



Senate Special Committee on Aging

Senator Sheldon Whitehouse, Chair

“Honoring Final Wishes: How to Respect Americans’ Choices at the End of Life”

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Testimony

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Good morning. I extend my thanks to Senator Sheldon Whitehouse and members of the Senate Special Committee on Aging for convening this hearing on “Honoring Final Wishes: How to Respect Americans’ Choices at the End of Life” and affording me the opportunity to provide testimony process from both a personal and professional perspective.

Too often, people don’t die in the setting of their choice, don’t have advance directives in place, and many fear dying in pain and without dignity or control. We can – and must, do better.

I have been personally committed to ensuring the rights of all Americans to receive high quality, person-centered care since 1983 when an 85 year old female patient taught me the importance of:

- comfortably discussing death and dying,
- sharing prognostication that allows an individual sufficient time to close one’s life,
- participating actively in the advance care planning process and ensuring informed medical decision-making so that patients and families recognize whether a treatment is necessary; the benefits and burdens of that treatment; if there is hope for recovery and if so, what life will be like afterwards; and most importantly, exploring what the patient values,
- person-centered care – she taught me, “It is my life and my death, not yours.”
- separating my beliefs from a patient’s beliefs.

She gently reminded me why I originally choose medicine as a career. At an early age, I witnessed the negative impact of ineffective end-of-life care of my maternal grandmother and several other relatives on the health of family members for many subsequent years. My father died suddenly three weeks before I graduated from medical school in 1979 and medical school trained me to save lives – not care for the dying.

In the past nine months, my family and I have experienced the loss of four significant elder family members, namely, my mother, paternal aunt, paternal uncle and maternal uncle. I was engaged in the advance care planning process and ensuring my mother and two unmarried uncles’ final wishes were honored and that they received effective end-of-life care. I was unable to be directly involved in my aunt’s care as she died two weeks before my mother. Their final wishes were openly discussed with our family long before their illnesses and death.

- I was privileged to care for my mother during the last 15 months of her life. She died in our home after receiving in-home hospice care for nearly three months subsequent to being diagnosed with a serious illness when she was hospitalized with acute abdominal pain, while visiting my sister in another state. Her Medical Orders for Life-Sustaining Treatment (MOLST) form traveled with her and the medical orders were honored.
- My paternal uncle died after a cascade of medical events subsequent to a fall experienced two weeks after my mother’s death. While on the apparent road to recovery, he sustained an acute event associated with multisystem organ failure. He was treated with aggressive palliative care measures and died peacefully in an ICU in less than 24 hours after admission and appropriate assessment.
- My maternal uncle, the last remaining sibling of my mother and our family’s surrogate father, died peacefully on September 17th in a free-standing inpatient Hospice Home, four days after admission. Significantly, he was admitted to an ICU nine days prior to his death and was able to be transferred from the ICU to the Hospice Home in less than 48 hours after the need for effective palliative care was recognized. He had no prior hospitalizations during the antecedent two years.
- Each of my relatives accepted and embraced a natural death and recognized the limitations and burdens of life-sustaining treatment. While the scenarios and clinical settings varied, each received appropriate aggressive palliative treatment and experienced a peaceful natural death.

As a geriatrician with 30 years of clinical experience in private practice, long term care and academic settings, I recognize failure to provide compassion and support at the end-of-life results in unnecessary suffering for the patient and family and poor quality of life for the patient.

Now as a medical director of a not-for-profit health plan, my work focuses on spearheading development, implementation and statewide expansion of

- community projects that focus on advance care planning, pain management, palliative care, end-of-life care, and elder abuse
- professional and community educational interventions that aim to overcome functional health illiteracy, and
- integration of these programs into our care management functions and products.

I am privileged to lead the ***Community-wide End-of-life/Palliative Care Initiative (Initiative)*** that focuses on a systems approach to advance care planning, pain management, palliative care and end-of-life care. Formed in 2001, members of the Initiative first examined the social, legal and institutional barriers to higher rates of advance directives and health care proxy documentation. The Initiative sought a patient-centered, system-based, community-wide solution to improving both completion rates of traditional advance directives and provider compliance that would ensure patient preferences would be honored across the continuum of care. View [information on the Initiative](#) and [Initiative outcomes](#) at the community web site, www.CompassionandSupport.org.

While the Initiative has several projects including Community Principles of Pain Management, palliative care programs, palliative medicine workforce development, PEG Tube Feeding Guidelines, professional and consumer educational interventions, I will focus my testimony on goals and outcomes of two complementary advance care planning programs developed by the Initiative that enhance the potential for improving patient-centered care:

- ***Community Conversations on Compassionate Care (CCCC)***, an advance care planning program designed to motivate all adults 18 years of age and older to complete traditional advance directives like the health care proxy and living will.
- ***Medical Orders for Life-Sustaining Treatment (MOLST) Program***, New York State's approved ***Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program***, designed to improve the quality of care seriously ill people receive at the end of life by "Writing Your Final Chapter: Know Your Choices...Share Your Wishes."

Community-wide End-of-life/Palliative Care Initiative (Initiative) **Background on Regional Efforts to Improve End-of-life Care in Upstate New York**

To understand these two advance care planning programs, it is important to recognize the

- Initiative's health care and community collaborative model
- context in which the Initiative initially developed local efforts to improve end-of-life care in Upstate New York
- strategy used for regional implementation, and
- steps taken to move the projects statewide and nationally.

Subsequent to the publication of the 1997 Institute of Medicine Report "Approaching Death: Improving Care at the End-of-Life", the Rochester Individual Practice Association and BlueCross BlueShield Rochester Region End-of-Life/Palliative Care Professional Advisory Committee was formed. This Committee developed and implemented the Rochester Community End-of-Life

Survey focused on advance directive completion rates, effective pain management and hospice referrals conducted in October – November 2000. [Survey results](#) revealed there was significant room for improvement in end-of-life care.

[Results were presented to the Rochester Health Care Forum in January 2001](#) and the Community-Wide End-of-Life/Palliative Care Initiative was launched in May 2001. Initially, more than 150 passionate community volunteers participated in launching the Initiative and the development of projects showcased on the community Web site, www.CompassionandSupport.org. Initiative leadership and membership includes a broad diverse representation of the community, including consumers. Partnerships with spiritual, religious and cultural organizations ensure the interventions are culturally sensitive. As the initiative began, leadership and the Advisory Group felt strongly that a focus should be placed on the development of projects that support the vision. “Rochester will be a preeminent leader in advocating for facilitated discussions on planning for end-of-life care and for ensuring excellence in the provision of End-of-Life/Palliative Care, serving all segments of our community.” Details are outlined in [A Report to the Community](#).

To assist the Advisory Group and gather community input, four workgroups were formed:

- [Workgroup 1](#) Exploring and communicating treatment wishes
- [Workgroup 2](#) Ensuring patient wishes are identified and honored at all sites of care
- [Workgroup 3](#) Relieving physical, psychological, spiritual symptoms and providing patient/family support
- [Workgroup 4](#) Facilitating communication and education, both community and professional.

Leadership and administrative support is provided by Excellus BlueCross BlueShield, including funding for operations, creative services, communication, distribution and fulfillment of educational materials, training, and quality improvement. Staff assists in monitoring performance, sharing best practices and lessons learned and establishing plans for sustainability.

The initiative has grown with countless individuals working on replicating Initiative projects across New York State. The [EPEC faculty](#) from across Upstate New York share our mission of providing high quality, person-centered, effective care at the end-of-life and play a critical role in collaborating on concrete projects and replicating our efforts in Upstate New York. Professionals and community volunteers from Western New York, Central New York, Utica Region, Southern Tier and the North Country participate in the development and implementation of these projects; for example, the Southern Tier End-of-Life Coalition, a coalition concerned with improving end-of-life care in the greater Binghamton area and the Community Health Foundation, a non-profit organization providing funding to seven Central and Western New York coalitions aiming to improve care for frail elders.

The Community-wide End-of-Life/Palliative Care Initiative collaborates with multiple stakeholders for its various projects, including national, state, regional and local organizations; hospital, long term care, EMS, home care, palliative care and hospice systems; physician and legal professional associations; academic institutions and quality improvement organizations; religious organizations and cultural groups; community agencies, business organizations and other insurers. [View a full list of collaborators](#).

Before initially developing strategy and plans, the Initiative examined the scope of the problem, researched existing models and outlined the needs assessment for traditional directives for all Americans and the need for “actionable medical orders” for seriously ill patients. The interventions developed were a direct result of these individual needs assessment.

Needs Assessment for Traditional Advance Directives for All Individuals

Workgroup 1 Exploring and communicating treatment wishes

Any individual can face sudden, unexpected life-limiting illness or injury. Advance care planning is a process of planning for future medical care preferences if one loses decisional capacity and for preparing for death. Thus, advance care planning is appropriate for all adults 18 years of age and older, not only the subset of Americans with life-limiting illness. The process addresses surrogate decision-making and end-of-life preferences and focuses on conversation among the patient, their family, physician and other health care providers, clarification of values and beliefs and choice of a trusted surrogate to represent them when they can no longer speak for themselves. The result is completion of accessible legal documents and a commitment to periodic reassessment and update.

Absence of legal documents can result in situations illustrated by Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo.

The advance directive completion rate in our nation has not significantly increased since the passage of the Patient Self-Determination Act in 1991. Means to a Better End, the first national report card on end-of-life care, revealed only 15-20% of Americans has some form of advance directiveⁱ. It is likely that even fewer have had the open, honest conversations regarding end-of-life care wishes, the other vital component to the Advance Care Planning process.

More recently, a nationwide poll conducted by the AARP Bulletin in 2007 found that more than 90% of adults 35 or older are aware of Health Care Proxies and Living Wills, but less than 40% have actually completed these forms.ⁱⁱ Similarly, a nationwide poll conducted by the Pew Research Center in 2005 found that 95% of adults had awareness but only 29% of Americans had completed an advance directive, specifically a living will; Health Care Proxy completion rates were not addressed.ⁱⁱⁱ

Community Conversations on Compassionate Care (CCCC) Program:

Workgroup 1 Intervention - Traditional Advance Directives for All Individuals

The *Community Conversations on Compassionate Care (CCCC)* Program aims to promote conversations and actions that motivate all persons 18 years of age and older, including healthy individuals to complete traditional advance directives, not only the subset of Americans with life-limiting illness.

The CCCC Program combines storytelling with Five Easy Steps for completing an advance directive integrating Prochaska's behavioral readiness theory:

1. Learn about Advance Directives
2. Remove barriers
3. Motivate yourself
4. Complete the Health Care Proxy form
 - a. Have a conversation with your family
 - b. Choose the right Health Care Agent
 - c. Discuss what is important to you.
 - d. Understand life-sustaining treatment
 - e. Share copies of your directives
5. Review and update

The program features consistent messaging on Advance Care Planning and community resources including an advance care planning booklet, an interactive workshop, video, online resources at www.compassionandsupport.org and internal tracking and evaluation.

In addition, the CCCC Program has been integrated into care management functions as well as the new product, Healthy Blue and developed internally as a Worksite Wellness Program.

CCCC Program History:

The Initiative launched the Advance Care Planning program with a press conference in Rochester in September 2002 press conference that featured David Klein, CEO and President, Dr. Patricia A. Bomba, Vice President and Medical Director, Geriatrics, ten spiritual leaders and community members. The spiritual leaders, including Catholic, Episcopal, Jewish, and Muslim leaders, ceremonially signed their advance directives during the press conference. The spiritual leaders vouched for the role Advance Care Planning plays in end-of-life care and confirmed Advance Care Planning is consistent with the teachings of their respective faith. The community members discussed how Advance Care Planning helped alleviate the stress and burden associated with the death of a loved one. Excellus BCBS copies this format for Advance Care Planning programs launched in other regions. [View Press Conference with Spiritual Leaders.](#)

Studies have demonstrated that physician counseling markedly increases the completion rate of advance directives.^{iv,v,vi,vii,viii,ix,x} To be effective, counseling should include key elements of the advance care planning process and be individualized according to the patient's current condition and behavioral readiness to complete an advance directive.^{xi} Given physician-reported barriers of time and unwillingness to press discussions with patients, further research on effective interventions^{xii,xiii} is needed.

From the patient perspective, advance care planning is not based solely on autonomy and the exercise of control, but also on personal relationships and relieving burdens placed on others. Advance care planning is a gift to self and family that decreases turmoil and suffering at the end-of-life, thus easing the burden for families of persons with life-limiting illness. By recognizing that advance care planning does not occur solely within the context of the physician-patient relationship, counseling should include advising conversations within the patient/family unit and within relationships with close loved ones. An integrative approach to advance care planning can be provided by physician, nurse, social worker, and/or patient advocate in the primary care setting.^{xiv}

Tools and Resources:

The [Advance Care Planning booklet](#) is divided into five main sections:

1. Clarifying values and beliefs
2. Choosing an appropriate Spokesperson
3. Discussing your values, beliefs, wishes and goals of care with loved ones, your Spokesperson and physician
4. Documenting your wishes using the appropriate legal forms
5. Practical issues related to Advance Care Planning including accessibility and reviewing and updating as needed

The booklet, available in English and Spanish, is distributed free of charge by Excellus BlueCross BlueShield and is available in the advance care planning section of the [Resource Directory](#).

An interactive Advance Care Planning workshop called [Community Conversations on Compassionate Care \(CCCC\)](#). CCCC is a free one-and-a-half hour workshop designed to increase comfort with discussing death and dying through storytelling and improve community members' involvement in Advance Care Planning. The focus on storytelling is designed to engage the consumer in the conversation and motivate the behavioral change needed to participate in the Advance Care Planning program. Each attendee receives a folder of material containing the Advance Care Planning booklet, a handout of the PowerPoint presentation and a two-page outline covering the vital aspects of Advance Care Planning. View [Community Conversations on Compassionate Care \(CCCC\)](#).

To expand educational efforts on traditional advance directives, the [Community Conversations on Compassionate Care \(CCCC\) video](#) was produced. It is based on the CCCC workshop. The [CCCC video](#) is a video that aims to motivate healthy individuals to complete traditional advance directives. The program uniquely combines a storytelling approach with "Five Easy Steps" based on Prochaska's behavioral readiness theory and has been recognized by the National Quality Forum. It can now be viewed on-line at www.CompassionandSupport.org. Go to the callout area labeled CCCC video preview at the bottom of the home page of www.CompassionandSupport.org to view a 2 minute excerpt. [View the entire CCCC video along with the Five Easy Steps here.](#)

Training of Health Care Professionals:

To extend the reach of the CCCC workshop throughout Upstate New York, Excellus BCBS developed a Facilitator Training Workshop. The Facilitator Training Workshop is a full-day training session that provides the attendees with the tools needed to facilitate the workshop. This training is also ideal for individuals that deal with Advance Care Planning on a daily basis or perform one-on-one Advance Care Planning education. Topics covered in the Facilitator Training Workshop include Facilitator Skills, Workshop Logistics, Advance Care Planning along the Health-Illness Continuum, the Patient Voice in End-of-Life Transitions, Life-Sustaining Treatments and Medical Orders for Life-Sustaining Treatments (MOLST).

Each Facilitator Training Workshop attendee receives a comprehensive binder of information including the aforementioned topics, plus CCCC workshop information and facilitator supporting information. A CD-ROM, featuring the binder information in PDF format and CCCC PowerPoint presentation, is also included in the binder.

Excellus BCBS successfully trained numerous local partners to offer the CCCC workshop to the community and to facilitate discussions on Advance Care Planning on a one-on-one basis. Excellus BCBS supports the partners by supplying workshop folders and booklets. Excellus BCBS also collects post-workshop data and analyzes pre- and post-workshop data for the partners.

Pertinent resources on [Advance Care Planning](#) are available in the Web site's [section for Professionals](#), the [Resource Directory](#), and the [References](#) section.

- [Community Conversations on Compassionate Care \(CCCC\) Video](#)
- Advance Care Planning Clinical Pathways
 - [Life Expectancy >1 Year](#)
 - [Life Expectancy <1 Year](#)

Training for Patients/Families/Community:

The CompassionandSupport Web site is a community Web site dedicated to educating and empowering patients, families and professionals on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. The Web site was developed in 2001

to overcome functional health illiteracy, and was enhanced in 2007. View the [Patients & Families section](#) of the Web site.

Pertinent resources on [Advance Care Planning](#) are available in the [Resource Directory](#), along with an array of resources on related topics.

CCCC Program Outcomes Evaluation – Upstate New York Community Survey Results:

The CCCC Program's success is validated by the [End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report, 2008](#).

To assess consumer attitudes and actions regarding two important advance directives (Health Care Proxies and Living Wills), Excellus BlueCross BlueShield commissioned United Marketing Research to conduct interviews with a random sample of residents living in a 39-county area of upstate New York. Between March 6, 2008 and April 6, 2008, a total of 2,000 adults, 18 and older, were interviewed by telephone. Respondents were selected at random using a random digit dialing (RDD) sample. A quota sampling approach also was used to ensure that a meaningful number of individuals (about 400) would be surveyed within each of five regions (Rochester, Central New York, Utica, the Southern Tier and Western New York). Quotas also were established for respondents 55 and older to help minimize age bias associated with telephone surveys. The margin of error for the overall sample (n = 2,000) is approximately $\pm 2.5\%$; for each region, the margin of error was $\pm 5\%$.

Specific issues explored on the survey included:

- Awareness and knowledge of Health Care Proxies and Living Wills
- Completion rates for Health Care Proxies and Living Wills
- Attitudes toward Health Care Proxies and Living Wills
- Reasons for not completing a Health Care Proxy form
- Discussions of Health Care Proxies and Living Wills with family and personal doctor

The results from the survey are intended to provide attitudinal and behavioral assessments for two important advance directives and to identify demographic factors that have the most influence on these attitudes and behaviors.

Key findings and conclusions of the survey included:

- A significant disparity exists between attitudes and actions as they relate to two key advance directives (Health Care Proxies and Living Wills). While most adults in upstate New York feel that Health Care Proxies (88%) and Living Wills (80%) are important for them to have, only 42% have designated a Health Care Proxy and just 26% have completed a Living Will.
- Significant regional variations exist in completion rates for Health Care Proxies. The highest rate is in Rochester (47%) and lowest in Utica (35%). Evidence suggests that the difference is driven, in part, by physician communications with patients as the highest rate of discussion with doctors occurred in Rochester (47%) vs. Utica (27%). Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives.^{xv xvi xvii xviii xix xx xxi}
- Age is the most important factor affecting completion rates for Health Care Proxies and Living Wills. As people grow older, they are much more likely to engage in advance care

planning, especially after they reach age 65. Other demographic factors that influence the decision to act include gender and level of education.

- Age, gender, and level of education also affect awareness of and attitudes toward advance directives. In general, women and adults age 35 and older are more likely to perceive Health Care Proxies and Living Wills to be important.

CCCC Program Outcomes Evaluation – Serial Employee Healthcare Decisions Survey Results:

The CCCC Program's success is also validated by the serial increase in completion rates among Health Plan employees.

- [View the on-line 2008 Employee Healthcare Decisions Survey.](#)
- [View the Employee Healthcare Decisions Survey Report, 2008.](#)

An advance care planning employee campaign held in October through November 2007 was initiated by an email message from CEO David Klein followed by a series of emails from Dr. Patricia Bomba, a national expert on advance care planning. Interventions utilized were developed in response to information derived from the 2006 Employee Healthcare Decisions Survey and included educational sessions, web-based information, the *Community Conversations on Compassionate Care* video and financial incentives.

In 2002 and 2006, Excellus BlueCross BlueShield conducted surveys of all its employees to assess their knowledge and actions regarding two key advance directives, Health Care Proxies and Living Wills. During the four-year period extending from 2002-2006, the completion rates for Health Care Proxies rose from 30% to 34% among employees, while completion of Living Wills remained essentially unchanged (18% in 2002 vs. 17% in 2006).^{xxii xxiii}

Few studies on advance directives have been conducted nationally. A nationwide poll conducted by the *AARP Bulletin* in 2007 found that more than 90% of adults 35 or older are aware of Health Care Proxies and Living Wills, but less than 40% have actually completed these forms (37% reported completing a Health Care Proxy and 36% a Living Will).^{xxiv} Similarly, a nationwide poll conducted by the *Pew Research Center* in 2005 found that 95% of adults had awareness but only 29% of Americans had completed an advance directive, specifically a living will; Health Care Proxy completion rates were not assessed.^{xxv}

In February 2008, Excellus conducted a third wave of the Employee Healthcare Decisions Survey (Employee Survey) to see whether employee knowledge and behavior regarding advance directives had changed over the past two years. The survey instrument and methodology were nearly identical to that used in the previous, 2006 Employee Survey. In both studies, an online methodology was used. On February 8th, all 4,343 Excellus Health Plan employees were sent an email inviting them to participate in the survey. Two follow-up emails were sent to non-respondents within two weeks of the initial mailing to help improve the response rate. Of the over 4,300 surveys sent to employees, 2,314 or 53% responded, about the same response rate reported in 2006 (52%). The response rate obtained in the 2002 Survey was significantly lower (only 35%), even though the survey tool used in that survey was much shorter (only 6 questions, compared with 23 questions in the 2006 and 2008 Surveys). However, the 2002 Survey was conducted by mail (not online) and only one survey was mailed to employees.

Some key findings include:

- During the past two years, the completion rates for Health Care Proxies and Living Wills have risen significantly within the Excellus employee population. Overall, the completion rate for Health Care Proxies now stands at about 43% for employees, up from 34% in 2006.
- Significant regional differences exist in completion rates for Health Care Proxies, a finding that was observed in the Community Survey as well. Completion rates among employees are highest in WNY (51%) and Rochester (45%) and lowest in Utica (31%).
- The completion rates for employees are somewhat higher than those of the upstate community, after adjusting for differences on key demographic factors known to significantly impact completion rates (e.g., age, region, gender).
- Comparisons of the employee results with those obtained from recent national surveys (e.g., AARP Bulletin, Pew Research) are difficult to make, due to significant differences between the demographics of our employee population and the populations targeted in the national surveys. The demographics of the populations surveyed are quite different, particularly with regard to age which has been shown to be a key factor in driving completion rates.
- Evidence from both the Employee and Community Surveys suggests that regional differences in completion rates may be driven, in part, by physician communications with patients. In both surveys, the highest rate of discussion with doctors occurred in Rochester while the lowest rate was observed in Utica.
- Further, evidence from the Employee and Community Surveys suggest community education makes a difference. Higher completion rates are present in regions where community education efforts have been initiated.
- Some evidence suggests that young adults (ages 18 to 24) can respond to behavioral interventions and be motivated to take action and complete a Health Care Proxy. Completion rates among young adult (ages 18 to 24) employees (25%) were noticeably higher than young adults in the community (9%).
- Personal experience with the end-of-life care of others appears to play a major role in the decision to designate a Health Care Proxy. Nearly half of those who had completed a Health Care Proxy form mentioned personal experience as playing a significant role in their decision to act.
- The results support the view that an advance care planning employee campaign that utilizes interventions that include incentives can motivate employees to take action to complete a Health Care Proxy.

CCCC Process Measures:

In addition, Excellus BCBS has a number of tracking and evaluation mechanisms to track and continuously improve the CCCC Program, including:

- number of booklets distributed
- number of web downloads made
- number of CCCC presentations given
- number of attendees at each presentation is tracked
- effectiveness of the CCCC workshop using the *Health Care Proxy Readiness Form* designed by Dr. Patricia Bomba, Dr. Andrew Doniger and Dan Vermilyea
- *CCCC Program* and *CCCC Facilitator Training Workshop* Evaluation forms

Number of booklets distributed:

To date, more than 350,000 copies of the Advance Care Planning booklets have been distributed throughout our service area. In addition, the booklet is available to download on both the corporate and community web sites.

During the prominent media exposure of the Terri Schiavo situation, Excellus BCBS distributed more than 22,000 copies of the booklet. In the same time period, an additional 28,176 Advance Care Planning booklets were downloaded from the web.

Number of web downloads made:

With the growth of the Initiative and concrete projects, the community web site www.CompassionandSupport.org was enhanced and launched on July 31, 2007. Google Analytics confirms a total of 24,371 visits from 17,829 unique visitors from 100 countries from inception through April 19, 2008. 22,209 visits from across the country, including 60% from New York State. Further, 166 title pages on this site were viewed a total of 85,826 times; 10 title pages containing "advance care planning" were viewed 5,431 times.

Number of CCCC presentations given, Number of attendees and Number of trained facilitators:

Since the CCCC workshop was created and as on December 2007, a total of 5,521 individuals attended one of the 241 free CCCC workshops offered to community members, internal employees and healthcare professionals. 422 trained facilitators are available throughout our service region to provide workshops and 1 on 1 facilitated discussion. The workshops were held throughout the community, including the workplace, senior living communities, houses of worship, community organizations, doctor's offices, hospitals and nursing homes. Trained facilitators track workshops but have not provided data on the number of 1 on 1 facilitated discussion.

Effectiveness of the CCCC workshop using the Health Care Proxy Readiness Form:

Data on the CCCC Workshop shows the workshop format motivates individuals to complete an advance directive; [view CCCC Pilot Results](#).

For those who attend a CCCC Workshop, 48% of those in attendance had an advance directive; 55% had an advance directive 6-8 weeks later. The difference is statistically significant (p-value = .01).

CCCC Program and CCCC Facilitator Training Workshop Evaluation forms:

Evaluations have consistently received high scores, generated positive feedback and interest in further training.

Needs Assessment for Actionable Medical Orders for Seriously Ill Patients

Workgroup 2 Ensuring patient wishes are identified and honored at all sites of care

Humane care for those approaching death is a social obligation not adequately met in the communities we serve. Too often, death is viewed as a medical failure rather than the final chapter of life. As a result, many people fear a protracted, technologically-overtreated death, abandonment during a time of need and profound suffering of self and family. Currently, conversations about death are too frequently avoided until a crisis occurs, resulting in inadequate Advance Care Planning and patient preferences not being known or honored. Surveys reveal more than 70 percent of surveyed Americans indicated that they wish to die at home. Yet, only 25 percent of Americans die in their home and 75 percent die in institutions^{xxvi}.

Since the Patient Self-Determination Act passed in 1991, the current system of communicating end-of-life care wishes solely using traditional advance directives, such as the living will, has proven insufficient. Traditional directives require individuals to recognize the importance of Advance Care Planning, understand medical interventions, evaluate personal values and beliefs and communicate their wishes to their agents, loved ones, physicians and health care providers. Unfortunately, even if this happens, traditional directives are often overlooked, ignored or not communicated once the individual enters the health care system.

Too often, advance directives are ignored in favor of continuing life-sustaining treatments out of fear of a negligent or wrongful death lawsuit from family and/or loved ones instead of honoring the wishes expressed in the directives.^{xxvii} Continuing to administer life-sustaining treatments beyond the patient's wishes is not without risk either. Numerous lawsuits, including Klavan v. Chester Crozier Medical Center et al., Estate of Leach v. Shapiro and Anderson v. St. Francis – St. George Hospital, Inc., found health care professionals can be held liable for medical malpractice, battery and/or negligence if life-sustaining treatments provided contradict expressed patient wishes^{xxviii}.

Further, there are significant regional variations in the cost of care, percentage of deaths occurring in hospitals and other measures of end-of-life care. High-spending regions reveal more inpatient-based and specialist-oriented care. However, there is no improvement in health outcomes, including mortality rates, quality of care, access to care or patient/family satisfaction.^{xxix}

A study by W.M. Tierney et al. found that elderly patients with chronic illnesses that discussed advance directives with their primary care physicians showed significantly greater satisfaction with their care than those who did not have advance care planning discussions. The strongest predictor of satisfaction with care was the presence of advance care planning discussions.^{xxx}

Unfortunately, traditional directives like the living will apply to future circumstances, require further interpretation by the agent and health care professionals and do not result in actionable medical orders. The situation is further complicated by the difficulty in defining “terminal” or “irreversible” conditions and accounting for the different perspective of physicians, agents and loved ones. For example, a patient with dementia nearing the end-of-life eats less, has difficulty managing secretions, aspirates and often develops pneumonia. While end-stage dementia is “terminal”, pneumonia may be potentially “reversible”. Decisions regarding care depend on interpretations of prior conversations, physician's estimates of prognosis, and, possibly, the personal convictions of the physician, agent and loved ones. The presence of the living will does not help clarify the patient's wishes in the absence of antecedent conversation with the family, close friends and the patient's personal physician. A study by Ditto et al. discovered that family members correctly identified the patient's wishes less than 70 percent of the time. Additionally, family members were two to three times more likely to choose over-treating versus under-treating the patient.^{xxxi}

Medical Orders for Life-Sustaining Treatment (MOLST) Program
New York State's Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program
Workgroup 2 Intervention - "Actionable Medical Orders" for Seriously Ill Patients

The MOLST Program is designed to improve the quality of care people receive at the end of life and is based on effective communication of patient wishes, documentation of medical orders on a brightly colored form and a promise by health care professionals to honor these wishes.

Effective communication between the patient or legally designated decision-maker and health care professionals ensures decisions are sound and based on the patient's understanding of their medical condition, their prognosis, the benefits and burdens of the life-sustaining treatment and their personal goals for care.

MOLST is one of six endorsed [POLST Paradigm Programs](#) nationally.

MOLST Program History:

MOLST is consistent with PHL§2977(3) and is used in all counties and all settings statewide. This was accomplished through collaborative work with the NYSDOH and legislative advocacy.

The MOLST Program is a project of the [Community-Wide End-of-life/Palliative Care Initiative](#) (Initiative), a community collaborative that focuses on implementation of a set of broad end-of-life/palliative care projects that result in quality improvements in the lives of those facing death.

- [View information on the Initiative.](#)
- [View outcomes of the Initiative.](#)

Through [leadership](#) and administrative support for the Initiative provided by Excellus BlueCross BlueShield, the Initiative, originally based in Rochester, has spread through the Health Plan service region in Upstate New York. With the MOLST Program, the reach of the Initiative extends across New York State. The success of the Program is attributable to partnerships with the New York State Department of Health, statewide professional associations, particularly the Medical Society of the State of New York, and healthcare and community collaborative partnerships throughout New York State.

Short-term goals were set:

- Consistent uniform application of the Medical Orders for Life-Sustaining Treatment (MOLST) program.
- Successful MOLST Community Pilot and adoption of a MOLST as a statewide program.
- Expanded cadre of volunteers prepared to engage in one-to-one and community conversations regarding end-of-life issues, options and the value of advance directives, including the MOLST form.

Short-term goals have been achieved.

Long -term goals were set:

- Informed and prudent use of life-sustaining technologies and intensive care services.
- Greater efficiencies in health care delivery.
- Improved patient and family satisfaction.
- Reduction in costs associated with medical liability and defensive medicine by providing physicians an efficient framework for discussing end-of-life options.

Six key steps were employed in the development and implementation of the Initiative and its projects like the MOLST Program:

1. Define Vision, Mission, Values
2. Employ results-oriented approach
3. Design effective, inclusive coalition membership
4. Create effective leadership
5. Demonstrate strong commitment to purpose
6. Monitor performance

The MOLST Program began with creation of a [MOLST Creation Workgroup](#) in Fall 2001. The form was completed in November 2003. MOLST was adapted from Oregon's POLST and integrates NYS Public Health Law. Implementation began on a voluntary basis in Rochester health care facilities shortly thereafter. A broader regional launch in January 2004 resulted in expansion to surrounding counties. As a result of discussion of the MOLST program at the Education for Physicians on End-of-life Care (EPEC) conferences sponsored twice annually in Upstate New York by Excellus BlueCross BlueShield, [EPEC faculty](#) and participants advocated for implementation in other regions in Upstate New York. Community consensus on the use of the MOLST program in Onondaga County was achieved in September 2004 and implementation of MOLST began in hospitals and long-term care facilities in Spring 2005. Interest in initiating the program has been raised in Utica, Cooperstown, Buffalo and other areas of Western New York and is currently underway. Expanding awareness of the MOLST program in Downstate New York is a result of professional collaborations in state organizations, through the Internet and Web sites and through attendance at the [Honoring Patient Preferences, The Role of Medical Orders for Life-Sustaining Treatment \(MOLST\) Conference](#) held in November 2005 in Rochester and collaborative work of the New York State Department of Health and the Greater New York Hospital Association.

As regional adoption ensued, simultaneous collaboration with NYSDOH began in March 2004. As a result, a revised form consistent with New York State Law was approved by the New York State Department of Health (NYSDOH) for use as an institutional DNR in ALL health care facilities throughout New York State in October 2005. NYSDOH sent a Dear Administrator Letter (DAL) on January 17, 2006 confirming its approval. [View the DAL Letter](#). This approval did not require legislative action but achieved significant growth in the MOLST Program across the state.

With passage of the MOLST Pilot Project Legislation (PHL § 2977(13)) (2005) and the Chapter Amendment (2006), New York State Department of Health (NYSDOH) approved the MOLST for use in the community as a Nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) in Monroe & Onondaga counties. A Monroe and Onondaga Counties MOLST Community Implementation Team (M & O TEAM), led by Dr. Bomba with administrative support from Excellus BlueCross BlueShield, was formed to oversee the pilot. A detailed work plan and timeline was prepared and commitment to the development of several final products was confirmed. [View the M & O Team](#).

Target performance outcome measures were established including:

- 1) New York State will amend public health law and make MOLST permanent and statewide
- 2) Patient preferences will be honored at the end-of-life.

Several process measures were created. Data sources were identified. Regular reporting of the data to the M & O Team and the New York State Department of Health was operationalized.

In addition to collaboration with the New York State Department of Health (NYSDOH), the MOLST Community Implementation Team partnered with the Medical Society of the State of New York (MSSNY), the Healthcare Association of New York State, New York State Health Facilities Association (NYSHFA), the New York Association of Homes and Services for the Aging (NYASHA), the Hospice and Palliative Care Association of New York State (HCPCANYS), New York State Office for the Aging (NYSOFA), New York State Society on Aging (NYSSA), New York State Bar Association (NYSBA), the Greater New York Hospital Association (GNYHA), and other professional associations, health care facilities, systems and agencies across NYS. [View a full list of collaborators.](#)

A successful MOLST Pilot Project resulted in Governor David Paterson signing into law a bill that made MOLST permanent and statewide, thereby changing the scope of practice for EMS across New York State. MOLST is consistent with PHL§2977(3) and cannot be altered. MOLST has been reviewed annually since 2005, complies with New York State Public Health Law, and has been adapted to meet clinical needs. [View the press release.](#)

Legal Barriers Overcome:

Nonhospital DNR Law before MOLST (PHL § 2977) dictated a DNR order must be on “standard form” issued by the Department of Health; by contrast, a hospital-based DNR order can be on any form. The “standard form” is a one page form with little detail beyond instruction not to resuscitate. Further, the Nonhospital DNR can be honored ONLY if patient is in FULL cardiopulmonary arrest. If the patient is NOT in full cardiac or respiratory arrest, FULL treatment must be provided. DNI was NOT covered in Nonhospital DNR law.

The MOLST Pilot Project Legislation (PHL § 2977(13)) permitted the New York State Department of Health to authorize using the MOLST form in lieu of the Nonhospital DNR in Monroe and Onondaga Counties. The “standard form” did NOT need to be used in pilot counties. The Regional Pilot in Monroe and Onondaga Counties was approved by NYSDOH in October 2005.

Because DNI was not covered in Nonhospital DNR Law (Public Health Law § 2977), passage of the 2006 Chapter Amendment permitted EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during the MOLST Community Pilot. The law provided for a carve-out for persons with Mental Retardation (MR) and Developmental Disabilities (DD) without capacity. Public Health (PH) DNR law for persons with MR/DD without capacity remained the same as it would be without MOLST. Persons with MR/DD with capacity could complete a MOLST form.

In Pilot counties, EMS personnel followed orders on the MOLST form for individuals living in Monroe and Onondaga counties. For individuals living in Monroe and Onondaga counties, a completed MOLST form could replace the NYS Nonhospital DNR form. For individuals living outside Monroe and Onondaga counties, the NYS Nonhospital DNR form had to be completed in addition to the MOLST. A MOLST form provided “clear and convincing evidence” to EMS Medical Control outside Monroe and Onondaga counties.

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State Laws and Regulations:

MOLST is consistent with PHL§2977(3) and can be used in all settings statewide. [View pertinent legislation and regulation.](#)

Facility Implementation of MOLST Program:

Use of the MOLST form has been integrated into policies and procedures regarding advance care planning at area hospitals and long-term care facilities. Permission has been granted to share sample policies and procedures with other systems throughout the state. [View samples of policies and procedures.](#)

Management:

The Community-Wide End-of-life/Palliative Care Initiative provides oversight of the MOLST Program. Statewide development and implementation efforts have been spearheaded by Dr. Pat Bomba, with Excellus BlueCross BlueShield generously providing support for legislative advocacy and administrative support for operations, including development, distribution and fulfillment of MOLST support materials and resources, education and training, quality improvement, monitoring performance and sharing best practices & lessons learned.

MOLST resources can be ordered online by using the [order form](#). The process for ordering MOLST materials has been enhanced as the program has grown and is moving to online ordering.

Training of Health Care Professionals:

To support statewide implementation and training needs, several final products were developed, including, but not limited to:

- [MOLST Training Center](#)
- [MOLST Training Videos with online CME/CE credits](#)
- [Tube Feeding Guidelines](#) developed by the [PEGS Workgroup](#)
- [Community Conversations on Compassionate Care \(CCCC\) Video](#)
- Advance Care Planning Clinical Pathways
 - [Life Expectancy >1 Year](#)
 - [Life Expectancy <1 Year](#)

Funding for production of the MOLST DVD and enhancement of the community web site www.CompassionandSupport.org was obtained through the Medical Society of the State of New York and Excellus BlueCross BlueShield Community Initiatives.

The [MOLST DVD](#) was produced to educate and empower patients and families and serve as a standardized training tool for professionals. The MOLST DVD is a statewide initiative presented by the Medical Society of the State of New York and Excellus BlueCross BlueShield in collaboration with the New York State Department of Health and the Monroe and Onondaga Counties MOLST Community Implementation Team. Development was led by the [MOLST DVD and Web-based Tools Subcommittee](#).

The **MOLST DVD** includes 2 videos and 3 refresher videos:

- “Writing Your Final Chapter: Know Your Choices...Share Your Wishes” is designed to inform patients, families and professionals about MOLST.
- “Honoring Patient Preferences: The Role of Medical Orders for Life-Sustaining Treatment (MOLST) in New York State,” an educational video for professionals, provides the core curriculum on MOLST.

Healthcare professionals can earn a maximum of 2.0 free educational credit hours by viewing both videos and completing the MOLST DVD posttest. Follow the simple steps on the [MOLST Training Video page](#).

Professionals are encouraged to share the MOLST DVD with seriously ill patients and their families. The videos and additional information can also be viewed at www.CompassionandSupport.org, specifically at the [MOLST Training Center](#).

Subsequent to passage of the MOLST legislation, a new web page was launched for statewide [EMS MOLST Training](#).

There are many resources available in the Web site's [section for Professionals](#), the [Resource Directory](#), and the [References](#) section. Professionals stay informed via the [News & Events](#) and [Current News](#). Upcoming opportunities are available at [Current Events](#); [online registration](#) is available for Initiative events.

Training for Patients/Families/Community:

The CompassionandSupport Web site is a community Web site dedicated to educating and empowering patients, families and professionals on advance care planning, MOLST, palliative care, pain management and hospice care and related topics. The Web site was developed in 2001 to overcome functional health illiteracy, and was enhanced in 2007. View the [Patients & Families section](#) of the Web site.

The award-winning video, [“Writing Your Final Chapter: Know Your Choices...Share Your Wishes”](#) is designed to inform patients, families and professionals about the MOLST Program.

CQI Projects and Research:

Initially, the project primarily focused on implementation, education and expansion. Excellus BlueCross BlueShield has developed an internal tracking system to monitor the distribution and fulfillment process of MOLST forms and guidebooks. As part of the implementation process, a survey of long-term care facilities in Rochester was done in January 2005 to share implementation issues, barriers and lessons learned with long-term care facilities in Onondaga and other counties.

A MOLST Quality Audit tool was developed to assess accuracy of form completion to support the MOLST Community Pilot. [View the Quality Improvement tool](#). Quality audits were conducted in 2006 and 2007. MOLST Quality Forums were held in both Monroe and Onondaga Counties in January 2008. [View the MOLST Quality Forum presentation](#). Results showed improvement in accuracy of form completion for both DNR and Life-Sustaining Treatment orders. Patient or Health Care Agent consent was present 100% of the times.

With regards to the Community MOLST Pilot Project, performance measures included:

- *Ability of out-of-hospital healthcare providers and first responders to correctly interpret and use the MOLST form*
- *Appropriate use of both Non-hospital DNR and MOLST forms by EMS regarding provision of CPR, intubation and appropriate transfer to hospital in accordance with patient wishes in Monroe and Onondaga Counties*
- *Regional utilization of the MOLST form and program for the appropriate cohort of patients in Pilot Counties*
- *MOLST training for EMS and first responders*

- *MOLST training per facility/organization*
- *MOLST utilization and degree of penetration in facility/organization/per county/region*
- *# MOLST forms and “Supplemental” Documentation Adult and Minor forms*
- *# MOLST educational booklets for health care professionals requests*
- *# MOLST educational brochures for patients and families requests*

Identified data sources include:

- EMS Quality data
- MOLST Facility Implementation Survey data in Monroe and Onondaga Counties
- MOLST Quality Improvement data, utilizing the MOLST QI Audit Tool
- Tracking data on distribution of MOLST educational resources across New York State
- Tracking data on MOLST educational sessions, conferences, training sessions
- Google Analytics on the community web site, www.CompassionandSupport.org.

Results are shared to facilitate best practice. [View the Research results.](#)

Initiative Links to National Efforts:

The Initiative aligned its efforts with the National Quality Forum’s Preferred Practices for Hospice and Palliative Care^{xxxii} published in 2006. Adapted for New York State, the preferred five practices for advance care planning include:

1. Document the designated agent (surrogate decision maker) in a Health Care Proxy for every patient in primary, acute and long-term care and in palliative and hospice care.
2. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as condition changes.
3. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, i.e., the Medical Orders for Life-Sustaining Treatment—MOLST, a POLST Paradigm Program.
4. Make advance directives and surrogacy designations available across care settings
5. Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals (e.g. Respecting Choices and Community Conversations on Compassionate Care)

ⁱ Means to a Better End: A Report on Dying in America Today, November 2002, p.9.

ⁱⁱ http://assets.aarp.org/rgcenter/il/getting_ready.pdf. Last accessed April 11, 2008

ⁱⁱⁱ <http://people-press.org/reports/pdf/266.pdf> Last accessed April 11, 2008

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