

New Jersey

Governor's Advisory Council on

End-of-Life Care

Report & Recommendations



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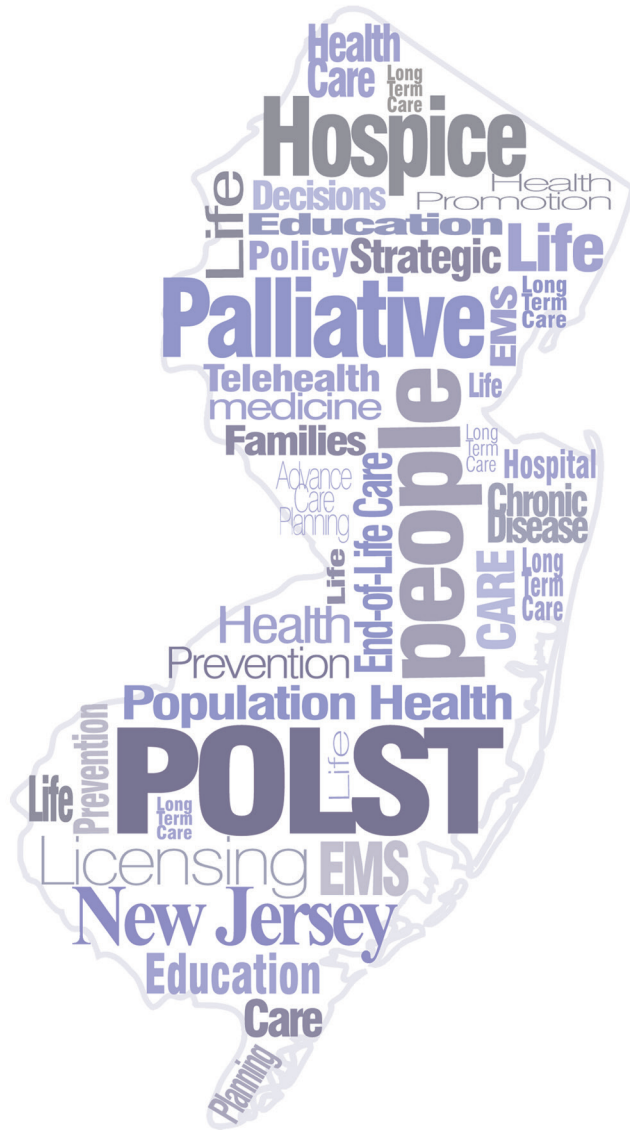


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Executive Summary

A growing consensus is emerging across the nation about the importance of expert end-of-life care, especially as it relates to honoring individual wishes and preferences in the context of an advanced or terminal illness. The need to improve the current state of end-of-life care delivery in New Jersey by establishing patient priorities and defining goals of care both through effective communication and better utilization of palliative care is urgent. To address the many issues surrounding end-of-life care, to consider options for improving how we consistently provide the best care to all, and to raise the general awareness of this important issue, the New Jersey Advisory Council on End-of-Life Care (Council) was convened in September of 2016.

In New Jersey, patients at the end-of-life are treated with more aggressive medical care than in any other state in the nation.

Over the last eighteen months, the Council met to:

- Better understand the various issues related to palliative and end-of-life care,
- Identify and review relevant recommendations on end-of-life care, and to
- Prioritize the recommendations surrounding the Council's legislative charge.

The Council's efforts resulted in the promulgation of several recommendations that were established in accordance with the specific areas outlined in the original charge. Briefly, these recommendations included: 1) Professional training and education on advance care planning, palliative care and end-of-life care; 2) Community awareness education and outreach; 3) Integration of palliative care and use of standardized screening tools across the continuum of healthcare; 4) Development of Palliative Care Fellowship Programs; 5) Promotion and effective implementation of the Practitioner Orders for Life-Sustaining Treatment (POLST); and 6) various other recommendations.

The overarching recommendation of the Council is the designation of an entity (e.g., Coalition or Workgroup) in New Jersey to carry out the work of this Council going forward. The Council recommends that funding be made available to support this entity. This would enable the entity to create a robust organization comprised of expert stakeholders dedicated to facilitating and sharing information related to better end-of-life care in New Jersey. The full complement of recommendations begins on page 17 along with a brief background for each recommendation. The Council hopes that these recommendations will serve as a catalyst for changes in policy and practice that yield improvements in end-of-life care. Changes are needed to reorient care for those with advanced serious illness to be aligned with the real wishes and preferences of patients and families.

I. Introduction:

How we die is a deeply emotional and personal issue that evokes different reactions, emotions and perceptions from individuals, families and communities. Death can occur suddenly, but most often is the result of chronic illness or advanced disease. Although we might hope for a “good death” whereby we will work, be productive and live healthily until the day we die, the harsh reality for most people is that death will result from one or more diseases that must be managed carefully over weeks, months, or even years, through episodes of exacerbations and stabilization. Individuals of all ages experience a chronic decline, sometimes accompanied by physical pain and suffering, impairments, and cognitive as well as emotional distress.

End-of-Life Care

What is end-of-life care? End-of-life care is a term that is broadly used in the literature to describe supportive and medical care given during the time surrounding death. When an individual or family is faced with a terminal illness, they often change the way they think, talk, and deal with dying, death and bereavement and more importantly, prepare for end-of-life care. To patients and families, it may mean the final hours or days of life. For physicians and healthcare professionals, end-of-life care may begin earlier, when they recognize a disease as incurable or resistant to medical treatments.

End-of-life care does not happen only in the moments before breathing and the heart stops, but can occur days, weeks, months and even years before death. Death may be accidental, intentional, the result of a natural aging process, or a result of serious illness. In the last instance, death may be preceded by an extended period of discomfort or actual suffering, typically accompanied by pain, loss of independence and/or diminished awareness. Distress may be attributed to medical interventions, such as ventilator dependence, artificial feeding, and other measures to merely prolong life and attempts to defer the natural process of death. Such circumstances present unique challenges for patients and their families across the healthcare continuum. These challenges include dealing with physical pain, depression, anxiety, a variety of intense emotions, loss of dignity, hopelessness, helplessness and others.

Providers and healthcare professionals must be equipped to plan and effectively communicate about difficult issues when treatments are no longer working. Knowing how to best discuss such sensitive issues and ascertain and communicate a patient’s wishes and preferences is extremely important in dealing with families and patients who are confronted with a serious illness and pending death. Patients and families need to

understand the prognosis associated with their illnesses to effectively make decisions surrounding end-of-life care. Current evidence, however, suggests that many lack this information. Patients and families want honest information about chances of survival and how illness will impact them in the future. Consistent with fully informed consent, providers and healthcare professionals must be prepared to address what is known about a patient's prognosis and to also communicate the uncertainty surrounding a patient's death.

Other challenges surrounding end-of-life care reflect many of the broader issues and problems of the current healthcare system. End-of-life care will become an even larger issue over the next several decades due to an aging population and increased prevalence of people living with serious illnesses. The number of persons age 65 and older in the United States has increased steadily since the 1960s and is projected to double from 46 million today to more than 98 million by 2060¹. Between 2020 and 2030 alone, the number of older persons is projected to increase by almost 18 million as the last largest generational demographic cohort (baby boomers) reaches age 65². With the oldest boomers continuing to move into their senior years, the nation's 65 and older population surged to 44.7 million in 2013, up 3.6 percent from 2012³. Those aged 65 and older made up 15 percent of the state's total population in 2016, compared with 13.5 percent in 2010⁴. The elderly population (65 & over) is projected to grow by 62 percent between 2010 and 2030 and will account for 19.9 percent of the state's total population in 2030⁵. There is no clear vision of how the healthcare system will be able to meet the obvious growing needs for chronic, palliative, and end-of-life care. This increasing demand, as well as the need for improvements in accessing palliative and end-of-life care, are key challenges.

1. Population Reference Bureau Fact Sheet: Aging in the United States, (2015). Available at:

<https://www.prb.org/aging-unitedstates-fact-sheet/>.

2. *Ibid.*

3. *Ibid.*

4. *Ibid.*

5. An Aging Nation: The Older Population in the United States, (2015). Available at: <https://www.census.gov>.

More than one-quarter of all adults, including those aged 75 and older, have given little or no thought to their end-of-life wishes and even fewer have captured their goals of care in writing or through a conversation with family or healthcare providers⁶. This is the case despite recent polls that show Americans worry more about the potential high costs of end-of-life care and have expressed a desire not to be a burden to their family members. As the baby boomer generation continues to age, public interest and receptivity to address issues surrounding end-of-life care may increase.

To prepare for the challenges ahead, the need to improve end-of-life care must be addressed now. It has taken decades to improve the present system of hospice and palliative care in acute care, long-term care, and assisted living settings, yet these improvements only begin to address the problem. This report is an effort to improve end-of-life care in New Jersey by identifying the issues, barriers, challenges and, more importantly, making recommendations that can serve as a roadmap to ensure optimum advance care planning and end-of-life care for New Jersey residents.

6. Kaiser Family Foundation, (2017). Views and Experiences with End-of-Life Medical Care in the U.S. Available at: <http://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/#>

II. Background

A growing consensus is emerging across New Jersey about the importance of advance care planning and end-of-life care. Knowledge of advance care planning and end-of-life care is essential for everyone involved in the delivery of healthcare. Advance care planning includes having conversations with patients and their families about values, care goals and treatment preferences. Unfortunately, the honoring of individual preferences and wishes for care and treatment remains problematic. In recognition of this fact, and to consider options for improving advance care planning and end-of-life care in New Jersey, the Governor's Advisory Council on End-of-Life care was convened in September of 2016.

Problem Statement

End-of-life care in the United States and within New Jersey is strikingly variable and often misaligned with a patient's preference and wishes. Although a majority of patients report a desire to spend the last part of their lives at home, in reality much of this time is spent in a hospital or nursing home setting. In 2015, 31 percent of deaths occurred in a hospital, 25 percent in a nursing home, 6 percent in a hospice facility and only 30 percent at home. The percentage of deaths occurring at home statewide has increased slightly in the last ten years (from 28 percent in 2002) while the percentage of deaths occurring in a hospital decreased slightly (from 34 percent in 2002)⁷. However, more work must be done to increase the number of people in New Jersey who spend the end of their lives receiving the type of care that they wish in the setting they prefer.

Additionally, family members and friends of patients at the end-of-life report that the care they receive is not always consistent with patient wishes and in many circumstances, is associated with unwanted aggressive treatment. In fact, New Jersey patients received more aggressive care than any other state, ranking first in order of magnitude on resource consumption.⁸

7. New Jersey Death Certificate Database, New Jersey Department of Health.

8. Dartmouth Atlas of Health Care, Available at: <http://www.dartmouthatlas.org>.

Aging in the Nation and New Jersey

People in the United States are living longer than ever before – According to a 2016 report by U.S. News and World Report, an estimated 72 million, or one in five Americans, will be at least age 65 or older and most people with a serious illness will be in this age group.⁹ The percentage of the population age 65 or older is steadily increasing. Among the total population this group represented 13 percent in 2010 and is projected to reach 20 percent by 2050.¹⁰ According to the U.S. Census Bureau, there were an estimated 19.2 million Americans age 75 or older in 2012, accounting for approximately 6.1 percent of the total population.¹¹ This figure is projected to reach 23.2 million (6.9 percent) by the year 2020, and 34.2 million (9.5 percent) by 2030.¹² Driven largely by the aging baby boomer generation, this trend is not expected to slow until at least 2035.¹³

9. U.S. News Report: Aging in America, (2017). Available at: <https://www.usnews.com/topics/series/aging-in-america>.

10. Projections of the Size and Composition of the U.S. Population: 2014 to 2050 (2015), Available at: <https://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf>.

11. Ibid.

12. Ibid.

13. Ibid.

New Jersey ranks 9th in the nation in the number of seniors age 65 or older. It is the nation's most densely populated state (at 1,218 persons per square mile) and one of the most ethnically diverse states in the nation with more than one in four persons speaking a language other than English at home.¹⁴ According to the U.S. Census Bureau's 2015 American Community Survey, 56.2 percent of the population of New Jersey was white, 19.7 percent was Hispanic, 12.7 percent was African American, 9.5 percent was Asian, 0.1 percent was American Indian/Alaska Native, and 1.5 percent reported two or more races.¹⁵ New Jersey's racial and ethnic mix continues to evolve, while the white population is projected to decline by the year 2025 to about 55 percent of the total population.¹⁶ African Americans, who now compromise about 15 percent of the population are expected to increase their relative proportion of the population to near 20 percent by 2025.¹⁷ By 2025 Hispanics, will become the largest minority group, with an estimated increase to just under 20 percent of the total population (compared to the approximate 11 percent estimated in 2010).¹⁸

Senior citizens are expected to make up 20 percent of our state's population by the year 2030. From 2000-2010, the percentage of New Jersey residents age 60 and older grew by 15 percent.¹⁹ This age group represented 19 percent of the state's population in 2010 and by 2030, this figure is expected to rise to 2.5 million.²⁰ The largest population growth was among the youngest in this cohort, age 60-64 years, at 45.3 percent, and the oldest in this senior cohort, age 85 and over, at 32 percent.²¹

14. New Jersey Department of Health. New Jersey State Health Assessment Data, (2018). Available at: <https://www26.state.nj.us/doh-shad/home/Welcome.html>.

15. U.S. Census Bureau; 2016 American Community Survey, American Fact Finder, Available at: <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

16. New Jersey State Health Assessment Data, (2017). Available at: <https://www26.state.nj.us/doh-shad/home/Welcome.html>.

17. Ibid.

18. Ibid.

19. New Jersey State Strategic Plan on Aging, (2013-2017). Available at:

<http://www.nj.gov/humanservices/news/reports/2013%20State%20Plan%20Final%20for%20Web%20Posting%2012.4.13.pdf>

20. Ibid.

21. Ibid.

Today, medical advances and technological changes such as telemedicine have contributed to persons living longer and enjoying healthier lifestyles. However, with increasing life expectancy, individuals are more likely to be living with serious health conditions such as heart disease, diabetes, stroke, cancer, chronic lung disease, dementia and others. Over half (51.7 percent) of all Americans have at least one chronic health condition. The Centers for Disease Control and Prevention estimates that chronic diseases are responsible for about 70 percent of all deaths nationally and lead to disabilities for nearly 10 percent of Americans.²² The ten leading causes of death in New Jersey, as in the U.S., have been the same for many years, however, in 2015 unintentional injury deaths, primarily those due to opioids, caused unintentional injury to become the fourth leading cause of death.²³ In 2015, heart disease, cancer, stroke and diabetes resulted in 59 percent of deaths in New Jersey. For older adults in New Jersey, the next leading causes of death are cancer, heart disease, stroke, and diabetes.²⁴

According to the Centers for Disease Control and Prevention, eighty-six percent of the nation's \$2.7 trillion annual healthcare expenditures are for persons with chronic and mental health conditions.²⁵ Experts estimate that chronic conditions account for about 86 percent of healthcare spending in the U.S.²⁶ It is not surprising then that chronic diseases remain a leading cause of death among older adults. Although older adults are a diverse group, what they have in common is the high likelihood that they will require extensive care and may appear repeatedly in the emergency department. These repeated visits often result in advanced life-saving emergency treatment without consideration to patient wishes and concerns. This is especially true in New Jersey and the potential to over treat is more evident in New Jersey acute care facilities than in any other state.

22. The National Center for Chronic Disease Prevention and Health Promotion, (2016). Available at:

<https://www.cdc.gov/chronicdisease/resources/publications/aag/NCCDPHP.htm>.

23. New Jersey State Health Assessment Data, (2017). Available at: <https://www26.state.nj.us/doh-shad/home/Welcome.html>.

24. Ibid.

25. Centers for Disease Control and Prevention: Chronic Diseases, (2015). The Leading Causes of Death and Disability in the United States, Available at: <https://www.cdc.gov/chronicdisease/overview/index.htm>.

26. Multiple Chronic Conditions Chartbook, (2014). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5798200/>.

End-of-Life Care in New Jersey is Different

The Dartmouth Atlas Project provides clear evidence that supports the conclusion that end-of-life care in New Jersey is both quantitatively and qualitatively different compared to other states. For more than 20 years, the Dartmouth Atlas Project has documented significant variations in medical practices, resource consumption and spending across the nation. The Dartmouth Atlas Project uses Medicare data to provide comprehensive information and analysis about national, regional, and local markets, as well as individual hospitals and their affiliated physicians. The results are often stark. The Dartmouth Atlas Project revealed that in New Jersey patients experienced more aggressive care at the end-of-life without evidence to suggest a corresponding medical benefit.²⁷ In fact, across many measures New Jersey patients received more aggressive care compared to any other state, ranking first in order of magnitude on resource consumption, often by large margins. In the table below, the measures in which the care in New Jersey exceeds the cost or intensity of all other states is summarized. It is important to note, however, that the Dartmouth Atlas Project does not measure the medical outcomes of care, but only measures the resources that are consumed.²⁸ One might debate that New Jerseyans receive better care and have better outcomes because of more aggressive practice patterns, but there is no evidence to support this proposition.

27. The Dartmouth Atlas of Health Care, Available at: <http://www.dartmouthatlas.org>.

28. Centers for Disease Control and Prevention: Chronic Diseases, (2015). The Leading Causes of Death and Disability in the United States, Available at: <https://www.cdc.gov/chronicdisease/overview/index.htm>.

28. Multiple Chronic Conditions Chartbook, (2014). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5798200/>.

28. The Dartmouth Atlas of Health Care, Available at: <http://www.dartmouthatlas.org>.

Medicare beneficiaries nearing end-of-life in New Jersey consume more resources than any other state in the nation. Below is a summary for which New Jersey's resource consumption ranked number one nationwide:

- Total Medicare reimbursements per enrollee during the last two years of life
- Total Medicare reimbursements made during the last six months of life
- Inpatient reimbursements per decedent during the last two years of life
- Inpatient reimbursements per decedent during the last six months of life
- Outpatient reimbursement per decedent during the last two years of life
- Average co-payments per decedent for physician services during the last two years of life
- Total full-time equivalent (FTE) primary care physician labor inputs per 1,000 decedents during the last two years of life
- Total FTE medical specialist labor inputs per 1,000 decedents during the last two years of life
- Hospital days per decedent during the last two years of life
- Total intensive care unit days per decedent during the last two years of life
- High-Intensity intensive care unit/critical care unit days per decedent during the last two years of life
- Total physician visits per decedent during last two years of life
- Medical specialist visits per decedent during the last two years of life
- Primary care physician visits per decedent during the last two years of life
- Percent of decedents seeing 10 or more different physicians during the last six months of life
- Number of different physicians seen per decedent during the last six months of life.²⁹

29. The Dartmouth Atlas of Healthcare, (2003-2017). Available at: <http://www.dartmouthatlas.org>

III. Purpose of the Council

The New Jersey Governor's Advisory Council on End-of-Life Care, (Council) created by Public Act 2011, Chapter 113, was mandated to advise the Governor on policy issues related to end-of-life care in New Jersey; to identify best practices and programs; formulate and recommend strategies for disseminating information to the public; and to develop goals and benchmarks to improve patient access and providing high-quality, cost-effective palliative and end-of-life care. This Act, signed into law by former Governor Chris Christie on August 18, 2011 was sponsored by Senators Ruiz, Weinberg, Grace, Vitale, Cunningham, Van Drew, Gordon, Beach, Stack and former Senator Beck. The Act will expire upon the submission of this report to the Governor and the Legislature.³⁰

Specifically, the legislative charge of the Council is to:

1. Identify existing practices and programs in this State that have demonstrated measurable success in providing patient access to, and choice of, high-quality, cost-effective palliative care and end-of-life care services and ways to promote the expansion and dissemination of those practices and programs;
2. Identify an effective mechanism for disseminating information to the general public, on as widespread a basis as is practicable, to assist patients and their families in making informed healthcare decisions about palliative care and end-of-life care; and
3. Develop goals and benchmarks for efforts which may be undertaken by the Department of Health or other relevant entities acting singly or in collaboration with each other, to accomplish the purposes: providing patient access to, and choice of, high-quality, cost-effective palliative care and end-of-life care services; and assisting patients and their families in making informed healthcare decisions about such care.

30. A copy of the Executive Order is attached hereto as Appendix A.

IV. Barriers Surrounding Palliative and End-of-Life Care

Although New Jersey has made significant strides in creating a framework for end-of-life care, several barriers and challenges remain. Following are summaries of identified barriers and future challenges in our state.

Barrier # 1: Shortage of Palliative and End-of-Life Care Services

To care for an aging population, our healthcare workforce must be equipped with the skills to deliver end-of-life care to a broad diversity of New Jersey residents. Currently, students graduating from medical, nursing and other allied health professional schools have very little, if any, training in the core concepts of advance care planning and the communication skills, cultural competency, and end-of-life care nuances necessary to provide patient centered care at end-of-life. As a result, there is a growing gap between the number of seriously ill patients and the number of healthcare professionals with the knowledge and skills to care for them. This lack of capacity impacts the care of the seriously ill patients in New Jersey, especially for individuals over the age of 65 who would benefit from palliative care. The growing demand for palliative care far outpaces the capacity in New Jersey. Palliative care specialists are in short supply, and certification programs are limited. There are currently only two accredited palliative care fellowship programs in New Jersey due in large part to a lack of reliable funding sources. While knowledge is growing about palliative care, practitioners struggle with the coordination of patient care due to the increased need for an interdisciplinary team approach. This coordination can be difficult, especially after a patient is discharged from a hospital to their home. Patients, their caregivers and often family members are left trying to manage and finance increasingly complex care at home.

Barrier # 2: Lack of Communication and Conversations

Communication between practitioners and patients with advanced illness is often stressed, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst. Although practitioners have access to numerous resources on how to facilitate difficult discussions, actual training to develop effective communication skills is still lacking in most medical and nursing curricula. Consequently, many practitioners struggle with advance care planning and end-of-life care discussions, and shy away from delivering bad news or having honest conversations with patients near the end-of-life.

Barrier # 3: Lack of Culturally Competent End-of-Life Care

Race and ethnicity are associated with differences in end-of-life care preferences and quality of care. While diverse individuals and groups have differing attitudes, values, expectations, beliefs and communication styles toward end-of-life care, ethnicity alone does not predict the type of end-of-life care that people prefer. Many individuals assume that minority patients more often want intensive interventions and life-prolonging treatment in the face of advanced serious illness. In fact, minority patients have been reported as having a higher willingness to exhaust personal financial resources on medical care to extend life.

Cultural differences also present challenges to healthcare practitioners. A lack of open and culturally sensitive discussions between patients and practitioners can have significant consequences for patients, possibly meaning the difference between choosing aggressive life support and a more natural death. A healthcare practitioner's culture, religion, and ethnicity also play an active role in a decision to explain palliative and end-of-life care to patients. Studies suggest that when practitioners and patients differ in culture, religious beliefs, and ethnicity, the practitioner is less likely to engage or explain palliative and end-of-life care.³¹ Nevertheless, practitioners have an obligation to engage in culturally competent care.

31. No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients, (2015). Available at: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0122321>.

Other Barriers to End-of-Life Care

A review of the literature reveals other barriers and includes:

- A perceived lack of time among primary care practitioners to discuss planning for the last stages of life with patients and families.
- A lack of support services to help patients and caregivers at home, or to help them manage chronic illnesses at home. It is challenging to obtain reliable home care services, even though these services are critical during the last stages of life.
- Perceptions of medicine as only having a role in saving and extending lives rather than helping people prepare and cope with physical decline, and the eventual need for end-of-life care.
- Older adults, particularly those who are alone and faced with physical decline, find it difficult to navigate the healthcare system during the last stages of life.
- Palliative care services remain largely based in hospitals, and are hard to access in the outpatient setting.
- A lack of funding and reimbursement for end-of-life care options, late referrals to hospice services, poor understanding of the benefits of palliative care during treatment for serious illness, and the influence of advancing healthcare technologies that increase the difficulty of decision making.³²

In 2016 the John A. Hartford Foundation, Cambia Health Foundation, and the California Healthcare Foundation conducted a national survey among primary care physicians and specialists who regularly see patients 65 years and older.³³ Of more than 760 physicians surveyed 99 percent agreed that end-of-life care counseling was of value and 95 percent indicated that they would likely have such conversations, if reimbursed by Medicare. One of the most striking findings from the survey was that only 14 percent of those initiated such a conversation with a patient and billed Medicare for it.³⁴

32. Institute of Medicine, (2015). "Dying in America, Improving quality and honoring individual preferences near the end of life." Washington, DC.: The National Academies Press. DC.

33. The John A. Hartford Foundation, (2016). "Talking with Patients about End-of-Life Care: New Poll Reveals How Physicians Really Feel." Available at:
<https://www.johnhartford.org/blog/view/talking-with-patients-about-end-of-life-care-new-poll-reveals-how-physician#>.

34. Ibid.

Lack of Public Awareness

In New Jersey, people care and think about end-of-life care, but many remain unaware of what opportunities and resources are available. This lack of awareness contributes to poor utilization and is best evidenced from a 2016 statewide poll of 886 adults on end-of-life care in New Jersey which found the following:

- Only three out of 10 New Jersey adult residents who are 65 years and older are aware of Advance Directives “Five Wishes” or POLST.
- 33 percent of New Jersey residents have not had conversations about advanced care planning and 6 in 10 have not put their wishes in writing. And while most residents (78 percent) are familiar with hospice care, approximately 50 percent are unaware of the New Jersey’s state law on advance directives. Fewer recognize and understand the importance and benefits of palliative care for advanced illnesses even when not at end-of-life.³⁵

35. New Jersey Health Care Quality Institute and Rutgers Eagleton Center for Public Interest Polling “Health Matters Poll: End-of-Life Care in New Jersey.” Available at: <http://eagletonpoll.rutgers.edu/rutgers.edu/rutgers-eagleton-nj-health-care-quality-institute-endof-life-apr2016>.

V. Recommendations of the Council

The following recommendations are the result of many Council meetings, guest speakers, stakeholder discussions and responses to public survey on end-of-life care. During the last several months the Council met to discuss end-of-life issues, especially as it relates to New Jersey healthcare facilities and residents. The Council was comprised of healthcare practitioners, policymakers, legislators, religious leaders, advocacy groups, bioethics consultants, palliative care leaders and others with expertise in end-of-life care. It had been meeting to: 1) understand issues on palliative and end-of-life care, 2) identify and review relevant recommendations on end-of-life care, and to 3) prioritize the recommendations relevant to the Council's legislative charge.

Implementation of the recommendations will require patience, understanding, political leadership and an openness to new ideas from stakeholders who can further the work and activities of the Council. Further research and increased understanding of how medical advances and new practices such as telehealth may shape and affect the needs and well-being of dying patients and their families are also required.

The work of this Council is not finished, even though its legislative authorization to operate expired upon the issuance of this report. The importance of end-of-life care as a public health policy issue and the severe limitations on time and resources faced by this Council require the need for a continuing and enhanced effort to improve end-of-life care, to monitor implementation of the recommendations presented in this report, and to develop further policy recommendations over time.

The number one recommendation of the Council is the designation of an entity (Coalition or Workgroup) to coordinate all future efforts in our state related to palliative and end-of-life care in New Jersey. Specifically, the Council recommends that funding be made available to this entity to ensure appropriate staffing and support. This allocation of resources would enable such an entity to operationalize the efforts of this Council and establish a robust organization dedicated to facilitating and sharing information related to the best end-of-life care in New Jersey.

Recommendation 1:

Create a statewide entity (e.g., Coalition or Workgroup) with broad stakeholder input and support to further the work, activities and implementation of the Council's recommendations. This entity should be responsible for:

- Implementation of the Council's recommendations; reporting on performance improvement activities and
- Recommending strategies for further improvement in this area, partnering with stakeholders to improve end-of-life care for all New Jersey residents, identifying best practices for advancing palliative care for those with serious illness and hospice for those who are nearing the end-of-life, including minimizing disparities in healthcare delivery, and furthering ongoing efforts of other groups such as the New Jersey Health Care Executive Leadership Academy (NJHELA).

Background:

Ever since the Dartmouth Atlas Study highlighted the obvious need for better end-of-life care and advance care planning in New Jersey, several organizations have taken on the challenge to effectuate positive change in this area. Bringing such individual efforts together into a broader, credible, committed, and an influential entity should effectuate change on an ongoing and greater level. Examples of successful entities already exist in other states (e.g., Coalition for Compassionate Care of California, Massachusetts Coalition for Serious Illness Care). Such an entity in New Jersey could serve to further the Council's goals and recommendations for end-of-life care improvement. The Council recommends that this entity should be independent and include, but not be limited to, members from the following organizations and areas:

New Jersey Department of Health
New Jersey Department of Human Services
New Jersey Hospital Association (sponsor of NJHELA Program)
Medical Society of New Jersey (sponsor of NJHELA Program)
New Jersey Association of Health Plans (sponsor of NJHELA Program)
American Association of Retired Persons (Local Chapter)

*Home Care and Hospice Association of New Jersey
New Jersey Palliative Advance Practice Nurse Consortium
New Jersey Health Care Quality Institute
New Jersey Chapter of American Association of Retired Persons
New Jersey Association of Mental Health and Addiction Agencies
Faith-based organizations
Payers
Consumer groups
Entities representing and advocating for persons with Intellectual and Developmental Disabilities and other non-profit entities that are dedicated to improving end-of-life care in New Jersey.*

Recommendation 2:

Ensure a mechanism to examine any legislative, regulatory, or other policy changes necessary to implement the Council's recommendations. The entity (e.g., Coalition or Workgroup) referenced in Recommendation #1 or other such entity would be well positioned to assume this role.

Background:

Coupled with a growing awareness and technological advances surrounding palliative care, New Jersey can benefit from laws and policies that contain provisions aimed at improving advance care planning, palliative care, hospice care and end-of-life care. Several states have introduced and passed legislation and regulations aimed at improving advance care planning and end-of-life care through the establishment of a statewide entity.

Recommendation 3:

Work with the various medical specialty organizations (American College of Cardiology, American Society for Clinical Oncology, American Academy of Pediatrics etc.) to develop robust training programs for professionals as well as specific educational tools to best inform patients and the public on issues that must be discussed in preparation for end-of-life decisions.

Background:

The need for palliative and end-of-life care is increasing due to continuing demands, technological changes and complexity of the healthcare system. It is necessary to work with the various medical specialty organizations (e.g., oncologists, pediatricians & others) in New Jersey to develop robust training programs and educational tools for healthcare professionals. Changing how physicians, nurses, and other healthcare professionals are educated and trained in palliative and end-of-life care will help advance the care of persons with advanced serious illnesses and meet the growing needs of New Jersey's aging population.

Physicians and healthcare professionals across all disciplines and specialties who care for persons with advanced serious illnesses should be competent in palliative care – notably communication skills (e.g., ability to engage in “difficult conversations”) and interdisciplinary collaboration. The development of specialty educational tools is necessary to help providers inform patients and the public on making decisions surrounding advance care planning and end-of-life care.

Recommendation 4:

Develop and require education on end-of-life care options and planning for all licensed physicians, nursing professionals, nursing students, medical residents, medical students, social workers, mental health/addiction counselors, chaplains, administrators and managers who work in hospitals, emergency medical services, nursing homes, long term care, assisted living, and hospice facility staff to increase their knowledge of the applicability on palliative care for patients with advanced serious illnesses.

Background:

Communicating with patients/families about advance care planning and end-of-life care can be an intimidating task, particularly for providers with minimal training. Although effective communication with patients and family members is recognized as a core component of quality end-of-life care, recent research reveals deficits in patient and family-provider communication. Delivering bad news, discussing death and dying, making related healthcare decisions, identifying goals of care and managing diverse cultural perspectives present challenges to improving end-of-life care. Most health professionals have had little or no training in working with patients and families at the end of their life, and may lack the skills to effectively communicate and respect a patient's wishes. The timing of when this conversation occurs is often vital to determining if a patient needs palliative and hospice services at the appropriate time. For example, there are many times when a long-term care resident could have been receiving beneficial hospice services but did not. The physician or long-term care provider may not have realized that the person was eligible to receive these services.

It is important for all providers (including physicians, nurses, social workers, psychologists, mental health/addiction counselors, clergy and others) to be competent in at least the basic skills of discussing palliative care as well as symptom management. This requires that medical schools, teaching hospitals and continuing educational programs include palliative care training directly in the curriculum at the various stages of the learning process.

The medical school curriculum in New Jersey is inadequate as it pertains to end-of-life care education and does not consistently include didactic and clinical experiences where students observe role-modeling of competent and compassionate palliative care

providers. Similarly, palliative and end-of-life care curricula should be incorporated within nursing, social work and other disciplines. Since professional schools are accredited by outside agencies, state legislation may be required as it relates to state funding.

The New Jersey State Board of Medical Examiners currently requires 100 hours of continuing medical education every two years, of which at least 2 Category 1 Credits must relate to end-of-life care. This mandatory licensure requirement should be continued to ensure physician knowledge, skills and competency in palliative and end-of-life care.

Recommendation 5:

Identify opportunities and funding for further development of Palliative Care Fellowship Programs in New Jersey for physicians, psychiatrists, and advanced practice nurses and educational programs for other healthcare professionals such as registered professional nurses, physician assistants, social workers, mental health and addiction professionals, behavioral health professionals, chaplains and others.

Background:

Currently, there are only two one-year palliative care fellowships in New Jersey. One accredited fellowship is at Cooper Medical School of Rowan University. This fellowship, accredited by the Accreditation Council for Graduate Medical Education (ACGME) is approved for one position. Eligible applicants must have completed a residency in either anesthesiology, emergency medicine, family medicine, internal medicine, neurology, obstetrics/gynecology, pediatrics, physical medicine and rehabilitation, psychiatry, radiation oncology, or surgery. The other program approved by the American Osteopathic Association is housed at the Rowan University School of Osteopathic Medicine. Currently, this program is working on transitioning to an ACGME program and is funded for only one position.

Due to the shortage of Palliative Care Fellowship Programs in New Jersey, there is a growing need and opportunity for improvement in end-of-life care. Multidisciplinary palliative care teams are needed in both the inpatient and outpatient settings. In addition, New Jersey legislators should work collaboratively with Congress to help fund this important need. Examples of such public advocacy could include a carve out from the Centers for Medicare & Medicaid Services graduate medical education funding cap for Palliative Care and Geriatric Medicine fellowships (similar to current Podiatry and

Dental Residencies). State designated graduate medical education payments could also target institutions looking to create Palliative Care Fellowship Programs. Legislative support for the Palliative Care and Hospice Education and Training Act (PCHETA) and the Patient Choice & Quality Care Act of 2017 would also facilitate this effort.

- Encourage academic medical centers to establish Departments of Palliative Care (or Sections of Palliative Care within other relevant departments). This would advance the educational goals and clinical practice in end-of-life care.

Traditional medical education focuses on providing physicians with the skills to diagnose and treat illness. Optimal end-of-life care requires a physician to be able to diagnose, prognosticate, establish goals of care with the patient based on the prognosis, and then provide treatment to best respect and effectuate the mutually agreed upon goals of care. Although all physicians, especially primary care physicians, should have the skills to do this, medicine has become more technological and specialized since the 1950's. Care has also become more fragmented, especially with transitions between the outpatient and inpatient settings. As such, there is a need for physicians specializing in palliative care to effectively communicate with patients and their families on advance care planning, end-of-life care and informed consent discussions.

Recommendation 6:

Require education on advance care planning and end-of-life care in hospitals, assisted living facilities, long-term care facilities, skilled nurse facilities, dementia care facilities and others. Education should be a facility licensure requirement since these facilities are licensed by the New Jersey Department of Health.

Specifically:

- Annual education on advance care planning, end-of-life care and POLST should be required for administrative and clinical staff at these facilities.
- Educational courses should be approved by the New Jersey Department of Health or an entity designated by the Department of Health.
- The Department of Health should require that assisted living and long-term care facilities make available education to its residents and their families on POLST, advance directives, and the benefits of hospice and palliative care and
- Long-term care, assisted living facilities and dementia homes should establish and implement policies to better identify and address end-of-life issues upon admission.

Background:

With few exceptions, independent, assisted living and long-term care facilities do not require that staff receive training and education on advance care planning and end-of-life care options. Those employed are not provided with formal training and do not necessarily understand the advance care planning process in its entirety or the purpose of an advance directive and POLST.

Most staff at these facilities would be unable to identify the components involved in advance care planning or effectively conduct a meaningful conversation about goals of care and end-of-life preferences. Fortunately, a few facilities have specialized programs (e.g., United Health) that utilize an advanced practice nurse with specific skills in this arena. These programs, however, are the exception rather than the rule. About 70 to 80 percent of the population with dementia die in nursing homes, yet the skill level of the staff is often inadequate in meeting the needs of residents and family members in skillfully addressing end-of-life questions. This situation may lead to unnecessary hospital transfers, aggressive life-sustaining treatments, and underutilization of hospice and palliative care services.

Recommendation 7:

Advocate that the New Jersey Supreme Court institute a requirement for attorneys who practice Elder Law, Wills, and Estate Planning, and Health Care Law for continuing legal education that addresses the core elements of advance care planning (Living Wills and Health Care Representative Designations). These attorneys routinely advise clients and draft legal documents meant to direct end-of-life care when patients can no longer speak for themselves. Education should include information on hospice, palliative care, POLST, advance directives as well as the importance of careful articulation of individual values, conveying one's unique quality of life measures, and identifying trusted surrogate decision makers.

Background:

The medical profession has routinely encountered poorly drafted, vague, confusing, and sometimes contradictory language in advance directives. This creates an educational opportunity for collaboration between the medical and legal professions in New Jersey. The courts, legislature, and the New Jersey Bar Association should come together to consider an effective, pragmatic educational requirement for relevant (practicing) attorneys in this area. In addition, the development/identification or adaptation of a Professional Guide for Attorneys to Better Understand End-of-Life Issues and Options, would be invaluable.

Recommendation 8:

Develop standardized educational modules for the training of physicians, advanced practice nurses, emergency personnel and other healthcare professionals that incorporate into the curriculum the implementation of POLST and advance directives in all healthcare settings.

Background:

There is a need to provide standardized educational modules for training physicians, advanced practice nurses, physician assistants, emergency personnel and other healthcare professionals. Although the education of healthcare professionals has improved in the past decade, serious problems remain. Most importantly, this improved

knowledge base has not necessarily been transferred to healthcare professionals caring for people with a serious illness or nearing end-of-life.

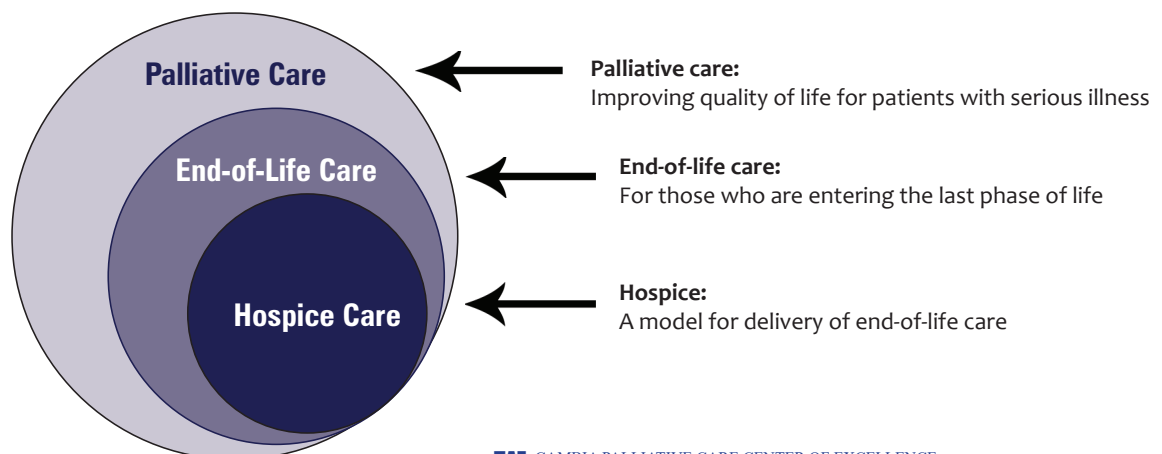
Recommendation 9:

Define the terms that are used frequently to describe palliative care, hospice, advance care planning and end-of-life care.

Background:

Discussions about end-of-life issues can be difficult for many reasons including: 1) dying and death are not openly discussed in many cultures, 2) rapid changes in medical technology and 3) dying and death are rooted in cultural norms, individual beliefs and behaviors that have precluded a universal vocabulary. Fourth, issues of life and death are deeply personal and expecting persons to understand or have meaningful conversations about end-of-life care issues presumes a common vocabulary. National surveys, however, reveal that people do not understand what palliative care is or what role it plays before or near the end of life. Even some physicians and healthcare professionals mistakenly confuse palliative care (care oriented toward quality of life for persons with serious advanced illnesses) with hospice (a model for delivering palliative care for people in their last months of life).

It is important to distinguish between palliative, hospice and end-of-life care. While interrelated as illustrated, in the graphic below, a clear understanding of these terms will help better equip and assist healthcare professionals when discussing these options in a timely fashion with patients.



Specifically, the model illustrates the integration of palliative, end-of-life and hospice care. Palliative care may begin at any stage during the life cycle because it recognizes that young children and adults with a serious or terminal illness may benefit from receiving palliative care. Although the needs of pediatric patients and their families differ in many ways from adults, the delivery of end-of-life care remains the same throughout the life cycle. Using this model, patients will have access to care while receiving life prolonging treatments until those treatments are no longer beneficial.

Recommendation 10:

Integrate palliative care services in the Emergency Department (ED). Adopt a brief standardized screening tool for use by ED providers, nurses, advanced practice nurses and physician assistants, to rapidly identify patients who need palliative care and/or a referral, including those that present with intellectual and/or developmental disabilities and behavioral health issues.

Background:

Patients with advanced illness and end-stage disease often present to the ED for acute symptom management and pain relief. Once in the ED, the care received may not be consistent with the patient's previously determined goals of care and preferences. Upon presentation, ED physicians have a unique opportunity to introduce palliative care to: 1) improve a patient's quality of life, 2) reduce repeated ED visits, 3) decrease length of stay, 4) control costs and 5) improve patient and family satisfaction.

Three quarters of older adults will visit the ED in the last six months of their lives. Many of these individuals are admitted and eventually die in the hospital. For those not admitted, the ED may signal a turning point in their illness, predicting more rapid disease progression and an increase in the use of acute care. Although palliative care has been shown to improve quality of life by decreasing depression, alleviating pain and anxiety, increasing patient and caregiver satisfaction, lowering the number of hospital admissions and readmissions, and lowering intensive care unit utilization rates and overall costs, these services are often not integrated into routine ED practice.

However, ED physicians often face barriers to integrating palliative care including time constraints in a busy ED, lack of a complete medical history, and the absence of evidence-based outcomes to identify patients who may benefit from an immediate palliative care consultation. In one study, a panel of palliative care experts was convened

to develop a content-validated screening tool for patients needing palliative care in the ED. This tool, taking less than two minutes to complete, combined a physician's overall assessment and validated a prognostic question, "Would you be surprised if this patient died in the next 12 months?" This simple approach proved to be valuable to patients and family members by decreasing the use of inappropriate treatments, reducing unnecessary admissions and controlling costs.

Recommendation 11:

Develop and adopt effective, user friendly on-line decision-making tools that may be used routinely for all adult patients with and without decision making capacity (whatever their medical status) to create a robust, electronically generated record of their values, beliefs, and preferences for goals of care as well as medical care throughout the continuum of care.

- Once developed, provide an effective mechanism for disseminating decision-making tools as well as informative materials and resources on palliative care, hospice and end-of-life care to families, caregivers and designated surrogate decision makers.

Background:

To improve end-of-life care in New Jersey, we must engage and integrate "conversations" and use on-line decision making tools to expand the knowledge and use of palliative care and end-of-life care planning efforts. Effective conversations and the use of on-line decision making tools will help advance care planning and ensure that the goals of care and treatment preferences of seriously ill persons are considered and met with respect.

Innovative tools are available and should contain a wide variety of methodologies to reach diverse (including underserved, minority, and rural) communities. It is important to identify effective decision making tools which may be distributed electronically (or by hard copy) to healthy individuals, seriously ill persons, and those facing terminal illness, especially as they consider the care choices they face now or in the future and as their medical condition may change. In a recently published study in the Journal of the American Medical Association, researchers determined that the use of an interactive web-based advance care planning tool plus a user-friendly advance directive significantly increased advance care planning, documentation of this process, and important patient

engagement without unwanted clinician interventions. These tools/aides should be completed by individuals to 1) record current goals of care, 2) indicate feelings about benefits/burdens of life-sustaining treatments, 3) explain how much risk they are willing to accept under what conditions and 4) consider the trade-offs to determine what constitutes remaining quality of life for them. The data gathered from this process can be integrated into documents such as advance directives and POLST order form, when appropriate.

Recommendation 12:

Require and implement a standard tool for hospitals, skilled nursing facilities, long-term care facilities and assisted living facilities that assures the patient/personhood assessments meet the professionally recognized standards of care and outcomes of care are recorded in the medical record and patient's treatment plan. The development and use of a screening assessment tool will assure that the scope of the assessment is appropriate and fully integrated in the care and treatment of a patient.

Background:

The specialty of palliative care is guided by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care. When utilizing palliative screenings or assessments it is essential to use the eight domains of palliative care as a quality guideline. This ensures best practice and encourages implementation of evidence based processes in hospitals, skilled nursing facilities, long-term care facilities, and assisted living facilities settings. There are palliative care screening tools used to identify which patients would benefit the most from an intervention. This institutional screening process, referred to as domain one, can assist with differentiating primary palliative needs from the specialty palliative needs a person may have.

Patients should be assessed and screened with clinical personhood (referred to in domains two through six) in mind. Underlying psychosocial or existential distress can be historic in nature, originating prior to illness, or be cumulative during the illness trajectory and can increase suffering of patients.

Recommendation 13:

Hospitals, skilled nursing facilities, long term care and assisted living facilities should establish and implement policies to address palliative care and end-of-life issues for patients upon admission.

Background

Healthcare facilities are required by statute to have an admission process in which they ask about the existence of an advance directive. Since this is often perceived as an uncomfortable issue, staff at these facilities often view this as a necessary legal requirement as opposed to a user-friendly process. Nursing homes typically ask about dietary needs, preferred roommates (if there is to be one), and other adult daily living activities, but rarely engage in conversations about advance care planning to ensure a resident's healthcare preferences are known and respected. There is no practical requirement in long-term care facilities that mandates a periodic review when a resident's medical status (physical) changes and their condition deteriorates (i.e., there is usually no documentation of the person's evolving goals of care and priorities). Developing a uniform, standardized advance care planning process would be invaluable to patients/residents and their family members.

Recommendation 14:

Develop, promote, monitor and evaluate a statewide electronic registry for POLST and advance directives that are transportable and recognized in all healthcare settings (hospitals, assisted living facilities, long term care facilities, emergency medical services and ambulatory care settings).

Background:

On December 21, 2011, former New Jersey Governor Christie signed into law the Practitioner Orders for Life-Sustaining Treatment Act ("POLST Act"). The POLST Act is designed to provide a mechanism for patients who: 1) have advanced chronic progressive illness, 2) a life expectancy of less than five years; or 3) who otherwise wish to further define their preferences on life-sustaining treatment or other medical interventions.

Responsibility for the development of POLST was delegated to the New Jersey Hospital Association, a Patient Safety Organization recognized in New Jersey. This responsibility included the establishment of procedures for completion, execution, and implementation of POLST in healthcare facilities. The New Jersey Department of Health established a Memorandum of Agreement (April 1, 2017 through March 31, 2021) to designate the New Jersey Hospital Association (NJHA) as the Patient Safety Organization with the responsibility to carry out the imperatives of the POLST legislation. This designation allows the NJHA to house the POLST repository and carry out the implementation and utilization of the electronic POLST form. This is a new paradigm for eliciting and documenting patient wishes. Patient wishes start with open and detailed conversations between medical providers and their seriously ill patients about prognosis, treatment options, and the patient's personal preferences and wishes. These conversations result in a standard set of medical orders, signed by the patient and provider, indicating the types of life-sustaining treatment that the patient does and does not want. Printed on distinctive green paper, the POLST form travels with the patient throughout various healthcare settings.

POLST must be signed by a healthcare provider (physician or advanced practice nurse) and signed by the patient or surrogate decision-maker. It allows a patient to specify whether they want aggressive medical interventions such as cardiopulmonary resuscitation and whether their treatment should be focused on comfort measures, limited interventions, or full treatment. The POLST should be updated to reflect changes in a patient's preferences or medical condition.

The electronic POLST provides patients with an easy-to-use, secure way to upload the form to this repository and then gain access anytime, anywhere, through a smartphone or tablet. Healthcare providers can check the statewide repository of electronic POLST forms to ensure that every individual's needs and preferences are being honored, even if the individual is incapacitated or the paper form is not available. This gives healthcare providers a streamlined way of locating an individual's POLST, particularly when a patient is no longer able to make decisions.

There is an urgent need for the electronic POLST since a significant number of patients, for whom a POLST document was created, have received medically inappropriate and unwanted treatments due to the lack of a readily available POLST (e.g., not available in the Emergency Department at the time of contact). One study of emergency medical technicians found that POLST form availability changed treatment for 45 percent of patients when presented with the form.

It is widely known that conversations regarding end-of-life care planning are better conducted prior to a patient arriving at the Emergency Department. Documentation regarding goals of care that stem from such conversations are instrumental in ensuring proper transitions of care and respecting a patient's autonomy. Therefore, a POLST form should be made available across the continuum of care to emergency medical services, emergency department personnel and others. POLST is one vehicle to achieve this aim and should be used to evaluate the situation and improve patient outcomes.

Recommendation 15:

Provide support for the hospital pilot sites to begin building the statewide electronic registry (emPOLST) for creation, storage and access to POLST documentation as recommended by the National POLST Paradigm. Upon completion of the pilot, incentives for New Jersey hospitals, post-acute care facilities, medical practices, clinics and emergency medical service organizations should be provided to improve access and utilization of the registry.

Background:

Lack of reimbursement has served as a deterrent to physicians and other practitioners from spending time to engage patients and their families in palliative care and end-of-life discussions. Providing a reimbursement mechanism as a standard benefit would help incentivize providers to spend time having meaningful discussions and educating patients on their choices. There are healthcare payer systems that incentivize the completion of POLST forms and provide financial bonuses for institutions to do so.

Recommendation 16:

Initiate a public campaign to call attention to November's National Hospice and Palliative Care Awareness Month. Work with stakeholders to develop a public awareness campaign that promotes an understanding and proper use of the definitions of palliative care and hospice care that differentiates both programs and dispels the myths and misinformation associated with them. Promote the importance of having early conversations with loved ones about preferences and advance care planning to improve decision making about end-of-life care (e.g., expanding New Jersey's Conversation of Your Life Program).

Background:

A campaign is necessary to raise and promote public awareness surrounding advance care planning, hospice and end-of-life care.

Recommendation 17:

Change the New Jersey Mobile Intensive Care Paramedic enabling legislation and regulations to allow mobile intensive care paramedics to provide non-emergency home visits to patients with chronic and serious illnesses (such as heart failure, chronic obstructive pulmonary disease (COPD), cancer, Alzheimer's Dementia, advanced Parkinson's, and others) who need palliative care and do not qualify for home care or hospice services. This approach would allow patients to be monitored and treated for non-life-threatening symptoms in the comfort of their own home. Similarly, high risk patients who need close monitoring to prevent further decline of their healthcare condition could be managed at home, thus avoiding unnecessary and costly visits to the ED. Patients nearing the end-of-life want to remain in their homes where personalized care and comfort measures can be provided.

Background:

There have been several successful demonstration projects conducted in Canada and some U.S. States such as Massachusetts utilizing paramedic services to supplement home visits for patients who suffer from chronic illnesses and are at risk for frequent readmissions to the hospital. Paramedics have the knowledge, skills and training to

assess patients, start intravenous fluids, draw blood, administer intravenous medications, monitor and evaluate cardiac rhythms, manage respiratory treatments, and communicate with patients, families and a hospital-based physician (using telemetry) to reduce unwanted and unnecessary trips to the hospital. These advanced life support skills are routinely utilized by paramedics when caring for 911 emergency patients. New Jersey patients, their families and caregivers would benefit from expanding the role of paramedics to include home visits for the chronically ill who need frequent monitoring and close communication with their healthcare provider.

Recommendation 18:

The Department of Health should actively promote and require increased palliative care and end-of-life care training for Emergency Medical Service (EMS) providers in New Jersey through the Office of Emergency Medical Services by:

- A. Requiring end-of-life care education covering advance directives, out-of-hospital do not resuscitate (DNR) orders and POLST for EMS providers who are certified by the New Jersey Department of Health, Office of EMS. All providers should understand their role and responsibility in dealing with such patients and these critical documents.
- B. Requiring all non-certified EMS personnel who are affiliated with the EMS Council of NJ to be educated about advance directives, DNR orders and POLST documents and the role of EMS when encountering these patient documents.
- C. Exploring the incorporation of the POLST confidentiality statement into the EMS certification system along with the existing questions in preparation for the State POLST electronic registry (emPOLST).

Background:

Emergency Medical Services (EMS) in NJ include first responders, EMTs (Emergency Medical Technicians) and paramedics (advanced life support providers) who provide care when a person calls 911 for a medical emergency. EMS responders are the front lines of caring for those suffering from trauma, a serious illness, terminal illness or an acute medical condition. They are the first to arrive on the scene and provide the care in line with a patient's wishes and preferences for care. Many individuals already have documents such as an Advance Directive for Health Care, Do Not Resuscitate Orders and POLST. Because these documents may vary, every EMS responder needs to know and

understand their responsibilities when presented with these documents, designed by law to protect a patient's preferences and wishes for care. Education and training of EMS providers are critical to protect the rights of patients when faced with an emergency medical condition.

Recommendation 19:

Promote community-wide outreach and discussions on how to have conversations regarding personal goals of care and the type of care desired at the end-of-life with family members, friends, and healthcare providers. The importance of having an advance directive and the difference between POLST and an advanced directive are necessary components of this dialogue. Education on standardized approved definitions of palliative care, hospice, comfort care and other end-of-life terms are important aspects of such efforts. Coupled with promoting community-wide discussions, develop and disseminate culturally and linguistically sensitive information to increase awareness of advance care planning, advance directives and POLST.

One example to facilitate the expansion of a community-based initiative is the "Conversation of Your Life" program, under the Mayor's Wellness Campaign.

Background:

Ensuring that these life conversations are part of community group discussions earlier in life will go a long way to normalizing advance care planning and increasing the comfort levels of individuals when eventually confronted by a serious or terminal illness. The ability to have meaningful community-wide discussions, depends upon the training and skills of the facilitators. Facilitators can be spiritual leaders, community leaders, retired healthcare professionals, or other community members interested in offering this service. There are robust community programs across the state that offer culturally sensitive training to meet the needs of patient and family members. Many programs include community workshops and train advance care planning facilitators to meet the needs of diverse communities. These programs and workshops can include discussions on the following: 1) the importance of advance care planning, 2) choosing a durable power of attorney for health care, 3) communicating about end-of-life care and 4) how to complete a POLST form. New Jersey has the capability of expanding community training programs, which can be tailored to the needs of diverse communities in New Jersey. To achieve the goals of the above recommendation, the Council suggests the utilization of community leaders (mayors, business leaders,

librarians, clergy, teachers, healthcare professionals, media, faith-based organizations, community-based organizations, professional societies, governmental agencies, and others) to become the face of this public awareness campaign.

Recommendation 20:

Ensure that education about considerations of treatment and service options surrounding palliative care and end-of-life care are culturally and linguistically sensitive to diverse populations.

Background:

New Jersey is considerably more racially and ethnically diverse when compared to the rest of the country. Recognizing New Jersey's unique level of diversity, communicating information, options and services about advance care planning and end-of-life care within the cultural context of a patient and family members is of paramount importance. All educational resource materials should be, at a minimum, available in languages that reflect New Jersey's population.

Recommendation 21:

Develop a mechanism within hospital and community-based ethic committees to collaborate with state appointed guardians to facilitate timely complex healthcare decisions for patients with intellectual and/or developmental disabilities (I/DD):

- Develop an advance care planning process that addresses the preferences and wishes of I/DD persons who lack the ability to complete a legal advance directive.
- Promote the development of specialized I/DD hospital based healthcare advocates to assist with conflict resolution and assessment of a person's diagnosis, prognosis, risks and benefits of treatment, and wishes.
- Develop a procedure that is consistent with state statutes and regulation to enable I/DD patients to participate in advance care planning even if they are unable to complete an advance directive.

Background:

People with disabilities face many of the same issues at the end of life as people without disabilities and often have additional challenges. Today the life expectancy of a person with an I/DD is nearly the same as it would be for a typical age peer – this is the first generation of persons with significant disabilities outliving their parents and siblings. Healthcare advocates familiar with the philosophies, methodologies and models of supporting the rights of autonomy and self-determination through shared decision making are key. Frequently, healthcare professionals, including palliative care and hospice staff, lack training on the challenges and needs of people with intellectual disabilities as well as the methods to assess their decisional capacity.

Recommendation 22:

Develop processes across the entire continuum of healthcare, including hospitals, assisted living facilities, sub-acute and acute rehabilitation facilities, long-term care facilities, and primary care offices to verify or capture a patient/resident end-of-life wishes and a designated surrogate decision maker in the event the patient/resident loses decision making capacity. Such wishes and identification of surrogate decision makers should be documented, regularly reviewed and updated as needed, (i.e., clinical condition changes or surrogate decision makers no longer available) especially in assisted living and long-term care facilities. Patient/resident choice of surrogate decision makers needs to be respected including identified close friends, family members regardless of degree of the relationship, and individuals sharing non-traditional living arrangements and other relationships with the patient/resident. Use of the POLST forms should be considered when appropriate to document the goals of care and current surrogate decision makers.

Background:

A landmark study by the Institute of Medicine found that “most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.” Approximately 40 percent of adult medical inpatients, 44 to 69 percent of nursing home residents, and 70 percent of older adults facing treatment decisions are incapable of making those decisions themselves.” As the population ages, more adults will develop impaired decision-making capacity and have no one to represent them. It is not uncommon that certain patients/residents outlive their family, friends, and other initially-designated surrogate decision makers. It is thus of paramount importance that end-of-life wishes be made known to current and available surrogate decision makers before a patient/resident loses decision-making capacity and becomes socially isolated (aka unrepresented).

Recommendation 23:

Promote guardianship legislation to address the issue of socially isolated individuals (aka unrepresented individuals) and ensure end-of-life wishes and preferences for this population are respected in a timely manner. Legislation should include provisions for special circumstances to expedite the commencement and timely completion of special medical guardianships, temporary guardianships, emergency guardianships, and plenary guardianships. These procedures should include: 1) timely identification of patients in need of special advocacy, 2) timely coordination of obtaining medical evaluations and reports for guardianship applications, 3) timely follow up with court personnel for completion of guardianship proceedings and, 4) timely identification of safe and appropriate placement for patients upon discharge and to ensure patients are moved through the continuum of medical services to the most appropriate level of care as soon as medically appropriate. Judicial resources should be consistent and adequate across all counties to support these processes.

Background:

As the population ages, more adults will develop impaired decision-making capacity and have no one to represent them. Although, preventing this situation (as described in recommendation 22) is the best course, in many situations a professional guardian may need to be appointed by the courts. Patients often languish in inappropriate acute healthcare settings due to long delays in the guardianship process. Processes for emergent, routine, and end-of-life decision making need to be streamlined while also addressing the financial questions needed to move patients on to the next level of care.

Providers are well positioned to assist guardians with decision making while safeguarding the rights of these vulnerable patients. Moreover, increasingly older patients in need of assistance with end-of-life care decisions will be seen by providers who do not know them. In situations where patients become incapable of making decisions, guardianship becomes necessary to honor a patient's values, identify goals of care, and carry out treatment preferences.

Legislative reform to address guardianship issues surrounding the unrepresented and guardianship was introduced around the same time as the POLST legislation in 2012 and again in early 2018. A bill similar to the POLST legislation could serve as the starting point for discussion and a catalyst for change in this area. In addition, consideration should be

given to other legislative initiatives, as seen in other states, that have established non-judicial approaches to address the care needs of the socially isolated (unrepresented).

Recommendation 24:

Consider the establishment of a policy in New Jersey, similar to the initiative implemented in Washington State, regarding coding of drivers' licenses to identify the presence of an advance directive.

Background:

The State of Washington worked with its Motor Vehicle Department to add text on its drivers' licenses indicating the presence of an advance directive with the additional option of placing a "QR" code on the back of the license allowing direct access to the registry. When the "QR" code is scanned, users are directed to instructions on how to obtain a copy of the patient's advance directive and/or POLST form from the state registry. This approach would be one more way to ensure that an individual's end-of-life wishes, preferences and goals of care are honored in New Jersey.

Recommendation 25:

Look to organizations representing hospitals or the Entity (e.g., Coalition or Workgroup) referenced in recommendation one to develop model policies and pilot projects for New Jersey hospitals and make legislative recommendations to address the following:

Requests for potentially non-beneficial, harmful, or inappropriate medical treatments. Develop a model policy and/or suggest legislation that would provide guidance and support for physicians and hospitals in clinical decision making while providing emotional support for families in such situations. Such requests are often encountered in the intensive care unit setting and often involve questions regarding the efficacy and moral appropriateness of such treatments.

Background:

Conflict may arise when family members or other surrogate decision makers request medical interventions that are determined by providers to be medically non-beneficial and thus inappropriate for the patient. Patients gain little or no benefit from such treatment, and in many cases, suffer more harm. In addition, healthcare providers often experience significant moral and emotional distress when faced with situations such as when the requested care is not consistent with the prevailing standard of care, does not advance the patient's goals of care and their wishes for end-of-life care, or may be seen as inhumane. These high clinical intensity scenarios also often run counter to the bioethical principle of social justice. Other states have addressed this issue legislatively.

A statement published in the American Journal of Respiratory and Critical Care Medicine put forth guidance and recommendations for clinicians to prevent and manage treatment disputes in patients with an advanced serious illness. These recommendations include the following quote:

Institutions should implement strategies to prevent intractable treatment conflicts including proactive communication and early involvement of expert consultants. The term potentially inappropriate should be used, rather than futile, to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. Clinicians should explain and advocate for the treatment plan they believe is appropriate. Conflicts regarding potentially inappropriate treatments that remain intractable despite intensive communication and negotiation should be managed by a fair process of conflict resolution; this process should include hospital review, attempts to find a willing provider at another institution and opportunity for external review of decisions. When time pressures make it infeasible to complete all steps of the conflict resolution process and clinicians have a high degree of certainty that the requested treatment is outside accepted practice, they should seek procedural oversight to the extent allowed by the clinical situation and need not provide the requested treatment.

Use of the term futile should be restricted to the rare situation in which surrogates' request interventions that simply cannot accomplish their intended physiologic goals. Clinicians should not provide futile interventions.

The medical profession should lead public engagement efforts and advocate for policies and legislation regarding when life-prolonging technologies should not be used.³⁶

A model policy created for hospitals and healthcare facilities in New Jersey would inform clinicians to embrace and utilize these recommendations, leading to improved end-of-life care for all patients.

36. Bosslet, et al. "Policy Statement: Responding to Requests for Potentially Inappropriate Treatment in Intensive Care Units." (2015).

Available at: www.atsjournals.org.

Recommendation 26:

Provide palliative care, education and support to providers and healthcare professionals using “tele-mentoring” and “telehealth.”

Background:

Project Extension Community Healthcare Outcomes (ECHO) is recognized as national evidenced-based model on telehealth and tele-mentoring using a web-based video collaboration. This platform links a multi-disciplinary team of specialists with primary care providers, training the providers through peer-led case presentations and expert-led short didactics on topics germane to the clinic focus – in this case, palliative care. By enhancing providers’ skills, knowledge, and capacity to provide an expanded degree of care to patients in the primary care setting through participation in ECHO, research has demonstrated an improvement in patient outcomes, provider competencies and participant satisfaction.

VI. Conclusion:

Recognizing the rising cost of healthcare as well as an aging population, the need for effective and timely palliative care and fully informed discussions on end-of-life care options becomes increasingly more important in achieving patient centered care. Patients who receive palliative care avoid unnecessary ED visits and testing while at the same time improving patient satisfaction. Unfortunately, due to a shortage of palliative care providers, insufficient physician education, unpredictable patient and family demands, financial incentive misalignment, and poor coordination of care, these conversations often do not occur. To address these barriers, there need to be systems in place that will trigger and promote advance care planning and end-of-life care conversations by healthcare providers. There is little doubt that having conversations with patients about life expectancy and end-of-life care is a skill that can improve a patient's outcome and experience. To improve outcomes of care at end-of-life, we must ensure patient wishes are honored, and to meet family needs, we must educate healthcare providers about the importance of advance care planning and end-of-life care options.

This report includes recommendations that are immediate and long-term. Upon implementation of the recommendations, the Council is confident that when each of us confronts a serious or terminal illness, and when we face our own mortality, we and our families will be assured that we are being provided with quality care, respect, compassion and dignity, in every setting in New Jersey.

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Appendix A

CHAPTER 113

An Act establishing the New Jersey Advisory Council on End-of-Life Care in the Department of Health and Senior Services.

Be It Enacted by the Senate and General Assembly of the State of New Jersey:

1. The Legislature finds and declares that:

a. The current healthcare system in New Jersey often fails to meet the special needs of persons who are approaching the end of life by limiting the opportunity that they earnestly desire to spend their final months free of pain, in familiar surroundings, together with their friends and families, instead of being tethered to tubes and other medical apparatus in an intensive care unit or other acute care hospital setting;

b. At the same time, according to the Dartmouth Atlas of Health Care 2006 study on variations among states in the management of severe chronic illness, Medicare expenditures on many aspects of end-of-life care in New Jersey are among the highest of all states nationwide, and often greater than those in any other state, when measured by such indices as: days spent in a hospital per decedent during the last six months of life; days spent in an intensive care unit per decedent during the last six months of life; physician visits per decedent during the last six months of life; the percentage of deaths associated with an admission to intensive care; Medicare spending and resource inputs during the last two years of life; and standardized physician labor inputs per 1,000 decedents during the last two years of life;

c. Compared to the average American, New Jerseyans in the last six months of life spend 30% more days in the hospital, see physicians 43% more often, and spend 44% more days in the intensive care unit;

d. Expanded use of licensed hospice care programs, through more timely enrollment by persons in need of end-of-life care that responds to their needs and concerns, could help to avoid much of the expense for this type of care that is incurred in New Jersey;

e. In many cases, earlier referrals of persons with terminal conditions to hospice care could serve to improve their pain management and thereby enhance their quality of life and death,

by providing high-quality palliative care while also meeting the counseling and spiritual needs of these patients and their families;

f. Persons who are near the end of life have unique needs for respectful and responsive care, and concern for their comfort and dignity should guide all aspects of their care to alleviate their physical and mental suffering as much as possible;

g. At a minimum, the end-of-life care that a person receives should encompass dignified and respectful treatment at all times and aggressive pain management as appropriate to that person's needs;

h. As noted in the Report of the New Jersey Legislative Commission for the Study of Pain Management Policy, issued more than a decade ago, "the public policy of this State should support a compassionate and humane approach to caring for patients who are terminally ill which seeks to mitigate their physical pain and mental anguish and preserve as much of their peace and dignity as possible";

i. As further observed in that report, "We are all stakeholders in the public interest to be served by the advancement of a kinder and gentler approach to caring for patients as they approach the end of life because we will all take that journey"; and

j. It is manifestly in the public interest for this State to establish an advisory body, the membership of which would comprise individuals with suitable qualifications for this purpose, to examine those issues that it deems appropriate for the consideration of its P.L.2011, CHAPTER 113 2 members relative to the quality and cost-effectiveness of, and access to, end-of-life care services for all persons in this State, and to propose recommendations for the consideration of State agencies, policymakers, healthcare providers, and third party payers.

2. There is established the New Jersey Advisory Council on End-of-Life Care in the Department of Health and Senior Services.

a. The advisory council shall include 21 members as follows:

(1) the Commissioners of Health and Senior Services and Human Services and the Ombudsman for the Institutionalized Elderly, or their designees, as ex officio members;

(2) two members each from the Senate and the General Assembly, to be appointed by the President of the Senate and the Speaker of the General Assembly, respectively, who in each case shall be members of different political parties; and

(3) 14 public members who are residents of this State, to be appointed by the Governor with

the advice and consent of the Senate, including: one person who represents licensed hospice care programs in this State; two physicians licensed to practice in this State who have expertise in issues relating to pain management or end-of-life care, one of whom is an oncologist; two persons who represent general hospitals in this State, one of whom represents a religiously-affiliated hospital; one person who represents an organization in New Jersey that advocates on behalf of persons with mental illness; one person who represents an organization in New Jersey that advocates on behalf of persons with developmental disabilities; one person who represents nursing homes in this State; one registered professional nurse licensed to practice in this State; one attorney licensed to practice in this State who has expertise in healthcare law; one person who is employed as a patient advocate by a general hospital in this State; two members of the general public with expertise or interest in the work of the advisory council who are not licensed healthcare professionals, at least one of whom is a member of a minority racial or ethnic group; and one person representing academia who has expertise in biomedical ethical issues relating to end-of-life care and is not a licensed healthcare professional.

b. The public members of the advisory council shall serve without compensation but be reimbursed for any expenses incurred by them in the performance of their duties.

c. Legislative members shall serve during their terms of office. Vacancies shall be filled in the same manner as the original appointments were made.

d. The advisory council shall organize as soon as practicable after the appointment of its members. The Commissioner of Health and Senior Services or the commissioner's designee shall serve as chairperson, and the advisory council shall select a vice-chairperson from among its members and a secretary who need not be a member of the advisory council.

e. The advisory council shall be entitled to call to its assistance and avail itself of the services of the employees of any State, county, or municipal department, board, bureau, commission, or agency as it may require and as may be available to it for its purposes.

f. The Department of Health and Senior Services shall, within the limits of its existing staff and resources, provide such staff support as the advisory council requires to perform its duties.

3. The purpose of the advisory council shall be to:

a. Identify existing practices and programs in this State that have demonstrated measurable success in providing patient access to, and choice of, high-quality, cost-effective

palliative care and end-of-life care services and ways to promote the expansion and dissemination of those practices and programs; P.L.2011, CHAPTER 113 3.

b. Identify an effective mechanism for disseminating information to the general public, on as widespread a basis as is practicable, which information will assist patients and their families in making informed healthcare decisions with regard to palliative care and end-of-life care; and

c. Develop goals and benchmarks for efforts, which may be undertaken by the Department of Health and Senior Services or other relevant entities acting singly or in collaboration with each other, to accomplish the purposes of: providing patient access to, and choice of, high-quality, cost-effective palliative care and end-of-life care services; and assisting patients and their families in making informed healthcare decisions with regard to such care.

4. The advisory council, no later than 18 months after the date of its organization, shall report to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), on the results of its activities, and shall include in that report such recommendations for administrative, legislative, and other action as it desires to present pursuant to section 3 of this act, including policy recommendations for the consideration of State agencies, policymakers, healthcare providers, and third party payers. In developing its recommendations, the advisory council shall have, as its overriding concern, to promote an end-of-life care paradigm in which patients' wishes are paramount and they are provided with dignified and respectful treatment that seeks to alleviate their physical pain and mental anguish as much as possible.

5. This act shall take effect immediately and shall expire upon the issuance of the report by the advisory council pursuant to section 4 of this act.