



ANNUAL REPORT

PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE

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Submitted by:

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in partnership with members of the Palliative Care and Pain Management Task Force

I. PURPOSE

This report is submitted per Act 25 (2009) to the House Committee on Human Services and the Senate Health & Welfare Committee regarding recommendations, progress and activities related to the work of the Palliative Care and Pain Management Task Force.

II. RECOMMENDATIONS

Access to Opioids for Patients with Serious Illness and Those at End-of-Life:

The use of opioids remains a necessary and important tool in the management of some symptoms for patients with serious illness and/or at end-of-life. As Vermont continues its work to address the complex issues surrounding opiate use and abuse, it remains of critical importance that any revisions to current policy and any future proposed policies protect access to appropriate pain medication for hospice and hospice-eligible patients.

III. BACKGROUND INFORMATION

In 2014 the Institute of Medicine's report, *Dying in America: Improving Quality and Honoring Individuals Preferences at the End of Life*, called for systemic improvements in advance care planning and clinician-led conversations about goals, values and care preferences for patients with serious and life-threatening illness.ⁱ Such conversations are the hallmark of high quality, patient-centered palliative care. Numerous studies confirm that appropriately timed advance care planning conversations are associated with improved quality outcomes for patients and their families, including: better quality of life, reduced use of non-beneficial medical care near death, enhanced goal-concordant care, and reduced costs. The preferred and endorsed practices for palliative and hospice care by the National Quality Forum (NQF) and the National Consensus Project for Quality Palliative Care state that communication, shared decision making, and advance care planning are central to quality care for people with serious illness.ⁱⁱ In light of these recommended and preferred practices, palliative care educational efforts across that state are being directed at these core elements of communication and advance care planning.

IV. STATEWIDE & REGIONAL EFFORTS

Statewide Palliative Care Conference: In June of 2018, the Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force, hosted the 9th annual statewide palliative care conference, *Mastering Tough Conversations*. Approximately 150 interdisciplinary professionals from both Vermont and New Hampshire attended this event. The goal of the event was to cultivate & improve the skills necessary to master tough conversations with seriously ill patients in a range of settings—including the emergency department.

Plenary speakers featured Corita Grudzen, MD - Vice Chair of Research in the Ronald O. Perelman Department of Emergency Medicine & Associate Professor of Emergency Medicine & Population Health at NYU School of Medicine; Patricia Bomba, MD - Vice President & Medical Director, geriatrics, for Excellus BlueCross BlueShield of New York, and Robert Gramling, MD, the Holly and Bob Miller endowed Chair of Palliative

Medicine & Chief of the Division of Palliative Medicine at UVM Medical Center. These national experts presented content on mastering difficult conversations, palliation in the emergency department and the importance of portable medical orders. In addition to these speakers, breakout sessions were offered on shared decision-making in the absence of terminal disease, expanding advance care planning opportunities in the community and a review and update on Vermont's medical aid in dying law.

The Task Force is currently working on plans for the 2019 spring statewide conference. The theme in 2019 will focus on truth-telling and communication challenges for seriously ill patients amidst high emotion, denial and prognostic uncertainty.

Vermont Ethics Network (VEN): For over three decades a primary of focus of VEN's work has been to promote best practice in medical decision-making and appropriate use of advance care planning tools (i.e. advance directives, DNR/COLST orders, the Vermont Advance Directive Registry, etc.) across the state. Ethical obligations to provide care that is reflective of an individual's goals and values necessitates shared decision-making and conversations about preferences and priorities in the context of personal health. Studies routinely confirm that advance care planning is integral to excellent palliative care and is best implemented in stages, where discussions are appropriately aligned with patient needs and readiness to engage.

In FY18, VEN conducted over 40 educational workshops and trainings for both community and health care providers across the state on topics related to advance care planning, medical decision-making and care at the end-of-life. Additionally, VEN responded to over 400 calls and emails from across the state, with 4381 new registrants added to the Vermont Advance Directive Registry during this time. In this first half of FY19 over 20 workshops and trainings have been conducted and VEN has responded to over 247 calls and email inquiries pertaining to specific questions related to medical decision-making, advance directives, DNR/COLST orders, VADR and physician aid in dying (Act 39).

The Vermont Ethics Network's *Taking Steps Vermont* program, an education and resource initiative promoting a step-wise approach to advance care planning, was launched in early 2016.



Due to its success and increased interest from stakeholders, in the summer of 2018 VEN hired an advance care planning community outreach coordinator specifically to help coordinate this work in the community with regional and local champions from across the state. Highlights from local and statewide initiatives are summarized below:

- ***Taking Steps Brattleboro:*** Taking Steps Brattleboro is a program of Brattleboro Area Hospice. This project utilizes trained volunteer facilitators to support completion of advance directives in Windham County. Activities in 2018 included two weeks of events to promote Advance Care Planning in April in conjunction with the National Health Care Decision week.
 - A street banner was hung across Main Street promoting Advance Care Planning as A GIFT TO THOSE WHO LOVE YOU and included an image of an I DID MINE button. Actual buttons were given to everyone who had completed a directive with the program. The banner will go up each April to promote advance care planning activities.



Other activities included:

- A one week window display at the local Chamber of Commerce.
- A 50/50 raffle at a local concert of Rock Voices to benefit the project.
- The Hospice play VESTA was presented at the Brattleboro Museum and Arts Center with a panel discussion given at the Public Library. The panel was comprised of 5 community professionals discussing Advance Care Planning from their perspective.
- A week of River Garden brown bag lunches on Advance Care Planning including a talk by the local rescue squad.
- The local museum Curator arranged to have the original artwork for the book CAN'T WE TALK ABOUT SOMETHING MORE PLEASANT by the well known New Yorker cartoonist, Roz Chast, who also gave a talk to a sold out audience in August.
- Two independent film showings about end of life.



Finally, in 2018 Brattleboro Memorial Hospital began robust promotion of the Taking Steps initiative. Starting in June, every Wednesday a resource table staffed by volunteers is set up for three hours so that consumers may get information and make appointments for individual advance directive facilitation. Hospital registrars give anyone without an advance directive the BAH post card size handout about free Advance Care Planning support. The hospital computers, big screen TV and phone “please hold message” promote the importance of completing advance directives. Numbers of referrals from the hospital and local primary care practices have grown exponentially.



In 2019, BAH will offer a volunteer training to expand their resources to meet the growing number of people asking for help with advance directives.

- **Chittenden & Grand Isle Counties - *Who’s Your Person... What’s Your Plan?*** is a collective impact initiative of nine organizations (Age Well, BAYADA, Cathedral Square, Howard Center, OneCare Vermont, Support and Services at Home (SASH), The University of Vermont Medical Center, The University of Vermont Health Network Home Health & Hospice, Vermont Ethics Network) working in Chittenden and Grand Isle Counties to:

- **Partner with local businesses and organizations** to provide information and educational opportunities for staff and employees to plan for future medical decisions.
- **Encourage everyone** who is 18 years of age or older to take the first step in the advance care planning process and appoint a health care agent.
- **Engage the community** in discussing and planning for future health care needs.
- **Normalize conversations** about health care values, preferences and priorities.

Since the initiative began in July 2016, the group has conducted **41 community presentations** on advance care planning (including facilitated screenings of the PBS Frontline documentary *Being Mortal*) at area businesses, nonprofit organizations, local libraries, district offices of state agencies, local rotary clubs, assisted living facilities, and office practices. Through those presentations, **over 900 people** have been reached with advance care planning education. The initiative has **17 trained facilitators** and is in the process of training approximately **25 more**. Their community outreach initiatives have reached thousands more through digital ads, op-eds, a bus wrap, a ballpark sign, wellness fair tabling, etc.

Data collection from the project to date demonstrates an upward trend in advance directive completion:

- **The University of Vermont Medical Center** (as of December 2018): UVM Medical Center data indicates an increase of 69% in patients who indicated that they have an advance directive upon hospital admission between FY15 (just before this initiative began) and FY18, which ended September 30. In FY19 (in progress), the data shows that 19.7% of patients have indicated the presence of an advance directive, as compared to 7.88% in FY15, 9.72% in FY16, 12.2% in FY17, 13.3% in FY18 – a continuous upward trend.
- **Presentation Evaluations** (as of December 2018): Presentation evaluations indicate that 31% of attendees had no knowledge of advance care planning prior to attending a training and 82% were motivated to complete an advance directive afterward.
- **Post-Presentation Email Follow Up Survey** (as of December 2018) E-mail follow-up survey results (sent several months after attendance of a presentation) show that 75% of respondents have since had conversations with family and friends about health goals and priorities, 55% have appointed a health care agent, and 50% have completed a detailed advance directive.
- **Website Traffic** (as of December 2018) Website access data shows the following increase in visitor traffic in the second half of 2018, as compared to the same period in 2017:

- 172% increase in access of the Taking Steps Vermont page (takingstepsvt.org).
- 37% increase in access of the Who’s Your Person...What’s Your Plan? initiative page on the Vermont Ethics Network (VEN) website.
- 71% increase in access of the Appointment a Health Care Agent form on the VEN website.*
- 32% increase in access of the general advance directive forms page on the VEN website.*

*While these last two statistics cannot be directly attributed to the work of this regional initiative, a portion of the increased traffic is likely due to their efforts.

- **Central Vermont Medical Center (CVMC)/Berlin HSA - Increasing the Use of Hospice Care:** As part of the goals of the Berlin HSA’s Unified Care Collaborative Community Alliance for Health Excellence, an effort continues to increase the use of hospice care in this region. The average daily census of hospice patients at CVHHH and Bayada has been increasing, as has the average length of stay. Efforts to increase the use of hospice care in this region have focused on three areas:
 - **Community Outreach:** Approximately 325 adults have had conversations with the project via the “Who’s Your Person, What’s Your Plan?” initiative. These informational day-long sessions are held quarterly at CVMC.
 - **Provider Education and Training:** Annual continuing medical education sessions at CVMC, and targeted session on advance directives and DNR/COLST preparation are planned for 2019 at Woodridge Rehabilitation and Nursing. *TalkVermont*, an intensive daylong training program led by UVMC and CVMC faculty in mastering tough conversations with seriously ill patients, was launched locally in December 2018, training of 18 practitioners and a second session is planned for May of 2019.
 - **CVMC Palliative and Spiritual Care:** The expansion of this department is one of ten hospital-wide strategic initiatives targeted by CVMC for 2020 to address the need of seriously ill patients.

Bayada: BAYADA Hospice continues to provide hospice care to all of VT with offices in Norwich, Shelburne, Rutland and Brattleboro with an average daily census of 325. We have provided over 75,500 hours of direct patient care and are currently serving over 1000 families on our bereavement program. Our BAYADA Support program (Medicare Care Choices Model) averages a census of 10. Our plan to increase the census was altered due to the limited nursing resources in the state. As our traditional hospice program grew we needed to pull RN resources from our palliative program. BAYADA Hospice is dedicated to continue working with CMS innovation center to inform on future models of palliative care.

Rutland Regional Medical Center (RRMC)

The Palliative Care Program at RRMC was established in 2005 using a nurse-led model to support the established hospital care teams. In Fiscal Year 2017-2018 a team of three full-time and one per diem nurses provided on-site support seven days a week for a total of 1065 consultations to hospitalized patients with serious, chronic, or life-threatening conditions.

With the goals of expanding access to palliative care services in the community and increasing utilization of hospice care, the RRMC Palliative Care Team collaborates closely with Bayada Hospice and the Visiting Nurse Association and Hospice of the Southwest Region (VNAHSR). Education has been the main focus for these collaborative efforts. For professionals, the Hospice programs have offered a non-branded inservice to primary care practices across the county and CME presentations on hospice, palliative care and end-of-life decision-making. Shadowing with the Palliative Care Team has been included as a standard component of hospital orientation for newly hired and new graduate nurses, and is also offered electively to nursing students completing their clinical rotations at RRMC. For community education there have been biannual end-of-life film discussion events and seminars on advance directives.

The most recent collaborative project for the Rutland community hospice and palliative service providers is the formation of a task force to identify opportunities to provide access to palliative care for non-hospitalized patients who do not qualify for homecare-based services.

University of Vermont Health Network – Porter Medical Center: In February, 2017 a new part time pilot Palliative Medicine service was started at UVMHN-PMC. One MD working .3 FTE began to provide Palliative Care consultation services to patients at Porter Medical Center and Helen Porter Rehabilitation and Nursing. In order to measure success, a target number of consultations were established for the service. The service quickly became very busy, surpassing the target number of consults in the first few months. Demand was high enough that on May 1, 2018 the position was changed to .4 FTE. At the conclusion of FY 2018, the target number of consults had nearly doubled. Feedback from consultants, patients, families and the local community are very positive. Unfortunately, many consults had to be declined due to limited work force capacity.

Due to the success of the initial pilot, plans are currently underway to finalize approval for increasing Palliative MD time to .8 FTE with hopes that this will come close to covering the need at UVMCHN-Porter Medical Center and UVMHN-Helen Porter Rehab and Nursing. There are ongoing discussions to develop a plan to eventually expand Palliative Medicine services to the outpatient arena. Community interest in this remains high. Leadership at Porter Medical Center are navigating conflicting priorities as they balance many needs. In the current fee for service landscape, financial concerns about funding the service are the largest limiting factor for expanding more quickly.

In addition to direct clinical care, Palliative Medicine actively participates in the “Living with Dying” partnership; a multi-agency organization (ARCH, HVS, ACHHH, Porter Medical Center, Helen Porter) which has provided several clinical and community

presentations on a variety of advance care planning and end-of-life issues. The group publishes a monthly column in the local Addison Independent. There are plans to expand this work in 2019, including a *TalkVermont* (serious illness communication) workshop for providers which is scheduled for April.

University of Vermont Medical Center Palliative Care Service: Since establishing the Division of Palliative Medicine within the Department of Family Medicine at UVM in 2016, the program has been growing in clinical services, teaching programs, and research/innovation. The core group includes 5 physicians, 3 nurse practitioners, and 1 nurse with a closely affiliated chaplain and social worker and recently added pharmacist and psychiatrist.

During this past year, the UVM team was consulted more than 1600 times to care for seriously ill hospitalized adults and children. They have been offering TeleConsult follow-up home visits, outpatient consultations at Milton Family Practice, outpatient consultations at the Cancer Center, outpatient consultations for ALS patients at Fanny Allen, and consultations at Porter Medical Center (inpatient and long-term care). Substantial expansion of Telehealth services is planned for 2019.

Their teaching programs reach more than 300 learners each year and include inpatient observerships for first-year medical and nursing students, elective clinical rotations for medical students and residents, and a required 40-hour Palliative Medicine course for medical students during their 3rd year. They are preparing to launch a multi-disciplinary fellowship in the next four years and plan to expand education for clinical nurses in primary palliative care skills. In the fall of 2017, the Division established the Vermont Conversation Research Lab to understand and promote high quality communication in serious illness.

Highlights of additional projects of the UVM Palliative Care Service include:

- **TalkVermont:** TalkVermont is a multi-component intervention to improve serious illness conversations between clinicians and patients. The UVMHN team has collaborated with VitalTalk to create evidence-based communication skills training programs that are engaging, interprofessional, and focused on patient values. VitalTalk's methods have demonstrated success in not only improving clinician communication skills but also improving clinician resilience while simultaneously improving patients trust and connection with their clinicians. They have also partnered with Ariadne Labs (of Harvard School of Public Health) to create changes to the electronic health record and clinical workflows to facilitate serious illness conversations for clinicians and patients. The Ariadne Labs six-part program focuses on system-level support for clinicians and has demonstrated improvement in quality and frequency of the serious illness conversations with patients.

Since 2017, the UVM team has implemented the “Mastering Late Goals of Care Conversations” course, a full-day communication skills workshop for serious illness conversations. They have already trained over 120 clinicians (physicians, nurse practitioners, nurses, social workers, and chaplains) and 160 trainees

(nursing students, medical students, and medical residents). Moreover, these courses have brought together palliative care colleagues from across the state to co-teach these important skills and create culture change at their various institutions and beyond.

In 2019, the TalkVermont team plans to implement a new, Early Goals of Care course as well as TalkVermont refresher courses and communication skills coaching for interested clinicians. Over the next 3 years, they plan to expand courses for more than 500 clinicians throughout Vermont and the Adirondack region of New York. Additionally, they plan to use the Serious Illness Care Program implementation strategies to apply early goals of care initiatives within 5 local practices by “re-engineering” the clinical environment to promote the frequency and quality of serious illness conversations in the outpatient setting.

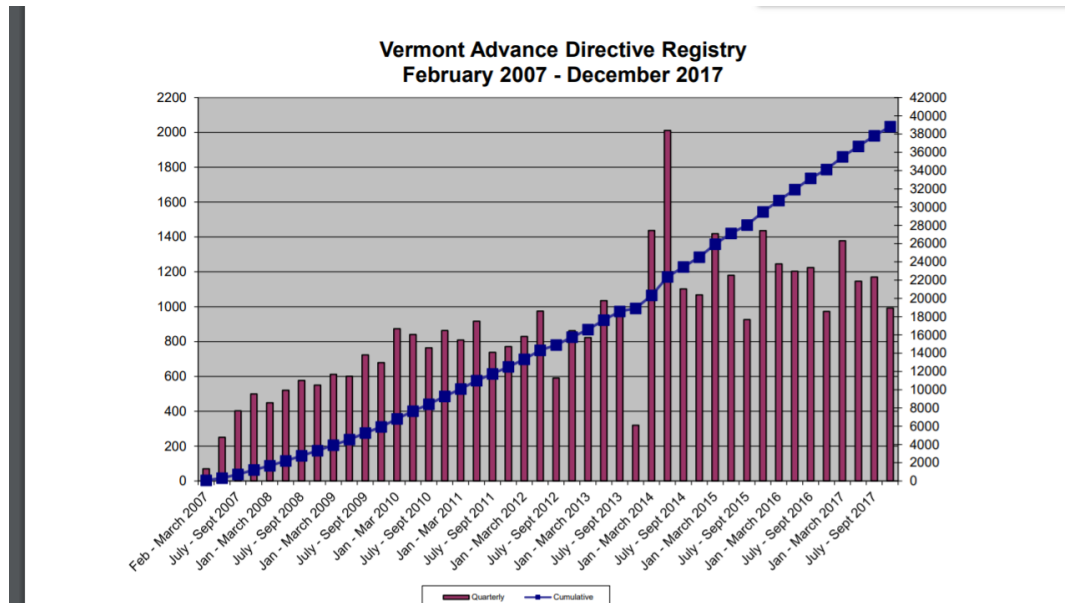
Early this month, Dr. Stephen Berns, co-director of TalkVermont, received a Cambia Health Sojourns Scholar Leadership Grant to further expand TalkVermont for rural health providers by developing a telecoaching program that targets primary care providers in rural settings. The goal of this project is to improve clinicians’ communication skills after taking a TalkVermont course and improve access to high quality palliative care skills, no matter where a patient lives.

- **AI Silence Project:** Systematically measuring indicators of communication quality is essential to transform how we value and incentivize clinical care. This project is using state of the art machine learning (*i.e.* artificial intelligence) and existing audio data from a large palliative care research study funded by the American Cancer Society to identify one clinically important indicator of human connection in serious illness conversations--compassionate silence.
- **TelePresence Projects:** TeleHealth (e.g. visits with a clinician by video) can increase the reach of specialty services in rural areas. Fostering a sense of "presence" is crucial for palliative care conversations but underdeveloped in healthcare telehealth technology. This project collaborates with gaming technology experts to develop the capacity for cultivating presence when serious illness conversations happen virtually. UVM has received grants to help support the expansion of Telehealth consultations. Dr. Robert Gramling received funding through the National Health Institute to create the Northern New England Palliative Care Teleconsult Research Network that will study the feasibility of specialty palliative care teleconsultation for patients with advanced cancer or heart failure. Additionally, Dr. Katherine Cheung, received funding through the National Palliative Care Research Center to examine the feasibility and acceptability of TelePalliative Care consultation for rural dialysis units.

Vermont Advance Directive Registry (VADR): In November of 2015, the Vermont Ethics Network (VEN) assumed responsibility from the Vermont Department of Health for all consumer and provider inquiries related to the VADR. In July of 2016, VEN assumed responsibility for management of the contract with US Living Will Registry

(USLWR), the vendor for the VADR, on behalf of the State of Vermont. The goal of this shift in oversight and management was to create a centralized and seamless mechanism for education and inquiries related to medical decision-making and improved support for the advance care planning needs of Vermonters and Vermont health care facilities. Presently, over 35,000 Vermonters have registered their directives with the VADR.

The graph below represents utilization in the Vermont Advance Directive Registry since it was first established in February of 2007 through December of 2017.



Vermont Medical Society (VMS): Palliative Care: In early November of 2017, the VMS adopted a revised and updated [policy on end-of-life care](#) that actively endorses comprehensive palliative care and multidisciplinary interventions to respond to the needs of patients at the end of life, including: adequate pain and symptom management, specialty consultation, hospice care, pastoral support and family counseling. The resolution also changes VMS’ opposition to Act 39, the state’s aid-in-dying law. Recognizing that under Act 39, medical aid in dying is now a legal option that can be made in the context of the physician-patient relationship, the resolution states that the Vermont Medical Society is committed to protecting its members' freedom to decide whether to participate in medical aid in dying according to their own values and beliefs.

In mid-November of 2017, the VMS hosted a CME accredited webinar on *End of Life Planning - Advanced Care Planning, DNR/COLST, Vermont’s Medical Aid in Dying Law*, featuring presenters Cindy Bruzzese, MPA, MSB, from the Vermont Ethics Network and David Englander, Esq., from the Vermont Department of Health. At the VMS 2018 Annual Collaborative Meeting, Dr. Allen Hutcheson, M.D., a family physician from Southwestern Vermont Family Medicine, presented, *Palliative Care Focus: Addressing Patient*

Requests for Hastened Death. Dr. Hutcheson's talk was designed to improve physicians' skills in engaging in exploratory conversations in response to patient requests for aid-in-dying. In November of 2018, the VMS hosted a webinar, *Difficult Conversations & Resources at the End of Life* with Dr. Diana Barnard, M.D., from University of Vermont Medical Center and Porter Medical Center.

Pain Management: The VMS also closely monitors the implementation of the state opioid prescribing rules to ensure that Vermont patients living with chronic conditions or needing end-of-life care have access to adequate pain management. VMS provided feedback to the Department of Health on their 2018 proposed updates to the prescribing rules. The VMS supports alternative pain management options and in September, 2018 hosted a webinar, *Advances in Pain Management & Treating Opioid Addiction: Integrating Alternative Pain Management Techniques, Opioid Tapering and MAT into Practice*, with presenters Dr. Jon Porter, M.D., from the University of Vermont Medical Center Comprehensive Pain Program and Dr. John Brooklyn, M.D., the Clinical Assistant Professor of Family Practice and Psychiatry at UVM College of Medicine. Dr. Porter also serves as a VMS representative on the 2018 Act 7 working group that is developing recommendations related to insurance coverage for non-opioid approaches, including non-pharmacological approaches, to treating and managing pain.

Vermonters Taking Action Against Cancer (VTAAC): VTAAC held its annual meeting on September 21st. The focus of this meeting was Challenges of Cancer in Rural Northern New England. Participants from ME, NH and VT were invited to discuss how we can best collaborate on our state cancer plans. Currently VTAAC has five active taskforces. The goal of our Skin Cancer Taskforce is to support and promote evidence-based collaborative strategies to improve skin cancer prevention and early detection to decrease the burden of skin cancers in Vermont. Our Lung Cancer Taskforce hosted a Lung Cancer Screening Summit on November 15th. Lung cancer screening teams as well as primary care physicians were invited to attend this educational conference. VTAAC recently formed a HPV taskforce to leverage the strengths of our partnerships and to identify shared objectives around HPV vaccination. Our Survivorship Care Plan Taskforce surveyed Vermont Cancer Centers to assess challenge and strengths they face with the formation and distribution of survivorship care plans. Finally, the goal of the CoC Taskforce is to examine how to share information and best practices across Vermont's CoC facilities and to consider coordinating projects to maximize impact and help meet the Vermont Cancer Plan goals.

V. CONCLUSION

As we look ahead to new models of health care delivery, best practice standards in medical decision-making, advance care planning and palliative care must be embedded into the system of care for all patients at all levels of care. Sudden illness or accident does not discriminate on the basis of age or baseline health, and we have learned that waiting to initiate conversations about treatment goals and health care priorities until a health crisis happens is too late in the care planning process. Failure to address these needs has consequences that go beyond the patient—affecting family members, care givers and population health overall. These conversations must begin earlier and be revisited as patients age, new diagnoses occur and/or health declines. Policy initiatives

that promote and support advance care planning, and enhance both documentation and sharing of advance care planning conversations across care settings are necessary to ensure that the care and treatment patients desire are aligned with the care and treatment patients receive.

This report was prepared in consultation with the following members of the Task Force

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<http://www.nationalacademies.org/hmd/~ /media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf>

ⁱⁱ Teno JM, Price RA, Makaroun LK. *Challenges of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families*. Health Affairs 26, No. 7 (2017).