

Delaware End-of-Life and Palliative Care Workgroup Final Report Annotated Outline DRAFT

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, 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

- Importance of person-centered care, especially during the end-of-life phase when multiple transitions among care settings and providers may occur. Reference alignment with other initiatives underway in DE)
- Palliative care association with higher quality of life
- Prevalence (or lack thereof) of awareness of palliative and EOL care best practices among providers in DE

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
- 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
- Need for incentives and standards to promote more frequent and productive clinician-patient discussions

Professional Education and Development

- Prevalence of educational programs and opportunities related to palliative care among educational institutions, systems of care, provider organizations, etc. in Delaware

Policies and Payment Systems

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

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

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

- Educational institutions, credentialing/accrediting boards and state regulatory agencies and health care delivery organizations should establish 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)
- 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