

**Delaware Health Care Commission  
End-of-Life Workgroup  
March 18, 2016 Meeting Notes**

**Attendees:** Jill Rogers, John Goodill, Susan Lloyd, Tim Rodden, Keagen Brown, Laura Waterland, Michael Alexander, Rep. Paul Baumbach, Julane Miller-Armbrister

**Other Attendees:** Laura Howard, Alex Parkowski, Mike Cordrey, Leslie Tremberth, Pete Haney, Bess McAneny, Kathy Collison, Jeanne Chiquoine, Maria Ash, Casey Walsh, Theresa Latorre-Tegtmeier

**Agenda**

- Recap of February 26 Meeting
- Final Report Draft Review
- Timeline Review
- Public Comment

**Summary of Discussion**

Recap of February 26 Meeting

- The workgroup briefly recapped the agenda and discussion from the February 26 meeting, which included:
  - A Review of the Final Draft Report
  - Timeline Review
  - Public Comment
- The workgroup was notified that roughly 25-30 different individuals or organizations outside of the workgroup membership submitted public comments on the workgroup's draft report.
- These comments will be redacted to remove any personal, identifiable information before posting compiled comments to the workgroup's website.

Final Report Draft Review – Preface

- A preface was added to the beginning of the draft report to provide an introduction to all readers and highlight some of the key themes to be seen throughout the report, namely the need for each individual to decide for him or herself what the appropriate level of care is.
- One workgroup member noted that language should be added to the preface to mention the intent of this report is also to empower individuals with more information in an effort to put them in control of their health and health care decisions.

Introduction

- The workgroup agreed that language identifying the charge should be included front and center in the report in order to appropriately set expectations for the reader.
- One workgroup member noted clarification will need to be provided regarding access to medical marijuana.
- A workgroup member stated the term “physician aid in dying” could be confusing for readers and would like to replace that term with “physician assisted end of life”. This would be a good addition to the Glossary.

- The workgroup agreed that the language of this report is very important needs to be very clear for all readers.

### Background

- One workgroup member mentioned that the term “patient engagement” should be used instead of “patient satisfaction.” A similar replacement should be made regarding patient and family satisfaction.
- A workgroup member requested the definition for hospice be revised to align more with the definition provided by the National Hospice and Palliative Care Organization. It was noted that hospice care is more than just a philosophy and has been identified as an established health care benefit.
- Workgroup members discussed a graphic included in the report which is meant to highlight the areas for differentiation and overlap between end-of-life care, palliative care and hospice care. One workgroup member noted the graphic is demographically appropriate. Another workgroup member stated it was hard to differentiate between the different services and noted that end-of-life care can be received outside of hospice care. Yet another workgroup member noted it might be helpful to sequentially show the various levels of care, including bereavement. A number of workgroup members were familiar with this graphic and will circulate to the workgroup.

### Increasing Prevalence of Palliative Care

- One workgroup member asked for the data mentioned on page 7 of the draft report to be discussed more at length.
- The form available through the Division of Services for Aging and Adults with Physical Disabilities will be out of date soon and will need to be updated to reflect the DMOST. The group agreed that keeping the link to the page where the form is available (and will presumably be updated) would be an appropriate way to address this.
- Throughout the report the term advance care planning should be replaced by advance directive.
- The mention of DMOST on page 11 of the draft report should be past tense. The regulation is final and is currently being implemented as forms will be available on 4/1/16.
- There is a need to define the metrics and standards mentioned by the Palliative Care Council survey. The workgroup should consider developing these definitions and surveying current programs to see if they are meeting the needs of the population.

### Approach

- There is currently a placeholder regarding the number of public comments received. The workgroup will include the final figure in this section.
- The workgroup will include a definition of the “Other” category displaying the location of deaths.
- One workgroup member reiterated the importance of highlighting the lack of data across the state.

### Findings and Recommendations

- The table of recommendations that appeared as section II of the previous draft report was removed to avoid repetition. Recommendations are now found only in section IV and broken out according to areas of focus.

- The order of recommendations reflects the workgroup’s extensive discussion from previous meetings on the importance of the governance structure for this work moving forward.
- This workgroup will be housed within the Health Care Commission for the time being.
- Funding for the support of the workgroup’s initiatives moving forward will be dependent on state funding.
- One workgroup member noted the importance of not losing momentum as the workgroup moves towards a transition phase.
- Workgroup members discussed the proposed public/private partnership for the governance structure moving forward. The Delaware End of Life Coalition will need to be expanded and modified to support this workgroup.
- Workgroup members discussed similar work done in other states and specifically mentioned the work done in Maryland and California to demonstrate the need to include more stakeholders and educators in the conversation.
- The End of Life Coalition will need to vote on this proposed structure; their current structure cannot be ignored.
- Workgroup members reinforced the need to be inclusive and get more organizations engaged such as nurses, social workers, hospitals, etc.
- The workgroup agreed on the need to form a sub-group to carry on this work in the coming months.

#### Consumer Outreach

- The workgroup agreed the likely potential cost for carrying on this work to be around \$1.5 million, at least initially.
- Not all of this work will need to be performed on a year-round basis (e.g. awareness campaign.)

#### Access

- Narrative will be added to recommendation #8 to reinforce the concept.
- Instead of bullets, the recommendations will be numbered 1, 1a, 2, 2a, etc.
- The second recommendation on page 21 could fall under the fourth recommendation or be stated more explicitly.

#### Other Recommendations

- The workgroup discussed the need to engage Delaware’s academic institutions to possibly conduct research and analyze any data. The University of Delaware’s Department of Sociology was mentioned as a possible partner as was the University of Delaware School of Nursing.
- Page 20 recommendation #1: The workgroup agreed that the terms “the care planning process” should be replaced by “the health care process”.

#### Appendices

- A glossary and acronyms will be updated to ensure only terms included in this report will be built into the glossary and acronyms in the appendices.
- The workgroup agreed on the need to include some context around the reasoning for identifying the responsible parties and explain what the End of Life Coalition, Delaware Center for Health Innovation, etc. are.
- The workgroup will use definitions from the Delaware Code whenever possible.
- The workgroup noted that providers and practitioners are treated differently in DMOST statute.

### Public Comment

- One individual delivered a public comment calling for the need to protect innocent lives. The individual stressed the need for increased collaboration between the patient, their family, and the entire medical team. Accordingly, all final decisions in the end-of-life process should be subject to final medical discussion and collaboration. The term power of attorney should also be included in the glossary. Any terms regarding “patient-centered” should be included as well.
- One individual from the public questioned workgroup members what their vision is for the future of palliative care in Delaware, namely, how will the capacity for these services change and how will they be increased? This individual also questioned how this work will be integrated with the Delaware Center for Health Innovation and their work on value-based payment. This individual noted it would be helpful for the workgroup to quantify the potential expansion of end-of-life and palliative care offerings and outline the path forward. Since there is an increased awareness of these services, both end-of-life and palliative care offerings should be mentioned by both patients and providers early on in medical consultations and conversations and “moved up” in the continuum of care.
- A member of the workgroup responded to this comment by stating that the intent of end-of-life and palliative care, and any advance directives that come as a result, are not intended to be limiting in any way. This should be addressed more clearly in the workgroup’s report. Both short and long-term implications will be considered in order to demonstrate the philosophical structure of providing end-of-life and palliative care.