



## **ANNUAL REPORT**

### **PALLIATIVE CARE AND PAIN MANAGEMENT TASK FORCE**

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*Submitted by:*

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## 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

**Advance Care Planning:** Two issues requiring legislative resolution have come to light relative to patient self-determination and support for the completion of advance directives and DNR/COLST orders. As such, the Task Force recommends the following changes to Vermont's advance directive statute:

a. **Expand the group of individuals authorized to serve as an explainer on an advance directive.** (18 V.S.A. § 9703)

Per current law, people who are being admitted to or already reside in a hospital, nursing home or residential care facility need to have an "explainer" sign the advance directive affirming that they have explained the nature and effect of the document to the principal. The group of individuals authorized to serve as the explainer are, in practice, so limited that it presents a barrier to completion of documents in these settings. Additionally, the current statute is also unclear as to whether the explainer on an advance directive can also serve as one of the two required witnesses. Resolution of both of these issues is necessary to appropriately support patients/residents in these facilities with their advance care planning needs.

b. **Revise the language to allow for out-of-state licensed clinicians to complete DNR/COLST orders for Vermont patients.** (18 V.S.A § 9708)

The advance directive statute uses a definition for clinician that limits clinicians who can complete DNR/COLST orders to Vermont-licensed clinicians only. This is problematic for Vermont patients who receive their care at Dartmouth (or another out-of-state facility) from a clinician who is only licensed in that state and not dually licensed in Vermont. Strictly speaking, per Vermont's statute, these out-of-state clinicians are not permitted to sign DNR/COLST orders for their Vermont patients. This is problematic from a quality care and patient self-determination standpoint.

To resolve both of these issues the Task Force, with support and approval of the Chair of the Senate Health & Welfare Committee and the Chair of the House Human Services Committee, has worked with legislative council to draft language to resolve these problems. The Task Force is recommending support and passage of S.211 in the current legislative session.

**Access to Opioids for Patients with Serious Illness and 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 revisions to current policy and any future proposed policies protect access to appropriate pain medication for this population of 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.<sup>i</sup> 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. Presently, 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 the quality of care for people with serious illness.<sup>ii</sup> In light of these recommended and preferred practices, educational efforts across that state have been and will continue to be directed at these core elements of communication and advance care planning.

### IV. STATEWIDE & REGIONAL EFFORTS

**Statewide Palliative Care Conference:** In May of 2017, the Vermont Ethics Network, in partnership with the Palliative Care and Pain Management Task Force hosted the 8<sup>th</sup> annual statewide palliative care conference, *Perspectives at End-of-Life: Suffering, Consciousness & the Power of the Patient's Narrative*. Approximately 140 interdisciplinary professionals from both Vermont and New Hampshire attended this event. The theme arose from concerns expressed by some in the Buddhist community about a possible over-reliance on morphine for pain management and the resultant impact this may have on a patient's desire and ability to remain conscious throughout the dying process. Thus, the goal of the event was to explore the importance of understanding the patient's narrative, and the integration of different faith beliefs and traditions into the care management needs of seriously ill and dying patients.

Plenary speakers consisted of Pulitzer Prize winner, Michael Vitez, Director of the Narrative Medicine Program at Temple University College of Medicine; palliative care physician, clinical ethicist and theologian, Farr Curlin, MD, from Duke University; and ZEN Buddhist, Koshin Paley-Ellison, co-founder of the New York Center for Contemplative Care – the first Zen-based organization to offer fully accredited clinical chaplaincy training in America. In addition to these presenters, there was an interfaith panel discussion and small group breakout sessions for attendees to take a deeper dive into specific content areas.

The Task Force is currently working on plans for the 2018 spring statewide conference. The theme in 2018 will center on communication and mastering tough conversations with seriously ill patients. Particular areas of focus will include: communication in the Emergency Department, challenges of prognostic uncertainty for the multi-morbidity patient, and improving DNR/COLST conversations across care settings.

**Vermont Ethics Network (VEN):** For over 30 years, the primary work of the Ethics Network 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.) statewide. 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 a preventive ethics strategy best implemented in stages, where discussions are appropriately aligned with patient needs and readiness to engage.

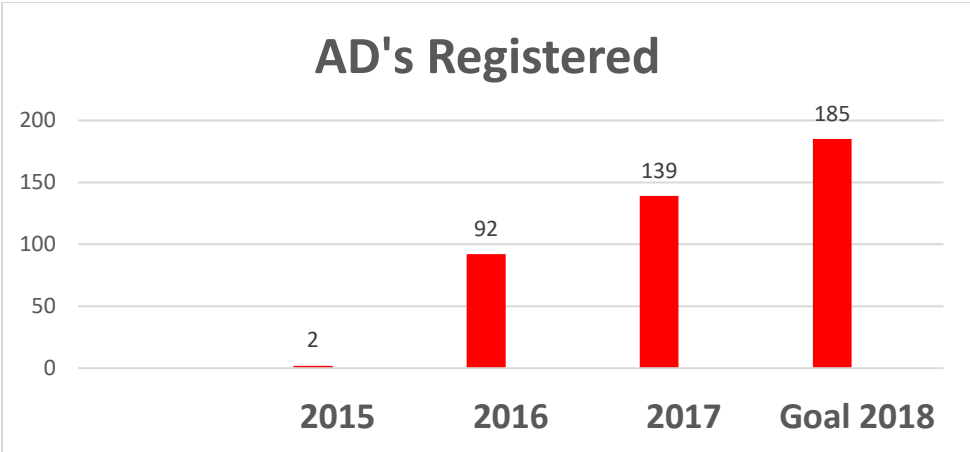
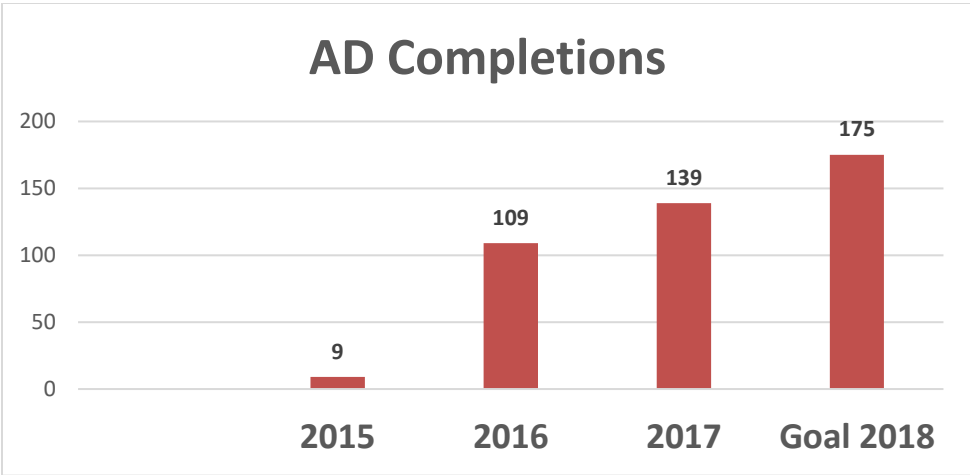
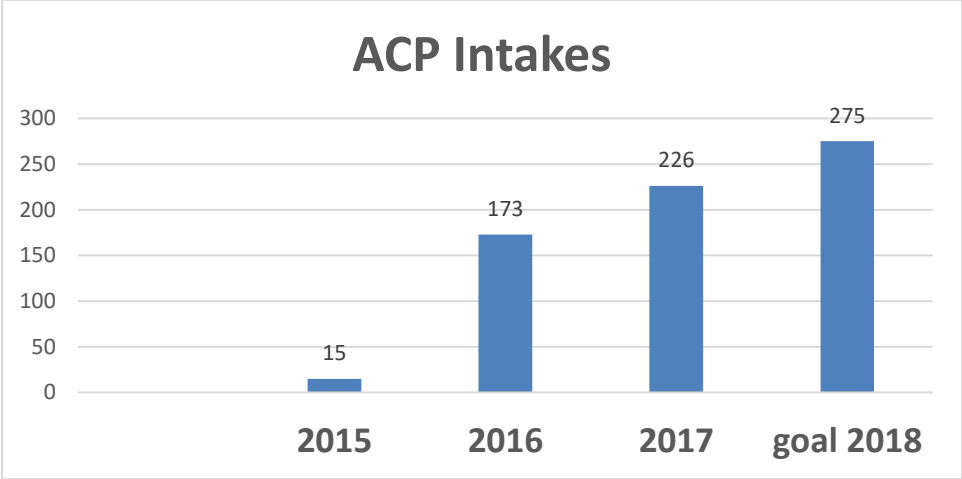
In 2016, VEN launched *Taking Steps Vermont*, an education and resource initiative promoting a step-wise approach to advance care planning.



Elements of this program are being implemented in regions across the state to improve knowledge of advance care planning and provide access to trained advance care planning facilitators. Highlights from these initiatives are outlined below:

- ***Taking Steps Brattleboro:*** The Taking Steps Brattleboro project is a program of Brattleboro Area Hospice. This project utilizes trained volunteer facilitators to support completion of advance directives in Windham County. In 2017, the project produced 49 advance care planning outreach events. In addition to extensive individual consultations, outreach events occurred at churches, community groups, work-place settings and in private homes for small groups. Data was collected to measure program utilization, advance directive completion rates and numbers of individuals who registered documents with the Vermont Advance Directive Registry.

Use of the program has increased since its inception and further increases are anticipated in 2018. The graphs below summarize their work to date.



In 2017 the Brattleboro project facilitated four (4) *Being Mortal* screenings followed by facilitated panel discussions featuring local experts. *Being Mortal* is a 60 minute PBS Frontline documentary that investigates the practice of caring for

the dying and explores the relationship between patients and providers. It follows Dr. Atul Gawande as he speaks with doctors about talking to patients as they near the end of their lives. The format of film screenings following by a discussion panel of community experts has been effective at engaging new audiences. More screenings are planned for the coming year.

The Brattleboro Community-wide Advance Care Planning Coalition and the End-of-Life Medical Group are both in their 3<sup>rd</sup> year of operation and are reviewing success and challenges and planning for next steps. Legal clarification surrounding who can serve as an explainer on an advance directive in skilled nursing facilities and expansion of those individuals to facilitate advance directive completion opportunities will be helpful.

- ***Who's Your Person... What's Your Plan?*** is a collective impact initiative of nine (9) organizations (Age Well, BAYADA, Cathedral Square, Howard Center, OneCare Vermont, Support and Services at Home (SASH), The University of Vermont Medical Center, Vermont Ethics Network, and the VNA of Chittenden & Grand Isle Counties) 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, priorities and issues at end-of-life.

Since the initiative began in July 2016, the group has conducted **26 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, a total of **600 people** have been reached with advance care planning education. The initiative has **17 trained facilitators**, including 6 UVM medical students who have enthusiastically joined in the work.

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

**Vermont Advance Directive Registry** (as of December 2017)

- **11% increase** in Vermont Advance Directive Registry submissions from Chittenden and Grand Isle Counties over the same period one year prior to the launch of the initiative.

- **65% increase** in Vermont Advance Directive Registry submissions from Chittenden and Grand Isle Counties over the same period two years prior to the launch of the initiative.

**The University of Vermont Medical Center** (as of December 2017)

- **18% increase** in General Internal Medicine patients with advance directives over the past two years.
- **19% increase** in Family Medicine patients with advance directives over the past two years.

**Presentation Evaluations** (as of December 2017)

- **30%** of attendees had no knowledge of advance care planning prior to attending a presentation.
- **85%** were motivated to appoint a health care agent and/or complete a detailed advance directive after attending a presentation.

**Post-Presentation Email Follow Up Survey** (based on an 11% response rate as of December 2017)

- **74%** of attendees have since had conversations with family and friends about their health goals and priorities.
- **53%** of attendees have since appointed a health care agent.

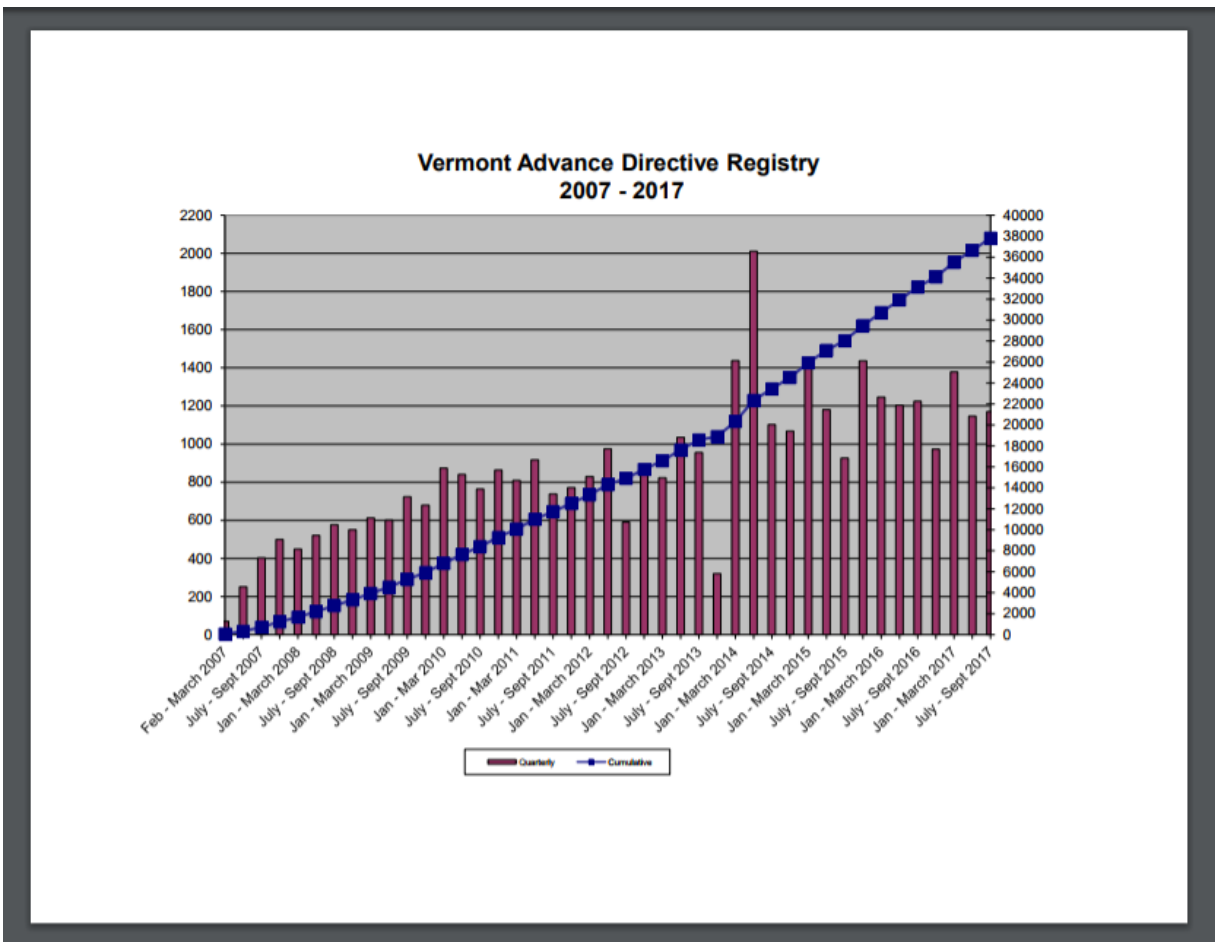
**Central Vermont Medical Center (CVMC)/Berlin HSA - Increasing the Use of Hospice Care:** As part of the goals of the Berlin HSA's Unified Care Collaborative Community Alliance for Health Excellence, an effort is underway to increase the use of hospice care in this region. This initiative is focusing on three primary areas:

- **Education**
  - To CVMC providers through continuing medical education and targeted educational sessions.
  - To CVMC emergency department nurses and registration staff through targeted educational sessions.
- **Community Workshops**--screening the *Being Mortal* documentary with a facilitated discussion session following. Sessions were held in Montpelier, Stowe, and St. Johnsbury, attracting over 150 attendees.
- **Systems Change**--improving the electronic health record infrastructure at CVMC to support improved access to advance directives and DNR/COLST orders.

**OneCare Vermont:** On September 25, 2017, OneCare Vermont hosted an Interdisciplinary Grand Rounds on Palliative Care. The session included presentations from Robert Gramling, MD (UVMHC), Diana Barnard, MD (Porter Medical Center), Tara Graham, MSW and Chelsea Chafant, RN (VNA of Chittenden & Grand Isle Counties), and a family who shared their story during the session. The objectives of the session focused on how to recognize when a referral to palliative care is appropriate, education on how to frame discussions with patients around palliative care, review of community resources available to patients and families in both the inpatient and outpatient settings, exploring the roles of the interdisciplinary team members across the care continuum, and learning how to help patients and families navigate from palliative care to hospice care.

**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.

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



**Bayada:** BAYADA Hospice is currently caring for over 300 patients in Vermont and serves over 1000 families with bereavement care. They have increased their workforce by 50% and have over 100 volunteers. This year the organization created a new position, Director of Clinical Operations, to help support clinical excellence and develop future hospice and palliative care leaders. The BAYADA Support Program, which is part of the Medicare Care Choices Model, is starting its third year. In 2017 they enrolled 23 new



patients into this palliative care program. Six have transitioned to hospice and one died on the palliative program. Currently this pilot is serving the Norwich area with plans to expand into the Brattleboro area in 2018.

**University of Vermont Medical Center Palliative Care:** In 2016, Palliative Medicine was established as an academic division within the Department of Family Medicine at UVM. Since then, the program has been growing in clinical services, teaching programs, and research/innovation. The core group includes five physicians, three nurse practitioners, and three nurses with a closely affiliated chaplain and social worker.

During this past year, the UVM team was consulted 1,340 times to care for seriously ill hospitalized adults and children. They are offering TeleConsult follow-up home visits, outpatient consultations at Milton Family Practice and consultations at Porter Medical Center (inpatient and long term care). Substantial expansion of their outpatient and Telehealth services is planned for 2018. Their teaching programs reach more than 250 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. They are preparing to launch a multi-disciplinary fellowship. 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 four additional projects of the UVM Palliative Care Service include:

- **Vermont Conversation Initiative:** High quality communication in serious illness is essential to achieve treatments that comport with patients' values and clinical realities. Such communication, however, is uncommon in modern medical care. This multimodal population health initiative addresses both culture change and system change to increase the quality of serious illness communication in Vermont.

Culture Change: In May and October of 2017, trained 30 UVM Health Network clinicians in the evidence-based communication coaching method developed by *VitalTalk*. From January 2018 until December 2020, will offer *VitalTalk*'s one-day workshop, "Mastering Tough Conversations", for more than 400 clinicians throughout Vermont and the Adirondack region of New York.

Systems Change: UVM has been selected as one of seven premier sites to implement the "Serious Illness Care Program" developed by Ariadne Labs at Harvard School of Public Health (Atul Gawande). The SICP "re-engineers" the clinical environment to promote timely, high quality serious illness conversations in the outpatient setting. Multiple clinical trials have shown SICP improves communication, lowers anxiety/depression, increases value-concordant treatment and decreases end-of-life healthcare costs. Over the next 3 years, UVM will implement the SICP in 5 local practices.

- **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.

- **Storytelling Project:** Loved ones often need to make decisions at end-of-life for patients who cannot communicate for themselves. A brief storytelling intervention (based on NPR's *StoryCorps*) has demonstrated benefits for lowering these surrogate decision-makers' risk of complicated grief (e.g. major depression, generalized anxiety, PTSD). This project will implement the storytelling intervention among families at high risk of complicated grief who met the palliative care team prior to their loved one's death.
- **TelePresence Project:** 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.

## V. CONCLUSION

As we look ahead to a changing health care delivery system, best practice standards in medical decision-making, advance care planning and palliative care must be embedded into the system of care delivery 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 settings are necessary to ensure that the care and treatment patients desire are aligned with the care and treatment patients receive.

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

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Carrie Noonan, BlueCrossBlueShield of Vermont  
Janet Nunziata, The Center on Aging at UVM  
Jill Olson, VNA's of Vermont  
Joanna Rueter, Brattleboro Area Hospice  
John Saroyan, BAYADA/VEN  
Jill Sudhoff-Guerin, Vermont Medical Society  
Sandra Knowlton-Soho, OneCareVermont  
Eva Zivitz, Rutland Regional Medical Center

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

<sup>ii</sup> 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).