Delaware Health Care Commission
End of Life Workgroup
December 4, 2015

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

Other Attendees: Maria Ash, Theresa Latorre-Tegtmeier, Laura Howard, Bess McAneny, Teresa LoPorto, Pat Maichle, Kathy Collison, Sarah Carmody, Cheyenne Luzader, Keith Goheen, Alex Parkowski, Mike Cordrey, Cyndy Fanning, Eileen Sparling, Jan Lee

Agenda

- Background
- Workgroup Goals and Objectives
- Recent Developments
- Discussion Items
- Timelines
- Other Items
- Public Comment

Summary of Discussion

Background

- In order to have standard definitions moving forward, the group spent time reviewing the formal definitions for both End of Life Care and Palliative medicine. This will be crucial to keep in mind as the terms can sometimes be confused.

Workgroup Goals and Objectives

- The workgroup reviewed their charge as stipulated by the HCC. The workgroup will conduct the following activities:
    - Review relevant information and best practices related to end of life care and palliative care.
    - Identify key end of life care issues, including advance care planning.
    - Develop recommendations and options for consideration regarding:
        - Consumer outreach and education activities
        - Professional outreach, training, support and education
        - Enabling access to palliative care services and supporting the capacity in the health care system.
        - Other recommendations
- This work will culminate with a final report due to the HCC on March 31, 2016. This deliverable will provide recommendations regarding the most appropriate approach to ongoing support and consideration of end of life issues in Delaware.
- Rep. Baumbach pointed out the “governance structure” language in the group’s charge. Jill Rogers noted that the group would be responsible for establishing at least a framework for ongoing consideration of palliative care and end-of-life issues in DE.

Recent Developments in Delaware

- There is a CMMI demonstration 'Care Choices' pilot project in place which would allow Medicare beneficiaries to receive both palliative and curative treatment while in hospice care. This effort will be rolled out at Delaware Hospice in Dover in January 2016, and once again in Milford in January of 2018.
- The IOM report will serve as a guiding light for the group and could potentially be a template down the road for the group's final report.
- Dr. Goodill noted the importance of continuing the efforts of Sen. Coons' roundtable, which highlighted the importance of this issue. On November 18, Senator Coons introduced S. 2297: Medicare Choices Empowerment and Protection Act, which is a bill to amend title XVIII of the Social Security Act to encourage Medicare beneficiaries to voluntarily adopt advance directives guiding the medical care they receive.
- In May, Delaware passed the DMOST legislation to create a set of portable end-of-life medical orders.
- Medicare recently announced that it will reimburse doctors for advance care planning discussions with patients. The group then discussed whether or not all of the health care providers across the state have been properly trained to conduct this work.
- The Delaware Palliative Care Council surveyed hospitals across the state to ask them about their palliative care programs and what they looked like. The group determined it would be helpful to view this data.
- Dr. Alexander expressed concern about the determinants of who qualifies for "end of life" care, suggesting these have not been well established.
- Jill Rogers emphasized the importance of tying the group's efforts to the innovation model work happening in Delaware.
- Yrene Waldron noted the importance of the faith/ministry community, pointing out that they are often contacted by patients and families when the medical system is unresponsive.
- While hospitals play a key role in end of life and palliative care, the group did acknowledge that it is still important to understand what happens outside the four walls of hospital. There needs to be adequate support in the community so patients do not end up coming back to the emergency room for palliative care services.
- The group discussed reimbursement and the fact that there is no formal reimbursement for palliative care for Medicaid patients, and it is very hard to get paid for palliative care services outside of the hospital. The group discussed asking the Delaware Division of Medicaid & Medical Assistance to build palliative care into the value-based payment model.
- Rep. Baumbach noted that while cost savings may be realized through palliative care initiatives, this is not the primary consideration from the patient perspective. Susan Lloyd suggested emphasizing "right care at the right time," to emphasize quality as well as efficiency.
- It will be important to consider the particular concerns and needs of the dual eligible population.
- Dr. Alexander emphasized the importance of focusing on the patient and family (rather than the medical system alone) when it comes to pediatric rights for those with disabilities.
- Dr. Goodill asked about the possibility of capturing data about the percentage of individuals who have completed advance directives/treatment plans in Delaware and nationally.

Discussion Items

- The group will need to remember that the final recommendations should take cultural competencies into consideration. This topic may be considered taboo and will have various considerations within the context of different cultures.
- The health systems across the state have never been engaged in developing advance directives. Likewise, patients and their families have not received much education on topics such as the power of attorney, particularly as it relates to financial decisions.
- The group also discussed the availability of services for parents of children with serious illnesses. DuPont did have a program in place.
- Outreach and education programs should be sure to include college classes, churches, and senior groups across the state. Health literacy is crucial to the success of this effort.
- The group discussed the challenges of making advance directives accessible to and understood by patients and families, especially since patients often don't know specifically what they want. DMOST is one tool, but each piece increases the likelihood that a patient will get the care he/she wants. Jill Rogers pointed out that these decisions also get easier in the hands of more empowered consumers.
- The group discussed provider certification regarding palliative care. Right now the group does not have an understanding on the number of Delaware providers certified to perform palliative care services. Also discussed was the importance of including providers at all ends of the spectrum in education and awareness efforts. Dr. Goodill mentioned several recent initiatives focused on palliative care within Delaware hospitals.
- The group would be well served to look at the Biden Breast Health Initiative as a best practice program. They are already engaged with high schools across the state, so the group should consider looking at their approach in an effort to determine how information around end of life care and palliative can be provided to students and their families.
- Rep. Baumbach asked to clarify the scope of the group's efforts. Jill Rogers suggested that the group's aim was to determine the "what, how and structure" of these efforts beyond the initial period of group activities. She noted the importance of soliciting input from a variety of stakeholders.
- The January edition of the Delaware Journal of Public Health will be focused on end of life care. This could be a good opportunity for the group to engage stakeholders and invite them to become part of the process.
- In terms of developing the final report, the group agreed it would be helpful to develop a plain-language version, as well as a list of frequently asked questions.
- The group agreed that input from the following individuals/organizations should be solicited as part of the group's efforts:
    - Bethany Hall-Long (D) from the State Senate should be engaged in the group's work, as she seems to be one of the go-to resources for health care issues and policies.
    - The Delaware Ecumenical Council on Children and Families work.
    - The Republican Caucus
    - Veterans Affairs
- For the consumer-focused listening sessions, the group agreed to provide one session in western Sussex County, and another in eastern Sussex County. The format will likely be a brief overview of information collected to date with plenty of time for public input.
- Rep. Baumbach asked about the process for adding new workgroup members. Jill Rogers indicated that it makes sense to find ways to incorporate input from additional stakeholders, whether or not that entails adding more individuals to the workgroup membership.

- Dr. Goodill asked about the possibility of collecting information about where people die (e.g. hospital, home, hospice, etc.) We will seek to gather this information for the next meeting.

Timelines

January 4 – Draft outline of final deliverable

February 5 – Listening sessions throughout DE

February 19 – Complete first draft of report

March 4 – Public comment period (completion)

March 11 – Review and incorporate public feedback into report; complete and circulate second draft to the workgroup

March 21 – Receive and incorporate workgroup feedback into report

March 28 – Complete final draft of report

March 31 – Submit final report to HCC

Proposed Meeting Schedule

Week of January 4

Week of February 8

Week of February 22

Week of March 14

Public Comment

- The group received 9 public comments, which are summarized below.
    - The para-transit schedule should be considered when scheduling the public listening sessions. This will allow for greater participation across the state. Stakeholders need to be engaged on a regular basis and not just during the listening sessions and public comment period. Individuals with disabilities need to be well represented and included during the group's decision making process. Finally, the group needs to continue to look for data around end of life care and palliative care for the dual eligible population in the state.
    - Conversation needs to continue around the advance directive. As of now, the information included in the advance directive does match the actual situation at the patient's bedside.
    - 20% of the state's adult population has some form of disability, further underscoring the need to include these individuals in the decision making process. The Georgetown Center for Child and Human Development recently released a tool that the group should look at. Finally, the group should make sure that stakeholders can submit feedback electronically and/or through the mail in addition to attending the listening sessions.
    - The group needs to work to ensure the "taboo" around end of life care and advance directives is removed. There needs to be some form of education module that can help providers, patients, and families get to this point. It was noted that the IOM does have a

public service announcement available for use. The group should also look at the following resource, https://prepareforyourcare.org/

- There were questions about whether or not doctors receive payment for completing advance directives. The commenter also mentioned that the group needs to highlight the differences between palliative care and hospice care. Finally, mental health services and patients need to be included in the decision making process.
- There was a comment that there is an app available for advance directives. This is made available through the American Bar Association. Patients would be able to work with their families to ensure their health wishes are documented in their smart devices.
- There was another question around the advance directive. Specifically, how many forms can a patient submit and how does the doctor get paid?
- The goals of end of life care and palliative care need to be communicated to the patient and their families.
- The VA should be engaged in the process.