



NEW JERSEY
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END-OF-LIFE CARE STRATEGIC PLAN FOR NEW JERSEY



The Nicholson  Foundation

Changing Systems, Changing Lives



Executive Summary

At the New Jersey Health Care Quality Institute (Quality Institute), our mission is to improve our state's health care system. One area we have long focused on is end-of-life care. End-of-life care refers to comprehensive care for a life-limiting illness that meets the patient's medical, physical, psychological, spiritual and social needs.¹ New Jersey performs poorly on end-of-life care compared with almost every other state in the nation. The statistics translate into real people treated with unnecessary and unwanted medical care at the end of their lives. Too many people who want to die at home instead die in Intensive Care Units (ICUs). Too few benefit from hospice care — or benefit too late.

We believe now, however, there is a determination and coordinated interest across communities, health care providers, and state leaders to improve end-of-life care in New Jersey. That is why the Quality Institute, with the support of The Nicholson Foundation, and in consultation with many of our member organizations and subject matter experts, created this compassionate and comprehensive strategic plan for end-of-life care in New Jersey. The issue touches every corner of health care, including hospitals, nursing homes, physicians, nurses, social workers, government and other health care payors, as well as families and communities. The Quality Institute has experience bringing leaders from all these areas together and is uniquely qualified to bring forth this comprehensive strategic plan.

We know that health care providers want to do the right thing for their patients, and families want to do the right thing for their loved ones. We have crafted a strategy that not only supports families and providers, but also ensures that people in our state have their wishes documented and honored. Our plan focuses on four key areas:

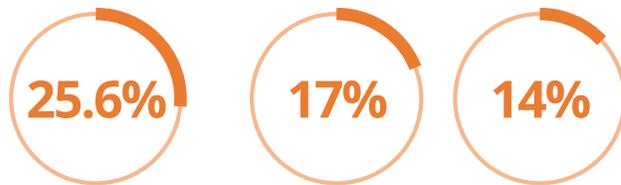
- **Technology.** We need a financially sustainable statewide electronic Practitioner Orders for Life Sustaining Treatment (POLST) registry so physicians and advanced practice nurses, in consultation with patients and caregivers, can document their end-of-life care wishes in a state recognized POLST form that is accessible to emergency and medical staff no matter where the person may be. We should connect Advance Directives and POLST forms to Electronic Health Records (EHR) systems, incorporate electronic reminders into the EHR to prompt providers to conduct advance care consultations with identified patients, and achieve widespread use of technology to identify those patients in greatest need of an end-of-life care plan. These steps are all achievable in the near term.
- **Payment.** We must increase reimbursement and expand how we reimburse for valuable end-of-life consultations to promote greater use of this service. This should be done in our state Medicaid program and State Health Benefit Program. In addition, we must rethink reimbursement policies and rates for palliative care. Moreover, alternative payment models should reward providers that perform well on end-of-life care quality measures.
- **Education.** Physicians and nurses in practice as well as those in medical and nursing school need education and coaching on how to have these difficult discussions with their patients and their caregivers. The medical and nursing schools in the state should develop a common curriculum to be implemented in their programs. Health systems and professional societies should provide and scale both web-based and in-person training, including simulation labs where providers can practice their skills with trained actors. Evidence based programs that address all of these education needs exist and can be implemented in short order.
- **Culture.** The issue goes beyond the world of medicine. We need to change the culture around end-of-life care discussions. This includes an awareness campaign to educate our residents about care options at the end-of-life, including how to discuss care preferences with their providers and caregivers, and how to document decisions so that they will be followed. This work involves community leaders, clergy, social workers, public health departments, senior centers and libraries, and county surrogates. This work must be culturally sensitive and shared in multiple languages.

This strategy requires leadership and commitment. We hope you will read our plan and join our effort to improve the universal journey each one of us will take one day.

Background: The Need to Improve End-of-Life Care Planning in New Jersey

New Jersey patients near the end of life are treated with more aggressive medical care than patients near the end of life in almost any other state in the country.²

For instance, in United Health Foundation's recent Senior Report 2018, New Jersey ranked 47th in hospital deaths for seniors at the end-of-life, at 25.6 percent. The top 10 performing states in the nation are between 14 and 17 percent.³



This high-intensity care is often unwanted and burdensome to both patients and their caregivers.

One challenge in New Jersey contributing to its high rate of intensive care at the end of life is the low rates of completion of **Living Wills** or **Advance Directives**⁴, **Proxy Directives**⁵, or POLST forms.⁶

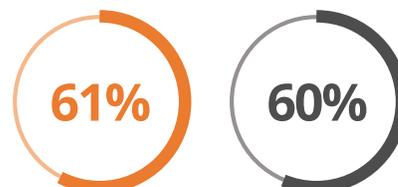
Living Will (Instruction Directive): A living will is a written, legal document that spells out medical treatments you would and would not want to be used to keep you alive, as well as other decisions such as pain management or organ donation. Have conversations with your primary care doctor, family, friends, and anyone you feel comfortable with to determine your personal wishes regarding these issues.

Advance Directive: An advance directive is a legal document that allows you to spell out your decisions about end-of-life care ahead of time. Each state's advance directive varies. In New Jersey, you do not need a lawyer to complete an advance directive. If you choose to get your advance directive notarized, you don't need additional witnesses; if you choose not to get your advance directive notarized, you must sign and date it in front of two adult witnesses who must also sign and date the document. The form can be updated and/or cancelled at any time. In New Jersey there are two parts to the Advance Directive – the Living Will (Instruction Directive) and the Durable Power of Attorney for Health Care (Proxy).

Durable Power of Attorney for Health Care (Proxy Directive): The Health Care Proxy is where you name a person to make decisions for you when you are unable to do so. This person can be anyone-family or friend-except for your personal physician. The Proxy will only go into effect if you are no longer able to speak for yourself.

A 2016 poll conducted by the Quality Institute and the Rutgers Eagleton Center for Public Interest Polling found 61 percent of New Jersey adults are comfortable with the idea of aging and have thought about their wishes for medical treatment near the end-of-life.

Yet 60 percent of New Jersey adults reported having no written documents expressing their wishes for their care at the end of their lives.⁷



Nationally, a 2015 Kaiser Family Foundation poll found that 89 percent of people surveyed said health care providers should discuss how to navigate end-of-life decisions with patients. Only 17 percent had those talks with providers.⁸



End-of-life care cannot be improved in New Jersey without informed conversations about end-of-life care options and documentation of these decisions. Currently, too few New Jersey residents are discussing and documenting their wishes, and many are unaware of or do not have accurate information on important end-of-life care options or advance care planning documents.

Likewise, physicians are not initiating these conversations with their patients and caregivers often enough. According to a national survey among physicians who regularly treat patients 65 and older, 99 percent of physicians surveyed report that they believe that having these conversations is important, yet just 14 percent have billed Medicare for this conversation for their fee-for-service patients. In addition, only 29 percent of physicians surveyed report having any formal training on how to talk with patients and their families about end-of-life care, and nearly half (46 percent) say they feel unsure of what to say during these conversations, and worry about caregiver resistance.⁹

Government Action to Date

Several preliminary, yet essential, steps have been taken at the state level to address end-of-life care. In 2011, New Jersey adopted a recognized form to enable patients to indicate their preferences regarding life-sustaining treatment through the **Practitioner Orders for Life Sustaining Treatment (POLST)** form.¹⁰ This form, signed by a patient's attending physician or advanced practice nurse, provides instructions for health care personnel to follow for a range of life-prolonging interventions. This form becomes part of a patient's medical records, following the patient from one health care setting to another, including hospital, nursing home or hospice. The use of the POLST will increase the ability of New Jerseyans to have their health care preferences respected. POLST forms are generally used by people in the later stages of life or those with an advanced illness, and may augment the use of advance directives. The POLST state law also directed that a Patient Safety Organization (PSO) in New Jersey (the non-profit arm of the New Jersey Hospital Association) be designated as the entity responsible for implementation, training, and other functions related to the POLST. As part of this law, physicians and nurses licensed to practice in New Jersey must obtain at least two credits of continuing education on topics related to end-of-life care as a condition of their biennial registration. This requirement is an important step to engage and train medical professionals in addressing this difficult topic with their patients and caregivers.

Practitioner Orders for Life-Sustaining Treatment (POLST): A POLST form is a medical order indicating your preferences for end-of-life care. In most states, this form is intended for use only during the final stages of life. In New Jersey, the POLST form can be filled out at any time. It is filled out with your physician or advanced practice nurse based on the contents of your directives, discussions with your practitioner, and your treatment preferences.

POLST forms are intended for people who have already been diagnosed with serious illness, so even if you have one before, it is important to speak with your practitioner regularly and update your POLST form as your preferences change as you age. The POLST serves as practitioner-ordered instructions — not unlike a prescription—to ensure that, in case of an emergency, you receive the treatment you prefer. A POLST travels with you, at whatever facility you are being cared for.

A separate law established the New Jersey Advisory Council on End-of-Life Care in the New Jersey Department of Health. The Advisory Council, which includes 21 members, is required to identify existing practices and programs 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.¹¹ Further, the Advisory Council is charged with identifying an effective mechanism for disseminating information to the general public. The aim is to assist patients and their families in making informed health care decisions regarding palliative care and end-of-life care, and develop goals and benchmarks for efforts undertaken by the Department of Health or other relevant entities to provide patient access to these services. The Advisory Council was directed to release a report of recommendations within 18 months after the date of its organization. The report is expected to be released in summer 2018. In the interim, the Department of Health created a webpage that contains many patient and provider resources.¹²

Palliative Care: A comprehensive approach to treating serious illness that focuses on the physical, psychological and spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and symptoms. Palliative care may be given at any time during a patient's illness, from diagnosis on.

Finally, Governor Murphy's Health Transition Team Report recommended that "within the first 100 days, the Governor should direct the Department of Health to create a comprehensive plan to increase provider and public awareness of the value of the POLST registry and Advance Directives, and explore policy options to implement a statewide POLST registry."¹³

At the federal level, in January 2016, Medicare began reimbursing physicians who see Medicare patients for advance care planning consultations. While this was an important step, over two-thirds of physicians (71 percent) report that they have not been trained in advance care planning conversations and many of them (86 percent) are not billing for this service.¹⁴ A 2017 National Quality Forum (NQF) report also suggests that despite CMS coverage for advance care planning consultations, questions remain about how to make advance care planning commonplace among providers and how to measure processes that drive performance improvement.¹⁵ Moreover, in the current system, two-thirds of physicians report that they do not have the time to hold thorough conversations with patients.¹⁶

Private Sector Action to Date

Fortunately, many groups outside government are also working on the issue of improving end-of-life care planning in New Jersey. This private sector work should be embraced by the State; and then coordinated and aligned as much as possible with government efforts in this area. By combining best practices from the private and public sectors we can make significant progress toward improving outcomes in this area.

New Jersey Health Care Quality Institute: The Quality Institute issued its **Medicaid 2.0 Blueprint for the Future**¹⁷, in 2017. The Blueprint recommended that the State adopt a model for end-of-life care that encourages greater use of hospice care, allows palliative care to co-exist with curative care, supports a statewide registry for POLST forms, pays for advance care planning provider visits, trains the current provider workforce and upcoming generations to have these important conversations with their patients, and engages the community through initiatives such as the Quality Institute's "Conversation of Your Life."¹⁸

The Quality Institute, through its Mayors Wellness Campaign, launched an initiative called "**Conversation of Your Life (COYL)**" in 2015 to address end-of-life care planning from a cultural and community perspective.¹⁹ COYL's mission is to integrate advance care planning into the cultural fabric of a community so that talking about death and end-of-life care becomes as comfortable as discussing other phases of life. Its goal is to increase the number of residents who have documented their end-of-life wishes and communicated them to their family and health care providers. COYL works through local task forces that include county and municipal leaders (public health officers, senior and social services agencies, county surrogates, elected officials, librarians), lay people, religious leaders, and health care professionals. The programming is engaging and disarming, and utilizes community book reads, film festivals, games, and art-related projects, along with facilitated sessions about advance care planning to initiate this conversation and educate the community. As of June 2018, COYL is active in fourteen counties across the state.



New Jersey Hospital Association ("NJHA"): In 2010, NJHA released an *End-of-Life Care in New Jersey Hospitals* report that made key recommendations for improving hospital staffing models, documentation of end-of-life wishes through the POLST form, and end-of-life education for medical staff. This report was a catalyst for the passage of the laws creating the POLST and Advisory Council.

Pursuant to the POLST law, the **NJHA PSO developed "emPOLST,"** an electronic format of the POLST and a statewide registry housed on the PSO protected site. The PSO is now in the final testing phase and supporters expect to begin use of emPOLST in 2018 with its first hospital system user, Hunterdon Medical Center. According to the PSO, the emPOLST registry will also have a mobile application. The PSO intends to pilot test the registry and have all 72 acute care hospitals participating in the next two years. This is a privately created and funded registry. The PSO intends to provide free access to the registry for Emergency Medical Service providers. Other non-hospital based health care practitioners, patients and their designated caregivers will also be able to access the registry and use it at no charge. However, if physicians want to connect the registry to their electronic health record (EHR) system they will have to pay an annual fee. Hospitals can get access to the registry for free but will pay an annual fee to fully integrate the emPOLST application, which includes an electronic form capture interfaced with the hospital's admission, discharge and transfer System (ADT), with their EHR. According to the PSO, the integration and workflow is estimated to cost between \$6,000 to \$14,000 annually per hospital. The goal of the emPOLST registry is to make the POLST form completion easier for practitioners and patients and to ensure that all clinical and non-clinical care teams can securely access a POLST form and respect a patient's end-of-life goals wherever they receive care.

Healthcare Quality Strategies, Inc., (HQSI): Since 2015, HQSI, which serves as the Medicare quality improvement organization for New Jersey as part of the regional Quality Improvement Network, has convened six community coalitions of health care and social service providers that work to improve coordination of care for Medicare beneficiaries. One area of focus for each of the coalitions is end-of-life care, through sharing information about initiatives to increase provider awareness, use of advance directives and POLST, palliative care services, and **hospice** services.

Hospice: Hospice offers medical care toward a different goal: maintaining or improving quality of life for someone whose illness, disease or condition is unlikely to be cured. Each patient's individualized care plan is updated as needed to address the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care also offers practical support for the caregiver(s) during the illness and grief support after the death. Hospice is something more that is available to the patient and the entire family when curative measures have been exhausted and life prognosis is six months or less.

Goals of Care Coalition of New Jersey is a nonprofit organization that is focused on encouraging patients, doctors and family members to talk about the care they want when facing a serious illness, and document their preferences in care plans. Its founding members include the Medical Society of New Jersey, the NJHA, the Home and Hospice Association, and other health care quality entities, including the Quality Institute.²⁰ Goals of Care Coalition of New Jersey, in partnership with its members, seeks to align the work of its members and further it throughout New Jersey. In addition, its founder, David Barile, MD, serves on the state Advisory Council and regularly speaks to both clinicians and community members on this topic.

Over the last few years, there has been a growing interest in improving end-of-life care in New Jersey across stakeholders. Indeed, the Medical Society of New Jersey (MSNJ), the New Jersey Hospital Association (NJHA) and the New Jersey Association of Health Plans (NJHAP) co-sponsored and launched the New Jersey Healthcare Executive Leadership Academy (NJHELA). The first two cohorts of NJHELA focused on improving end-of-life care in New Jersey.²¹

Five Wishes: The Five Wishes is an alternative form that is acceptable as an Advance Directive in the state of New Jersey. The Five Wishes form is written in everyday language and has become the most popular Advance Directive in America.

New Jersey Needs a Strategic Plan to Support Expansion of End-of-Life Care Planning

To better support patients and caregivers of patients that need end-of-life care and to change the cultural norms to promote the greater use of these services, a statewide Strategic Plan for End-of-life Care should be established and implemented by both the public and private sector in close cooperation. The objectives of the plan should be to:

- **Financially support technology solutions** including a state electronic POLST registry so physicians and advanced practice nurses, in consultation with patients and caregivers, can document their end-of-life care wishes in a state recognized POLST form that is accessible to emergency and medical staff no matter where the person may be. We should connect Advance Directives and POLST forms to Electronic Health Record (EHR) systems, incorporate electronic reminders into the EHR to prompt providers to conduct advance care consultations with identified patients, and achieve wide-spread use of technology to identify those patients in greatest need of an end-of-life care plan. These steps are all achievable in the near term.
- **Change payment policy** to support increased reimbursement, and expand how we reimburse for valuable end-of-life consultations to promote greater use of this service. This should be done in our state Medicaid and State Health Benefits Program. In addition, we must rethink reimbursement policies and rates for palliative care. Moreover, alternative payment models should reward providers that perform well on end-of-life care quality measures.
- **Engage and educate health care providers** and medical and nursing students to better enable them to have end-of-life care discussions with patients and caregivers. The medical and nursing schools in the state should develop a common curriculum to implement in their programs. Health systems and professional societies should provide and scale both web-based and in-person training, including simulation labs where providers can practice their skills with trained actors. Evidence based programs that address all of these education needs exist and can be implemented in short order.
- **Change the culture** around end-of-life care discussions. This includes an awareness campaign to educate our residents about care options at the end-of-life, including how to discuss care preferences with their providers and caregivers, and how to document decisions so that they will be followed. This work involves community leaders, clergy, social workers, public health departments, senior centers and libraries, and county surrogates. This work must be culturally sensitive and shared in multiple languages.

We expect that these objectives will be consistent with the upcoming report from the New Jersey Advisory Council on End-of-life Care efforts. The release of that report will be another opportunity to bring focus on the need for a public-private partnership to improve end-of-life care in New Jersey.

I. New Jersey Needs To Strengthen its POLST Registry and Other Technology Solutions

Forty-six states including New Jersey have enacted law creating a recognized POLST.²² California, New York, Oregon, Utah, and West Virginia have established electronic registries that store, manage, and provide access to POLST forms.²³

As discussed in the background section, New Jersey did not establish a state-funded registry. Instead, the PSO privately funded and created the emPOLST, which is now in the testing phase and will be funded through charges to health care facilities and providers. Notably, no other state uses a third party to fund its POLST registry. In Oregon, the state operates the registry at no cost to users — including providers and patients. Oregon's registry was developed at a cost of \$250,000 and requires annual operating funds of approximately \$380,000 for a population of nearly four million people. Based on discussions with the NJHA-led PSO and the experience of Oregon, we estimate that a New Jersey POLST registry could operate for approximately \$500,000-\$600,000 annually. To date, however, there is no firm commitment from any source for funding at this level.

The State, in partnership with the PSO, should create a sustainable funding model for the POLST registry. The registry must be connected to the statewide Health Information Network (HIN) so it can be accessed through and connect with all of the electronic health record systems and exchanges in the state. The currently projected PSO fees are not especially prohibitive for large organizations like hospitals, but the arrangement still requires a formal commitment from the institution that is under no obligation to participate in the registry. Moreover, the value of the registry will be limited if the participation level is limited in scope. Thus, direct state support and involvement is needed to ensure the registry's interoperability with other state health registries, health information exchanges, and the HIN.

In addition to the registry, other technology-based solutions should be used to: build advance care consultations into physician office scheduling and workflow; identify and risk stratify patients most in need for such consultations; embed alerts into providers' electronic health record systems to trigger the timing of such consultations; provide video based sessions to patients and caregivers to realistically show them what the levels of life sustaining care truly consist of; and other innovations to both document and provide further education on advance directives.

Finally, health systems and insurers, which have extensive websites and portals for their patients and members, also have an important role to play when it comes to education on end-of-life care options. One good example that should be replicated in New Jersey is Kaiser Permanente's website, which includes specific member resources including how to consider your values; how to choose your health care agent (proxy); how to decide on and express your wishes; and how to choose the right advance directive.²⁴ New Jersey health systems and insurers should include specific member resources like this on their websites and proactively share these resources with patients and members.

II. Change Benefit and Reimbursement Policies to Support Greater Usage of Advance Care Planning Consultations, Hospice, and Palliative Care Models

As the largest purchaser of health care in the state, the State itself can reform its benefit designs to promote more provider and patient consultations about end-of-life choices. New Jersey Medicaid should pay doctors, nurses and social workers for advance care planning consultative visits, as is done in Medicare. California Medicaid now covers these visits and other states are considering coverage. Governor Murphy's Health Transition Team report noted that "costs associated with advance care planning consultations in Medicaid would be relatively small – if 10,000 visits occur in the first year, the total cost (half federally funded) is estimated to be \$860,000 (if the State pays the same rate as Medicare). Ultimately, however, these consultation costs would be offset by reducing avoidable emergency department and hospitalization costs."

Another step is to support care models that introduce palliative care earlier in the course of treatment for certain patients. This could include supporting a model that utilizes palliative care for management of chronic medical illness. Presently, palliative care is under-utilized, in part because of the lack of adequate reimbursement. Palliative care could be utilized more in both the community and assisted living settings to decrease exacerbations in symptoms that lead to traumatic hospitalizations.

When it is not possible to begin palliative care in community or assisted living settings, it should be introduced as early as possible in the emergency department setting. St. Joseph's Regional Medical Center in Paterson expanded its palliative care program, also called Life Sustaining Management and Alternatives (LSMA), to its Emergency Department in 2010 to ensure that patients who would benefit from palliative care were able to start at an earlier stage of treatment than they otherwise would have.²⁵ New Jersey could pilot these models for all the care it purchases through the State Health Benefits Program and Medicaid and study the outcomes.

As the State drafts regulations for telehealth services, it should also consider telehealth use for end-of-life services. Other states are pursuing telehealth for hospice and palliative care with early success. One example is Anthem Blue Cross in California, which is using telehealth services to address access and transportation issues, especially in rural parts of the state.²⁶

Hospitals and nursing homes are measured on their quality using NQF endorsed measures including: *patients admitted to ICU who have care preferences documented, hospice and palliative care – treatment preferences, proportion of patients admitted to the ICU in the last 30 days of life, proportion not admitted to hospice, and proportion admitted to hospice for less than three days.*²⁷ These measures should be used in all health care benefits that the State pays for and should be built into outcomes-based payment models. Making measures such as these a priority, and putting financial incentives behind them will lead to changes in the way care is delivered in these facilities. Providing unwanted care when the patient has a POLST or DNR should be considered a "Never Event." These Never Events should be reported to the New Jersey Department of Health. Now is the time for our health systems and patient safety organizations to embark on a mission to eliminate Never Events related to life-sustaining treatment.

III. Engage and Educate Health Care Providers

Physicians and nurses play a crucial role in supporting patients considering end-of-life care planning. The treating clinician's relationship with the patient often means they are the first source of information for the patient and caregivers. Therefore, educating and coaching physicians, nurses and their staffs in both end-of-life care options as well as end-of-life patient counseling techniques is critical to improving the quality of end-of-life care in New Jersey. This training should also be encouraged for medical and nursing schools and residency programs. Nationally, physicians report that they are more likely to have these consultations with patients and caregivers if they are trained and feel comfortable doing so.²⁸ There are several established training programs that are web-based and in person.²⁹ Health care systems across the state should align in their commitment to build this type of training into their business models.

Hospitals across the country are investing in video simulation trainings to educate physicians, nurses, and social workers about the importance of holding end-of-life conversations with patients, and how to hold these conversations. Group and individual video trainings involve physicians, nurses, and social workers being filmed while interacting with actors playing patients and families during different scenarios that involve conversations about the patient's end-of-life care.³⁰ Participants then view their video footage and discuss with facilitators what to change during their next patient or family interaction. In addition, trainings focus on self-care for providers, who are in emotionally taxing situations.³¹ These trainings should be used in the state medical and nursing schools and encouraged throughout the state.

A critical part of physician education must take place early on, in medical schools. Four medical schools in Massachusetts jointly developed a standardized curriculum for medical students at Harvard Medical School, Tufts University School of Medicine, Boston University School of Medicine, and University of Massachusetts Medical School.³² This curriculum teaches young medical professionals how to discuss end-of-life care preferences with patients and their families early on. This curriculum should be replicated in New Jersey and standardized across New Jersey medical schools. Fellowship programs should also be created at the state and federal level to support young medical professionals' participation in palliative care fellowships.

In addition to mandatory education in medical and nursing schools, education on advance care planning documents should be required in Emergency Medical Services (EMS) training programs. EMS personnel are often the first to encounter patients when they are having a medical emergency. As such, EMS personnel need to know how to find POLST forms and other Advance Directives in an emergency.

Hospice providers, Social Workers, and other Mental Health Professionals all play a vital role in ensuring that patients' wishes are honored and that high-quality end-of-life care is provided. They should receive on-going training in end-of-life care and, in turn, provide training to professionals and the community, as they are best equipped to support others in this work.

IV. Changing the Culture: Increasing Public Awareness and Comfort Discussing End-of-life Care Options

A comprehensive outreach initiative that educates patients and caregivers on their end-of-life care options is needed to improve outcomes in New Jersey. The Quality Institute started this work through its COYL initiative, which is described above. COYL is funded by The Horizon Foundation for New Jersey and is volunteer led. In addition, the Quality Institute partners with many hospital systems, nursing homes, and hospice providers that also conduct community outreach and education events. The State should consider partnering with COYL and these other entities to promote and support efforts to scale this programming across the entire state. Equally important, COYL will need to be adapted to a variety of cultures, religions, and languages in New Jersey. The Quality Institute, in partnership with health systems, is developing materials and programs in Spanish, Korean, and Mandarin.³³

It is also important to measure the impact of this community-focused work. Currently COYL collects data on:

- The number of people who have received information about health care options at COYL events;
- Attendees' understanding of the subject area through pre- and post-event surveys;
- Readership volume of COYL designated books through library records;
- Focus groups and interviews of COYL task force members to gather qualitative information on the impact of the program; and
- Statewide polling of attitudes and awareness on end-of-life care.

Together, the State and these programs should facilitate the distribution of educational materials through an array of agencies and programs that touch applicable populations. The State should also regularly convene these groups and provide guidance and support in measuring and sustaining end-of-life care awareness efforts.³⁴ The ideal times to start a program and promote it are on or around April 16, which is National Healthcare Decisions Day, and in November, which is World Hospice and Palliative Care month. Washington State deployed such a strategy. Its Governor took the unique action of issuing a Governor's proclamation to demonstrate Washington's commitment to improving end-of-life care. Governor Jay Inslee recognized April 16, 2018 as Healthcare Decisions Day in Washington, and encouraged all Washington residents to join in observance.³⁵ New Jersey's Governor and his cabinet members could take a similar step to raise awareness and demonstrate the importance of having an Advance Directive.

In addition to educating health care providers and the public, the State should engage the legal community in collaboration with the New Jersey State Bar Association. This should include education on the types of advance care planning documents available in New Jersey.

Conclusion

By implementing the recommendations set forth in this strategic plan, together we can help New Jersey become a leader among states in end-of-life care. Specifically, New Jersey's health care stakeholders can join together with government and community leaders to create a more effective system that puts the patient, and the patient's wishes, at the center of the decision-making process. A more effective system will not only help patients but also help their grieving families, who may find comfort from knowing the wishes of their loved ones were honored. The goal of improving end-of-life care in New Jersey is achievable with hard work, commitment and collaboration.

Notes

- ¹ https://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx
- ² Dartmouth Atlas of Healthcare from 2008 - 2014.
- ³ <https://assets.americashealthrankings.org/app/uploads/ahrsenior18-finalv1.pdf>
- ⁴ <http://www.nj.gov/health/advancedirective/ad/forums-faqs/>
- ⁵ <http://www.nj.gov/health/advancedirective/ad/forums-faqs/>
- ⁶ <http://www.state.nj.us/health/advancedirective/polst/>
- ⁷ <http://www.njhqci.org/wp-content/uploads/2016/04/Rutgers-Eagleton-NJHCQI-EOL-Poll-for-Website.pdf>
- ⁸ <https://www.kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/>
- ⁹ https://www.johnhartford.org/images/uploads/resources/ConversationStopper_Poll_Memo.pdf
- ¹⁰ N.J.S.A. §§ 26:2H-129 through 26:2H-140 et al.
- ¹¹ P.L. 2011, Chapter 113, Establishes NJ Advisory Council on End-of-Life Care in DHSS and shall expire upon issuance of report.
- ¹² <http://www.state.nj.us/health/advancedirective/>
- ¹³ <http://nj.gov/governor/news/reports/docs/Healthcare%20Transition%20Report.pdf>
- ¹⁴ https://www.johnhartford.org/images/uploads/resources/ConversationStopper_Poll_Memo.pdf
- ¹⁵ National Quality Forum. *Palliative and End-of-Life Off-Cycle Measure Review 2017*. http://www.qualityforum.org/Publications/2017/09/Palliative_and_End-of-Life_Care_Off-Cycle_Measure_Review_2017.aspx
- ¹⁶ https://www.johnhartford.org/images/uploads/resources/ConversationStopper_Poll_Memo.pdf
- ¹⁷ Medicaid 2.0 Blueprint for the Future and the End-of-Life Care Strategic Plan for New Jersey are funded by The Nicholson Foundation.
- ¹⁸ <http://www.njhqci.org/COYL>
- ¹⁹ <http://www.njhqci.org/COYL>
- ²⁰ <http://www.goalsofcare.org/>
- ²¹ The proceedings from the first NJHELA cohort are available here: <http://www.msnj.org/njhela>
- ²² <http://polst.org/programs-in-your-state/>
- ²³ <http://polst.org/technology/>
- ²⁴ <https://healthy.kaiserpermanente.org/health-wellness/life-care-plan>
- ²⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3876308/>
- ²⁶ Interview with representative from Anthem Blue Cross in California, April 2018
- ²⁷ National Quality Forum. *Palliative and End-of-Life Off-Cycle Measure Review 2017*. http://www.qualityforum.org/Publications/2017/09/Palliative_and_End-of-Life_Care_Off-Cycle_Measure_Review_2017.aspx
- ²⁸ https://www.johnhartford.org/images/uploads/resources/ConversationStopper_Poll_Memo.pdf
- ²⁹ Training program examples include: **Alive SHARE Video Simulation Lab**: <https://www.alivehospice.org/healthcare-providers/simulation-lab-1>
Massachusetts Standardized Curriculum for Medical Students on End of Life Conversations: <https://www.bostonglobe.com/metro/2017/05/08/mass-medical-schools-plan-teach-how-discuss-patients-goals-for-care-and-for-life/fBa0sU7ijW9tZyFKxq8WWI/story.html>
Ariadne Labs Research Studies: <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/research/>
Columbia University School of Nursing Palliative Care Education: <http://nursing.columbia.edu/academics/academic-programs/sub-specialty-programs/palliative-and-end-life-care>
The Annual Assembly: Hospice & Palliative Care: <http://aahpm.org/meetings/assembly>
The Conversation Project Resources & Trainings for Health Care Professionals: <https://theconversationproject.org/resources/healthcare/>
Goals of Care Coalition of New Jersey: <https://www.goalsofcare.org/healthcare-professionals/>
Advance Care Planning Decisions: <https://acpdecisions.org/>
Physicians' Views Toward Advance Care Planning and End-of-life Care Conversations: https://www.johnhartford.org/images/uploads/resources/ConversationStopper_Poll_Memo.pdf
Coalition for Compassionate Care of California: <https://csupalliativecare.org/programs/advance-care-planning/>
Respecting Choices: <https://respectingchoices.org/types-of-curriculum-and-certification/facilitator-certification/>
West Virginia Center for End-of-Life Care: <http://wvethics.org/media/12072/why-and-how-to-have-end-of-life-care-discussions-with-your-patients.pdf>
- ³⁰ <https://www.alivehospice.org/healthcare-providers/simulation-lab-1>
- ³¹ <https://www.alivehospice.org/healthcare-providers/simulation-lab-1>
- ³² <http://maseriouscare.org/>
- ³³ Thank you to Holy Name Medical Center Asian Health Services for their partnership developing COYL program materials in Korean and Mandarin.
Thank you to the National Association of Hispanic Nurses – New Jersey chapter for their partnership developing COYL program materials in Spanish.
- ³⁴ **Groups to include in state government:** Department of Human Services, Department of Transportation, Division of Medicaid Services, Division of Aging, Division of Disabilities, and Commission for the Blind and Visually Impaired; **Department of Health:** Office of Minority and Multicultural Health; **Groups to include in local government:** County Executives, County Surrogates, Social Services, Area Agencies on Aging, Public Health Officers, Mayors, and Librarians; Community/interest groups to include: New Jersey Health Care Quality Institute's Mayors Wellness Campaign and Conversation of Your Life initiatives, New Jersey Hospital Association and PSO, New Jersey Goals of Care Coalition, Associations representing health care professionals and facilities, Associations representing seniors, Associations of insurers and business groups, religious organizations, senior centers, ethnic group centers and coalitions, elder law attorneys and state and local bar associations, special populations, and nonprofit entities and foundations.
- ³⁵ <http://www.wsha.org/wp-content/uploads/Healthcare-Decisions-Day.pdf>



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