

**Delaware Health Care Commission  
End-of-Life Workgroup Meeting Notes  
February 12, 2016**

**Attendees:** Jill Rogers, Julane Miller-Armbrister, John Goodill, Lexie McFassel, Rep. Paul Baumbach, Susan Lloyd, Tim Rodden, Tim Gibbs, Megan Alexander (for Keagan Brown), Laura Waterland, Michael Alexander (telephone), Kyle Hodges (for Daenise McMullin-Powell), Allison Gonzalez, Wayne Smith

**Other Attendees:** Angela Steele-Tilton, Cheyenne Luzader, Jim Luzader, Pat Maichle, Casey Walsh, Mike Cordrey, Alex Parkowski, Theresa Latorre-Tegtmeier, Jonathan Kaufman, Cyndy Fanning, Eileen Sparling, Cimone Philpotts, Cheryl Precourt, Yrene Waldron, Laura Howard

**Agenda**

- Recap of January Meeting
- Overview of Listening Sessions and Feedback Received
- Final Report Outline
- Recent Publications
  - DE Journal of Public Health issue
  - JAMA January 19 issue
- Timeline Review
- Public Comment

**Summary of Discussion**

Recap of January Meeting

- The workgroup reviewed the agenda from January's meeting, which included the following:
  - Presentation of key themes document which captured information shared to date;
  - Review of Delaware data and Palliative Care Council survey findings;
  - Discussion of listening session of preparations; and
  - Presentation of the draft outline for the workgroup's final report to the HCC.

Overview of Listening Sessions and Feedback Received

- The workgroup discussed the four listening sessions that were held in New Castle, Dover, Lewes and Seaford.
- Workgroup members who attended the listening sessions stressed that the main purpose of the sessions was to hear from participants about what end-of-life and palliative care issues are important to them.
- A number of key themes from the sessions were discussed. This information was presented to the workgroup members to ensure all information that was shared during the listening sessions was accurately captured in these slides.
- Key Theme #1: Each person must decide what is best for him or herself.
  - The workgroup acknowledged the intent is to help Delawareans during the end-of-life decision making process.
  - One workgroup member mentioned this key theme resonates with the Institute of Medicine's report, *Dying in America*, by speaking to patient empowerment and the need

of the health care system to ask patients and their loved ones what kind of care they actually want as they approach the end of life.

- Key Theme #2: Talk early and often with loved ones, caregivers, providers and others about personal wishes to encourage clear understanding.
  - Workgroup members stressed how this is not and should not be a process an individual goes through alone.
  - These decisions are evolving and are not a point-in-time decision. Conversation needs to be continuous and frequent.
  - One workgroup member highlighted a frequent comment heard during the listening sessions, which was that sometimes even when individuals complete an advance health care directive the document is still ignored once inside the hospital. The system needs to respect and protect the individual's decisions. Every choice needs to be honored.
  - Another workgroup member mentioned how the health system is changing dramatically and this leads to a lot of public misunderstanding. The concern here is that this change could potentially force people into certain health care services.
  - The workgroup emphasized that physician-assisted suicide is not part of its scope of work.
  - A workgroup member called for the Delaware Court of Chancery Guardianship to be included in the workgroup's communications.
  - The workgroup clarified they are not charged with developing any legislation around end-of-life and palliative care.
  - One workgroup member noted the need for communication between the legal professionals who help individuals complete advance health care directives and the health system.
  - The workgroup also discussed the role the power of attorney plays in the decision making process and what it actually means to serve in that role.
- Key Theme #3: Patients and their families often struggle to receive/provide the necessary care once an individual is released from the hospital.
  - Workgroup members discussed the importance and sometimes prohibitive cost of home nursing care.
  - The workgroup agreed work needs to be done around putting needed social supports in place for families with a loved one coming home from the hospital.
  - A workgroup member highlighted a common complaint heard during the listening sessions, which is the delay in receiving Medicaid long-term care services. In some cases individuals must wait up to 6 months until they receive the requested service. Another common problem is the inability of medical aides to administer medicine to patients.
  - Another workgroup member called for more caregiver training outside of the hospital.
  - Workgroup members agreed there is confusion among patients when it comes to the options available to them under Medicaid long-term care. There are also workforce capacity needs in this area.
- Key Theme #4: Delaware has many existing resources that can and should be leveraged for outreach and education purposes (Senior centers, community centers, faith communities, Navigators, Federally Qualified Health Centers, etc.)
- Key Theme #5: DMOST and Advance Care Directives
  - The medical order from the DMOST legislation is meant to be completed during an individual's last year of life.

- These medical orders will be available beginning April 1, 2016.
- Workgroup members acknowledged that many individuals fear that if they complete the medical order they are somehow limiting their options and that conversations around end-of-life care and planning will end. Workgroup members agreed this must be clarified moving forward.
- Key Theme #6: Providers need to receive education and training around end-of-life and palliative care so that they can properly and thoroughly address patient needs. The importance of cultural competency was noted.
  - The workgroup discussed any cultural biases that may be present for both patients and providers.
- Key Theme #7: Providers also need to participate directly in advance care planning discussions so that all parties understand options and implications of each choice.
- Key Theme #8: Palliative and hospice care are critical to supporting a good quality of life for patients with serious or terminal illness and providing support to caregivers. These services should be accessible regardless of ability to pay.
- Key Theme #9: Many participants expressed concern about cost factoring into end-of-life decisions and noted that this is especially difficult for patients and families with limited resources.
- Key Theme #10: Some participants expressed concern that conversations around withholding certain treatments put Delaware on a 'slippery slope' towards talking about euthanasia or physician assisted death, especially for those who may be considered a burden.
- Key Theme #11: There was much discussion around the importance of the compassionate care offered through palliative medicine and its role in improving quality of life for seriously or terminally ill patients. This is care designed to support patient and family preferences, offer options and ultimately provide whatever the patient wishes.
  - One workgroup member noted the importance of family support systems in addition to support for patient needs.

### Final Report Outline

- Feedback on the Key Findings section, Delivery of Person-Centered, Family-Oriented Care
  - One workgroup member mentioned the key here is care coordination and access to care. These issues need to be added to this section of the outline. Coordination among providers is also critical. The value-based payment model represents a cultural shift and the workgroup needs to ensure alignment with the Delaware Center for Health Innovation (DCHI).
  - The workgroup noted the need for evidence to support and ultimately answer these questions:
    - What do we have now?
    - What improvements have we made?
    - What else can we do?
  - This section of the outline, and thus the paper, would lend itself to be more readable if the workgroup identified gaps and addressed opportunities.

- Workgroup members discussed challenges around cost as a barrier. The perceived lack of awareness in the provider community of available palliative care services was also identified as a barrier.
- Workgroup members clarified that home care and wraparound services are distinct and that there are a number of out-of-facility care services available for use. However, the workgroup would be well served to acknowledge the cost of these services.
- Integration with the State Innovation Model: workgroup members discussed the possibility of working with the payer community to determine if they can help pay for these services.
- One workgroup member called for cultural competencies and personal biases to be included in this section of the outline.
- Feedback on the Key Findings section, Clinician-Patient Communication and Advance Care Planning
  - One workgroup member commented on the need to include palliative care in addition to end-of-life care in this section of the outline.
  - Health systems need to add palliative care services and programs to their normal workflows.
  - One workgroup member mentioned an opportunity for alignment with DCHI-sponsored Practice Transformation initiatives.
- Feedback on the Key Findings section, Professional Education and Development
  - One workgroup member would like to see Family Court included in this section of the outline. Other items mentioned for inclusion are the Delaware Court of Chancery and Guardianship as well as elder law and the bar association.
  - The training mentioned in this section should align with the DCHI Workforce and Education committee's health care workforce learning and re-learning curriculum.
- Feedback on the Key Findings section, Policies and Payment Systems
  - Again, workgroup members addressed Medicaid long-term care and the need to mention it in this section of the outline.
  - One workgroup member stated that the workgroup needs to review the policies that prohibit delegation of tasks to home health providers. Appropriate Medicaid reimbursement for these services must also be addressed.
  - The workgroup discussed the issue of guardians being reimbursed for services. There is a need for people to step up and serve that role or be supportive in the decision-making process.
  - There was additional discussion around the process for selecting a surrogate decision maker and helping individuals determine who that person should be.
  - The workgroup discussed the financial impact on family members that are forced to miss work to help care for their loved ones and the possibility of compensating them as caregivers.
  - One workgroup member noted that the managed care organizations often push people to justify why they cannot miss work in order to care for a loved one.
  - Sometimes family alone is not enough to help support a patient during the end of life.
- Feedback on Recommendations
  - Workgroup members addressed the need for data on our current work and what impact the recommendations will have.

- This is an opportunity to move forward in health systems as well across different care settings.
- One workgroup member requested the term delivery organizations be changed to providers.
- One member from the public noted that Wilmington University has a certificate program in place that addresses palliative care and end-of-life training. This is a college credit program.
- It was noted that technical schools are another avenue to explore for education.
- One workgroup member declared that Medicare is not friendly towards hearing and vision problems, which leads people to withdraw until a crisis engages them. Social welfare, community engineering, and short-sided federal policies need to be documented somewhere in the outline and report.
- The amount of national spending compared to other western countries was discussed, namely how the United States outspends most of those countries.
- One workgroup member noted the importance of paying attention to continuing legal education and pairing that with continuing medical education.
- A member from the public voiced their opinion that it would be helpful for the Electronic Medical Records (EMRs) to make patient wishes available and accessible.
- One workgroup member mentioned the possibility of integrating electronic medical records (EMRs) through the Delaware Health Information Network (DHIN).
- Another workgroup member discussed that the general structure of the final report should allow for the group's guiding principles to be addressed early on.
- The workgroup discussed the long-term plan for this work and the need for continuation after the report is submitted to the Health Care Commission on or before March 31. One member would like to see an on-going, advisory group established to continue the work of this workgroup.
- One of the goals of this work moving forward should be raising the level of awareness around end-of-life and palliative care. The workgroup will need to monitor education and stakeholder engagement appropriately.

### Recent Publications

- The DE Journal of Public Health issued its January issue, which included several articles related to palliative and end-of-life care. Additionally, the Journal of the American Medical Association (JAMA)'s January 19 issue included several articles related to end-of-life issues.

### Timeline Review

- The Health Care Commission will post the draft report for public comment and ask workgroup members to distribute as appropriate. Future workgroup meetings are scheduled for Friday February, 26, and Friday, March 18.

### Public Comment

- There are a number of issues that need to be considered here: medical, legal, and real life. The end-of-life stage should be a natural process and we complicate it. Right now end-of-life issues are abstract and we need to define it properly. There is no online list of what the relevant terms are. Additionally, doctors are asking unnecessary questions leaving family members feeling as though they need to bring a lawyer with them every time they go to the hospital. There is no

chance to mourn because the family is immediately filling out more paperwork and checking the appropriate boxes. Individuals should not have to defend themselves when caring for a loved one. Additionally, current laws actually keep drugs from those who need them the most.

- An attendee asked when DMOST education will be rolled out to providers. A workgroup member stated the Delaware Academy of Medicine will be responsible for conducting this training and will do so through a combination of live, in-person presentations and online webinars throughout the year. The medical orders resulting from DMOST become effective April 1, 2016.