over time. Developing any sort of metric will require a strategic partnership, which in turn requires support and resources.
- The workgroup members discussed the need to differentiate between advance planning and advance health care directive. It was also noted that a glossary of terms needs to be included and distributed to appropriate stakeholders across the state prior to sending the final report to the HCC for review. This will ensure consistent and appropriate language across the board.
- Again, the workgroup members discussed the need to establish or build upon any central resource center where patients and consumers can go for end-of-life and palliative care information.

- One workgroup member mentioned the difficulty of obtaining funding to continue to support this work and this information ought to be included in the report. The workgroup agreed the report needs to clearly articulate what needs to be done in order for change to occur. Discussion was held around the DE Cancer Consortium and whether a similar structure might be appropriate for this initiative.
- Building off this funding discussion, the workgroup talked about potentially attaching a price tag for certain tasks and items included in any outreach and awareness campaign that could occur down the road. The workgroup estimated that the initial funding required to continue this work could be sizeable, while maintenance and operation costs will be less.
- It was noted that California has done a nice job with end-of-life and palliative care and one workgroup member suggested developing a recommendation around following California's approach and tailoring to Delaware as appropriate. To that end, the workgroup agreed to research how much California spent on developing their end-of-life and palliative care resources.
- One workgroup member noted that the entire point of this work is helping patients and consumers navigate the choices about how they want to live their lives.

Feedback on the Structure of the Organizing Body Moving Forward

- The workgroup then spent the majority of the remaining time discussing what the structure of the end-of-life and palliative care organizing body should look like.
- The workgroup agreed that the ideal structure would be a partnership between the State and a non-profit organization. One organization discussed to potentially serve as the organizing body for the ongoing end-of-life and palliative care work is the Delaware End-of-Life Coalition (DEOLC).
- The DEOLC would need more resources in place to lead this work but does currently have many of the key players already engaged including Beebe, Bayhealth, Christiana Care and St. Francis. Pieces of the infrastructure are already in place and the right players are involved, but resources are needed. The DEOLC is currently funded by hospices and hospitals and has total revenue of \$11-12k per year.
- The State would also need to play a role by possibly providing some dedicated staff support (website design and updates). Other entities that could play a role include:
 - Delaware Health Care Commission
 - Delaware Center for Health Innovation – can help facilitate a conversation with the payer community. Also has a Workforce and Education Committee.
 - Delaware Healthcare Association
 - Medical Society of Delaware
- Other partners that need to be engaged:
 - Universities and training programs
 - Long term care community
 - Payers – in New York, Blue Cross Blue Shield has underwritten MOLST education efforts. In Delaware, Highmark has signaled interest in aiding with the DMOST legislation. Lots of silos exist now and this needs to be a coordinated group.
- In 2010/11, the University of Delaware collaborated with others to offer a thanatology certification and the participants were all non-Delawareans, and many were not from the U.S.
- The Medical Society currently works with the DEOLC on their education materials.
- The recommendation on what this organizing body should look like will be moved to the beginning of the report. This may include a list of pros and cons for each proposed structure.

- A question was raised about having the organizing body reside within the HCC. This may be a possibility although staff limitations might make this a challenge. Another option is that the HCC could play a coordinating role with different groups/initiatives. A question was raised about whether the HCC has the ability to receive corporate funds; it is believed that this is possible although limited in scope.
- Keagen Brown noted that the DEOLC might need to change its bylaws for integration with bodies such as the DCHI under a new structure. It was also suggested that a name change be considered by the Coalition to be more inclusive.
- No matter the structure, this future organizing body will need to be stakeholder-driven, just like the DCHI.
- Public feedback from listening sessions about concern over government involvement in healthcare was mentioned.
- The workgroup also discussed including a gap analysis in the report which identifies areas with room for improvement.
- Dr. Alexander provided commentary on the following:
 - References should be acknowledged and cited throughout the report.
 - Issues of access continue to be a challenge for people with limitations. He referenced a Journal of the American Medical Association article about helping seniors access the end-of-life options they need.
- Dr. Goodill noted that barriers to care should be called out more readily.

Public Comment

- A representative from Beebe Healthcare shared information regarding the 'File of Life', a resource currently distributed by Beebe throughout Sussex County. Beebe is developing an ambulatory power of care program and looking at opportunities to integrate DMOST. These packets could be updated to allow individuals to notify first responders they have a medical order in the house and direct them to it.
- Another individual asked to distinguish between recommendations for palliative and end-of-life care and suggested that the recommendations and responsible parties are likely to be different.