

**Delaware Health Care Commission
End of Life Workgroup
January 8, 2016**

Workgroup Member Attendees: Jill Rogers, Keagen Brown, John Goodill, Daniese McMullin-Powell, Michael Alexander, Tim Rodden, Laura Waterland, Lexie McFassel, Rep. Paul Baumbach, Tim Gibbs, Julane Miller-Armbrister

Other Attendees: Eileen Sparling, Laura Howard, Theresa Latorre-Tegtmeier, Joann Hasse, Mike Cordrey, Alex Parkowski, Jacqueline Thomas, Kelsey Mellette, Kyle Hodges, Maria Ash, Sarah Carmody, Kathy Collison, Peter Hartrauft, Sally Frechette, Teresa LoPorto, Bess McAneny, Cimone Philpotts, Cheyenne Luzader, Diana Price

Agenda

- Recap of Last Meeting
- State Innovation Model Integration
- Data Review
- Draft Outline of Final Report
- Public Comment

Summary of Discussion

Recap of Last Meeting

- The group reviewed the Key Themes document which was developed to capture and group information shared at the initial December 4, 2015 meeting.
- It was suggested that “hospice care” be removed from the Key Themes document so that there is no distinction between palliative care and hospice care.

State Innovation Model Integration

- Committee members reviewed the goals of Delaware’s State Innovation Model activities, which are as follows:
 - Improve health, health care quality and patient experience
 - Be one of the five healthiest states
 - Be among the top 10% of states in health care quality and patient experience
 - Bring the growth of health care costs in line with GDP growth.
 - Improve the provider experience
- The following core elements were also discussed:
 - Supporting local communities to enable healthier behavior living and better access to primary care;
 - Transforming primary care so that every Delawarean has access to a primary care provider and better coordinated care;
 - Facilitating a shift to payment models that reward high quality and better management of costs, with a common scorecard;
 - Enabling providers to access better information about performance and consumers to engage in their own health; and

- Providing resources to the current health care workforce and employing strategies to develop the future workforce.
- This led to a number of questions and discussions on a wide array of topics. Questions posed to the group, included, but were not limited to:
 - What is going on between the State Innovation Model and palliative care? Does a relationship currently exist?
 - Are we talking with the payers on palliative care yet?
 - Should Delaware consider amending the Nurse Practice Act? Nurse Practitioners cannot currently administer medication to patients and amending this act would allow them to do so. The same holds true for home health workers, and the committee recognized this is a barrier to providing common sense health care services in the home and helping people where they are.
 - There was an additional question on the Nurse Practice Act, specifically, which state agencies can use it?
 - It was noted that New York is a good example of a state which allows nurse practitioners and home health workers to administer medication.
 - Committee members agreed that community education will be crucial.

Existing Data: DE Population Statistics

- The committee reviewed data on death locations in Delaware from the Delaware Center for Health Statistics. One statistic that was mentioned specifically was the fact that 14.25% of deaths in Delaware were classified under an “Other” category. 85% of the deaths in this category occurred in hospice care. Committee members would like to have a better understanding of the percentage of deaths in hospice care in 2001 to allow for a year-over-year analysis.
- Committee members also requested this information from neighboring states, namely Maryland, New Jersey, and Pennsylvania.
- The Virtual Resource Data Center could be a potential source of information for the Committee, as it contains Medicare claims dating back to 2007.
- Committee members discussed the feasibility of excluding unexpected deaths from the data analysis. Examples include suicide, homicide, overdose, etc.

Palliative Care Council Survey Findings

- It was noted during the discussion of the PCC’s survey findings that referrals to palliative care are typically initiated by physicians or mid-level providers. Committee members wondered if this was a barrier to better care.
- The group also discussed the number of palliative care admits into hospitals. At Christiana Care, roughly 1% of admissions are for palliative care issues, while hospitals with very robust palliative care offerings (outside of DE) typically see roughly 5-10% palliative care admissions.
- Discussion also revolved around certifications and whether or not that is barrier to better care or a gold standard to strive for.
- One committee member noted that in some situations advance directives may be linked to palliative care while in the hospitals. Patients also might have the ability to seek a palliative care consultation.
- The prevalence of specific palliative services among survey responses is reflect of the data collection efforts and need to be taken with a grain of salt.

- Provider knowledge on the value of palliative care is lacking across Delaware.
- The PCC identified several opportunities for potentially increasing access to palliative care services, and the group agreed that with the development of this workgroup it is an opportunity to say what we want to do differently.

Compendium of Delaware Palliative Care Programs

- The goal is to compile detailed information about palliative care offerings in settings including non-hospital. For each program identified, the group wishes to document:
 - Settings in which programs are offered
 - Nature of program and service offerings
 - Target audience
 - Data about numbers served/reach of programs
- Workgroup members suggested reaching out to PCC survey respondents for specific information.
- Members also suggested the same approach for the hospice community.
- One member of the public suggested that it would be helpful to tie to the DMOST education program.
- The group recognized there is a deficit on the data Delaware has on the state of advance directives in Delaware.
- The Behavioral Risk Factor Surveillance System was recommended as an organization to pull data from as they have information on all three counties.
- The CDC might also have an educational module out on this topic.
- The group discussed transition of care and the fact that some hospitals do not accept some advance directives. The hospitals need to make sure that the person designated in the directive is actually willing to honor the patient's wishes no matter the circumstances.

Additional Data Sources: Consumer Survey

- Members noted it would be helpful to have a single website with all relevant information on palliative care and end of life care included. California and New Jersey are good examples for the group to investigate.
- It would also be helpful to have links to the number of forms patients and their families need to complete before, during, and after their care.

Additional Data Sources: Listening Sessions

- Listening sessions are intended to solicit public input on the issues and identify key areas of concern for future exploration and consideration.
- One session will be scheduled in Kent, one in New Castle, one in East Sussex, and one in West Sussex in order to promote accessibility.
- Elderly citizens are hesitant to drive at night, so the group should consider holding some of the listening sessions during the daytime and in locations that are easily accessible to/from DART stops.
- There was a lengthy discussion on how to best get the word out on these listening sessions.
- The HCC could potentially develop a media release.
- Target audiences should include bishops, churches, archdioceses, ecumenical council, etc.
- LaRed and Westside could be potential locations for listening sessions.

- Providers will also want to be kept in the loop and should be invited as well.

Draft Outline of Final Report

- The group touched on physician aid in dying and one member mentioned that California approved a bill on this topic.
- Oregon was mentioned as a national leader on the issue and allows for physician aid in dying.
- The group realized that everyone needs to be sure to not associate physician aid in dying with palliative and/or hospice care.
- It was noted that if the palliative care services in Delaware were improved then physician aid in dying would decrease as a result.
- Members noted that it is important to clarify these definitions in advance of the listening sessions and confirm what it is and what it is not.
- To that end, one member noted that hospice is essentially a philosophy of care, while palliative care is building on that philosophy and incorporating disease-specific treatments.
- A glossary of terms will need to be included in the final report to avoid any potential confusion.
- There was a discussion around the need for palliative care legislation in Delaware and the need for space on that topic in the final report. This will be determined at a later date.

Public Comment

- It was noted that a definition of palliative care found in the slide deck included a reference to palliative care (circular reference.)
- One member of the public noted her concern on DMOST and suggested that palliative care may be seen as a path towards physician-aided suicide. This individual also expressed concern that bias can impact treatment re: food and water and pain medication as well as provider aversion to engaging with patients.
- Another participant pointed out the focus on dying but noted that there are non-frail elderly and that end of life does not necessarily mean death in the next year.
- A representative from Sen. Coons' office mentioned the Medicare Choices and Empowerment Act that has been introduced at the federal level and would offer a \$75 incentive payment for Medicare patients to develop electronic advance directives. There is a chronic care committee within the Senate Finance Committee that is actively working to improve chronic care and end of life issues at the federal level and would appreciate any insight from Delaware's workgroup on any issues that the federal committees can consider in the future.