

Delaware End-of-Life and Palliative Care Workgroup

Final Report Annotated Outline DRAFT

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I. Introduction

A brief explanation of how the group came about and what it was tasked with. Re-state deliverables including the final report with recommendations as well as a particular recommendation about the most appropriate governance structure/framework for ongoing support and consideration of end-of-life issues.

II. Background

Information about how we came to be where we are in terms of the current landscape around end-of-life and palliative care and explanation of the context in which these recommendations are being made.

- Emphasis on person-centered care, with specific explanation of alignment with SIM work
- Aging population and increased prevalence of people living longer with chronic illnesses
- Better information and awareness leads to more empowered consumers taking an active role in accessing the care they need and want
- Review of recent developments on the national and Delaware landscapes
 - o Medicare reimbursement and hospice pilot
 - o Other state and national initiatives
 - o Delaware: DMOST, Medicare Choices Empowerment and Protection Act, EOL Roundtable, Palliative Care Council, other specific examples

III. Approach

An overview of how the group approached its work including:

- A summation of workgroup meetings and coordination activities
- Extensive review of Delaware and national research, reports, analyses, etc.
- Review and analysis of Delaware specific data (as available)
- Interviews and discussions with key players and experts in DE (outside of workgroup activities and if conducted)
- Statewide listening sessions
- Open public comment on draft report

IV. Key Findings

Delivery of Person-Centered, Family-Oriented Care

- Need for each individual to determine for him or herself goals, priorities and preferences regarding palliative and end-of-life care
- Importance of person-centered care, especially during the end-of-life phase when multiple transitions among care settings and providers may occur
- Palliative care association with higher quality of life
- Growing awareness of palliative and EOL care best practices among providers in DE with room for additional growth
- Opportunities presented by SIM initiative and national trends toward value based, person centered care
- Taking into account the needs and perspectives of loved ones and those responsible for making decisions on behalf of patients
- Many challenges and limitations in providing care to patients outside of the hospital setting. Home care is available but expensive and family members often have inadequate support or ability to address patient needs

Clinician-Patient Communication and Advance Care Planning

- Patients, especially nearing end-of-life, are often not physically, mentally or cognitively able to make their own decisions about care
- Individuals often do not think about end-of-life planning until a crisis arises, when decisions must be made under pressure
- Importance of advance care planning and medical directives to ensure that patients receive the care they want, especially if palliative care is preferred
- Importance of frequent clinician-patient conversations about end-of-life care to avoid unwanted treatment, including other family members and decision makers as possible
- Need for incentives and standards to promote more frequent and productive clinician-patient discussions

Professional Education and Development

- Review prevalence of educational programs and opportunities related to palliative care among educational institutions, systems of care, provider organizations, etc. in Delaware
- Providers do not always understand the system of palliative and end-of-life care and therefore may not refer patients to appropriate resources and supports
- Doctors may not know best when it comes to patient decisions, especially when faith and other considerations are factored in

Policies and Payment Systems

- Palliative care services including hospice improve patient outcomes and may reduce healthcare costs
- Review availability of reimbursement for palliative and advance care planning services in Delaware

- New Medicare rule allows for provider reimbursement for advance care planning discussions
- Patients desiring long-term supports and services from Medicare can wait 3-6 months before benefits arrive, which is often far too long
- Patients just above the Medicaid threshold may find themselves in limbo re: accessing care – “not quite poor or sick enough”
- Medicare’s Care Choices pilot will enable concurrent palliative and curative treatment in hospice and offer learning opportunities re: quality and cost of care

Public Education and Engagement

- Need for public education and engagement about end-of-life care issues at multiple levels (patients, families, caregivers, guardians, communities)
- Need to normalize conversations about death and dying
- Importance of cultural sensitivity in addressing and explaining the considerations and options around end-of-life care
- Delaware has many existing resources that may be leveraged to support a public awareness campaign (Senior and community centers, churches, FQHCs, Meals on Wheels, etc.)
- Many national resources can also be leveraged (Five Wishes, Conversation Project, Honoring Choices, etc.)
- Many people are unclear about the distinctions between end-of life, palliative and hospice care
- People are also unclear about the differences between advance care directives and DMOST form
- Families need education about what it means to be a surrogate and have decision making power for loved ones

V. Recommendations

Likely recommendations will include:

- Health care delivery organizations should take specific steps to formally incorporate palliative and advance care planning into care
- Professional societies and other organizations that establish quality standards should develop or formalize standards for clinician-patient communication and advance care planning, with formal input from the public
- Educational institutions, credentialing/accrediting boards and state regulatory agencies and health care delivery organizations should consider establishing appropriate training, certification and/or licensure requirements to strengthen palliative care knowledge and skills of clinicians

- State and private payers and programs should integrate financing of medical and social services to support the provision of quality palliative and end-of-life care services (Discuss options for linking this to SIM work)
- A Delaware-specific awareness campaign should engage an array of stakeholders and leverage a wealth of available resources in the state
- Create and continue to update a compendium of resources related to end-of-life and palliative care so that consumers know where to go for information about these services
- Conduct a survey of the public to further identify issues of greatest interest surrounding palliative and end-of-life care and determine areas of greatest priority for further action
- Need for civic leaders, state agencies, community organizations etc. to engage their constituents and provide fact-based information about palliative and EOL care, using appropriate media and other channels
- Develop standardized educational materials about palliative and end-of-life care and disseminate through multiple channels
- Work with relevant stakeholders to ensure that information about palliative and end-of-life care is developed and shared in a manner that is linguistically appropriate and culturally sensitive
- Formal recommendation about the ongoing nature and structure of the EOL workgroup