

Working together to improve health care quality, outcomes, and affordability in Washington State.

**End-of-Life Care Report and Recommendations** 

## **Table of Contents**

Executive Summary	1
Dr. Robert Bree Collaborative Background	3
Definitions	4
Problem Statement	6
Background	7
End-of-Life Care Goals	8
Recommendations	10
1. Increase awareness of advance care planning, advance directives, and POLST in Washington State	10
2. Increase the number of people who participate in advance care planning in clinical and community settings	
3. Increase the number of people who record their wishes and goals for end-of-life care using docume that: accurately represent their values; are easily understandable by all readers including family members, friends, and health care providers; and can be acted upon in the health care setting	
4. Increase the accessibility of completed advance directives and POLST for health systems and provide	
5. Increase the likelihood that a patient's end of life care choices are honored	22
Measurement	24
Stakeholder-Specific Recommendations	26
Provider Practices	26
Hospitals	26
Skilled Nursing Facilities	27
Health Plans	28
Employers/Purchasers	28
The State of Washington	28
End-of-Life Care Improvement Efforts in Washington State	30
Deferences	2.4

## **Appendices:**

Appendix A: List of Bree Collaborative Members

Appendix B: End-of-Life Workgroup Charter and Roster

Appendix C: Durable Power of Attorney for Health Care and Health Care Directive Form

Appendix D: Physician Orders for Life Sustaining Treatment

## **Executive Summary**

The Robert Bree Collaborative was established in 2011 to provide a forum in which public and private health care stakeholders can work together to improve quality, health outcomes, and cost-effectiveness of care in Washington State. End-of-life care was identified by the Bree Collaborative as an area with high variation and poor patient outcomes and the Bree Collaborative elected to form a workgroup to address end-of-life care issues.

The End-of-Life Care workgroup met from January 2014 to November 2014 to develop the following five focus areas corresponding to how an individual would ideally experience advance care planning for the end of life. These focus areas work to empower patients to voice their wishes and make sure that the care that all Washingtonians receive at the end of life is the care that they and their families want. The focus areas are supported by multi-stakeholder recommendations.

## 1. Increase awareness of advance care planning, advance directives, and POLST in Washington State

- a. Promote community-wide discussions about how to have conversations regarding personal goals of care and the type of care desired at the end of life with family members and health care providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive
- 2. Increase the number of people who participate in advance care planning in the clinical and community settings
  - Educate health care professionals on how to engage individuals and their families in advance care planning and how to refer to appropriate community-based advance care planning resources
  - b. Encourage the use of evidence-based advance care planning tools and programs
  - c. Encourage people and health care providers to involve family members and friends in advance care planning and designate a legal durable power of attorney for health care
  - d. Encourage appropriate timing of advance care planning conversations
  - e. Revise reimbursement policy to pay for advance care planning counseling and discussion with patients and their surrogate decision makers
  - f. Promote awareness of the value of hospice and encourage appropriate hospice referrals
  - g. Train qualified advance care planning facilitators
- Increase the number of people who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by all readers including family members, friends, and health care providers; and can be acted upon in the health care setting
  - a. Encourage the documentation of advance care planning discussions with easily understandable and culturally appropriate advance directives that include: a living will (also called a health care directive) that stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and a written personal statement that articulates the patient's values and goals regarding end-of-life care
  - b. Adopt resources meant to engage low-literacy patients in advance care planning and creation of advance directives

## 4. Increase the accessibility of completed advance directives and POLST for health systems and providers

- a. Contract with an existing registry to store and make accessible advance directives and POLST
- b. Work with the Department of Motor Vehicles to add text indicating the presence of an advance directive on the Washington State driver's license with the additional option of putting a QR code on the back of the driver's license to gain direct access to the registry

#### 5. Increase the likelihood that a patient's end-of-life care choices are honored

- a. Implement quality improvement programs within hospitals, nursing homes, and other settings to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation
- b. Encourage providers and facilities to measure family satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies
- Enact legislation providing legal immunity to health care providers who honor a patient's POLST, comparable to existing protections for providers who honor a patient's advance directive

The Bree Collaborative's goal is that all Washingtonians are informed about their end-of-life options, communicate their preferences in actionable terms, and receive end-of-life care that is aligned with their wishes, goals, and values.

#### Dr. Robert Bree Collaborative Background

The Robert Bree Collaborative was established in 2011 by Washington State House Bill 1311 "...to provide a mechanism through which public and private health care stakeholders can work together to improve quality, health outcomes, and cost effectiveness of care in Washington State." The Bree Collaborative was modeled after the Washington State Advanced Imaging Management (AIM) project and named in memory of Dr. Robert Bree, a pioneer in the imaging field and a key member of the AIM project.

Members are appointed by the Washington State Governor and include public health care purchasers for Washington State, private health care purchasers (employers and union trusts), health plans, physicians and other health care providers, hospitals, and quality improvement organizations. The Bree Collaborative is charged with identifying up to three health care services annually that have substantial variation in practice patterns, high utilization trends in Washington State, or patient safety issues. For each health care service, the Bree Collaborative identifies and recommends best-practice evidence-based approaches that build upon existing efforts and quality improvement activities aimed at decreasing variation. In the bill, the legislature does not authorize agreements among competing health care providers or health carriers as to the price or specific level of reimbursement for health care services. Furthermore, it is not the intent of the legislature to mandate payment or coverage decisions by private health care purchasers or carriers.

See **Appendix A** for a list of current Bree Collaborative members.

Recommendations are sent to the Washington State Health Care Authority for review and approval. The Health Care Authority (HCA) oversees Washington State's largest health care purchasers, Medicaid and the Public Employees Benefits Board Program, as well as other programs. The HCA uses the recommendations to guide state purchasing for these programs. The Bree Collaborative also strives to develop recommendations to improve patient health, health care service quality, and the affordability of health care for the private sector but does not have the authority to mandate implementation of recommendations.

For more information about the Bree Collaborative, please visit: www.breecollaborative.org.

End-of-life care was identified by the Bree Collaborative as an area with high variation and poor patient outcomes and Collaborative elected to form a workgroup to address end-of-life care issues. The workgroup met from January 2014 to November 2014 to develop the following recommendations. See **Appendix B** for the End-of-Life Care workgroup charter and a list of members.

#### **Definitions**

**Advance Care Planning**. Advance care planning is an ongoing shared decision-making process between patients, their families and/or caregivers, and health care providers. Different types of advance care planning may be appropriate at different life and illness stages, but should include the following three components: education, a structured approach to thinking about the choices a patient faces, and a method of communicating those choices.<sup>a</sup>

**Advance Directive.** This is a written instruction relating to the provision of **future** health care for a time when an individual is incapacitated. This document uses the term "advance directive" to refer to a collection of three documents, a durable power of attorney for health care form, a living will or health care directive, and a written personal statement about health care values and goals. Other documents can also be included under the umbrella term "advance directive" at an individual's discretion such as other forms (e.g., <u>Five Wishes</u>) or instructions for organ donation. Physician Orders for Life Sustaining Treatment (POLST) are not advance directives.

**Durable Power of Attorney for Health Care**. Part of an advance directive, this document, also known as "durable medical power of attorney" allows one individual to grant another individual the authority to give informed consent for medical decisions in the event that one individual is unable to express his or her preferences consistent with Washington State law RCW 11.94.010.<sup>b</sup> This individual is known as a "health care proxy," "health care surrogate," "health care agent," or "health care power of attorney." See **Appendix C** for an example of this form. The term "durable" refers to the fact that the form remains in effect and is relevant after the individual is no longer able to make medical decisions.

Living Will/Health Care Directive. Part of an advance directive, a living will or health care directive describes an individual's health care wishes for the end of life when that individual is unable to communicate those wishes consistent with the Washington State Natural Death Act, Washington State law RCW 70.122.030. This is different from physician orders that are outlined in the POLST. In Washington State this is known as the "health care directive," "directive to physicians," or "directive to withhold or withdraw life sustaining treatment." See Appendix C for an example of this form. This directive codifies the right of "Any adult person [to] execute a directive directing the withholding or withdrawal of life-sustaining treatment in a terminal condition or permanent unconscious condition" and is required to be signed by the declarer in the presence of two witnesses. The directive specifies whether the declarer does or does not want to "have artificially provided nutrition and hydration" if the declarer is "diagnosed to be in a terminal condition or in a permanent unconscious condition."

**Written personal statement**. Part of an advance directive, this is a summary of individuals' values and goals of care relating to their end-of-life care wishes. It is a personal story that helps families, surrogates, and health care providers understand patients as people apart from their illness and/or disability. This statement will help to fill in the gaps in health care requests that may occur in living wills/health care directives.

**Family.** This document uses the term "family" as defined by the patient and not restricted to blood relatives or legal next of kin. This definition may include friends and significant others.

<sup>&</sup>lt;sup>a</sup> Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision Aids for Advance Care Planning: An Overview of the State of the Science. Ann Intern Med. 2014 Jul 29.

<sup>&</sup>lt;sup>b</sup> Washington State Power of Attorney. Chapter 11.94 RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx?cite=11.94">apps.leg.wa.gov/rcw/default.aspx?cite=11.94</a>.

<sup>&</sup>lt;sup>c</sup> Washington State Natural Death Act. Chapter 70.122 RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx?cite=70.122">apps.leg.wa.gov/rcw/default.aspx?cite=70.122</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx">apps.leg.wa.gov/rcw/default.aspx</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx">apps.leg.wa.gov/rcw/default.aspx</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx">apps.leg.wa.gov/rcw/default.aspx</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx">apps.leg.wa.gov/rcw/default.aspx</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/default.aspx">apps.leg.wa.gov/rcw/rcw/default.aspx</a> RCW. Available: <a href="mailto:apps.leg.wa.gov/rcw/rcw/default.aspx">apps.

**Physician Orders for Life-Sustaining Treatment (POLST).** POLST is meant for individuals with serious illness or frailty, "for whom a health care professional would not be surprised if they died within one year." The POLST is not a replacement for an advance directive that provides instructions for **future** treatment. The POLST provides medical orders for **current** treatment to guide emergency medical personal and in-patient treatment decisions, when available. See **Appendix D** for an example of this form. See **Table 1** for a comparison of advance directives and POLST.

Washington State Natural Death Act. This act, known as Revised Code of Washington (RCW) 70.122 passed by the Washington State Legislature in 1992, "declares that the laws of the state of Washington shall recognize the right of an adult person to make a written directive instructing such person's physician to withhold or withdraw life-sustaining treatment in the event of a terminal condition or permanent unconscious condition. The legislature also recognizes that a person's right to control his or her health care may be exercised by an authorized representative who validly holds the person's durable power of attorney for health care." The act contains a health care directive to withhold or withdraw life-sustaining treatment.

**Table 1: Comparison of Advance Directives and POLST** 

_	Advance Directive			Physician Orders for
	Durable Power of Attorney for Health Care	Living Will/Health Care Directive	Written personal statement	Life-Sustaining Treatment (POLST)
Appropriate Population	All adults	All adults	All adults	Those with advanced progressive chronic conditions
Timeframe	Future care	Future care	Future care	Current care
Where Completed	Any setting	Any setting	Any setting	Medical setting
Product	Legal designation of a health care decision-making surrogate that is part of an advance directive in alignment with Washington State law RCW 11.94.010	Description of an individual's health care wishes for the end of life for a time when that individual is unable to communicate those wishes that is part of an advance directive in alignment with Washington State law RCW 70.122.030	Summary of personal values and goals of care relating to end-of-life care wishes that is part of an advance directive	Medical orders
Surrogate Role	Surrogate cannot complete	Surrogate cannot complete	Surrogate cannot complete	The designated surrogate can consent to POLST on behalf of an incapacitated patient
Responsible for Portability	Currently patient or family/friends	Currently patient or family/friends	Currently patient or family/friends	Provider/Health System
Responsible for Review	Patient or family/friends	Patient or family/friends	Patient or family/friends	Provider/Health System

Adapted from: Sabatino CP, Karp N. Improving Advanced Illness Care: The Evolution of State POLST Programs. AARP Public Policy Institute. April 2011. Available: <a href="https://www.aarp.org/health/doctors-hospitals/info-04-2011/polst-04-11.html">www.aarp.org/health/doctors-hospitals/info-04-2011/polst-04-11.html</a>.

<sup>&</sup>lt;sup>d</sup> About the National POLST Paradigm. POLST Physician Orders for Life-Sustaining Treatment Paradigm. Available: <a href="www.polst.org/about-the-national-polst-paradigm/">www.polst.org/about-the-national-polst-paradigm/</a>. Accessed: June 2014.

#### **Problem Statement**

End-of-life care in the United States and within Washington State is strikingly variable and often misaligned with patient preference. Although the majority of patients report wanting to spend the last part of their lives at home, in reality much of this time is spent in a hospital or nursing home. Nationally, the likelihood of a chronically ill Medicare beneficiary death occurring in a hospital declined from 32.2% in 2003 to 28.1% in 2007 and ranged from 19% to 45.8% across hospital referral regions. Similar to likelihood of death occurring in a hospital setting, number of inpatient days also varies significantly across hospital referral regions. See **Figure 1** for a comparison of inpatient days in end-of-life care.

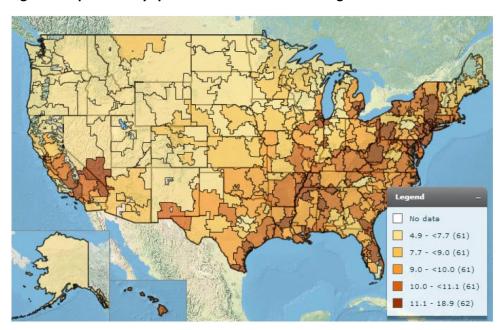


Figure 1: Inpatient Days per Medicare Decedent during the Last Six Months of Life, 2007.<sup>e,4</sup>

In Washington State, many people spend the end of their lives in a hospital or nursing home although the majority report wanting to die at home. In 2012, 30.51% of deaths occurred in a general hospital, 25.44% in a nursing home, 6.04% in a hospice facility, and only 32.6% at home. There is also variation county by county within Washington State, with 43.6% of decedents in 2012 dying in a hospital in Chelan County and deaths at home ranging from 83.3% in Wahkiakum County to 22.2% in Garfield County. There has been slow progress to align practice with patient preference. The percentage of deaths occurring at home statewide has increased slightly in the last ten years, from 28.8% in 2002 while the percentage of deaths occurring in a hospital decreased slightly from 34.6% in 2002. However, more work must be done to increase the number of people in Washington State who spend the end of their lives receiving the type of care that they wish and who spend the end of their lives in the location they wish.

Additionally, family members and friends of patients at the end of their life also report care not aligning with patient wishes, in many cases due to unwanted aggressive treatment, and significant financial impact of inhospital deaths.<sup>6,7</sup> Surviving family members have been shown to have symptoms of post-traumatic stress disorder after the death of a loved one in an intensive care unit.<sup>8</sup> Care that is at odds with patient wishes

<sup>&</sup>lt;sup>e</sup> Medicare enrollees aged 65-99 who died during the measurement year with rates are adjusted for age, sex, and race.

negatively impacts quality of patients' life, increases cost to families, and seriously overburdens patients and their families.

Appropriately timed advance care planning conversations between providers and patients and between patients and their families and/or caregivers and expressing end-of-life wishes in writing with advance directives and POLST if appropriate, can increase patient confidence, sense of dignity, and the probability that patient wishes are honored at the time of death. However, many adults do not discuss their preferences for end-of-life care with their providers, family, and friends and fewer complete advance directives. Many barriers to advance care planning conversations exist including confusion about what advance directives are and uncertainty whether patients or their health care providers are responsible for raising the topic of advance care planning. Increased referrals to hospice care and referrals earlier on in the illness trajectory may also improve symptoms and quality of life; decrease patient, family, friend, and caregiver stress; and honor patient, family, and friends' wishes and goals of care at the end of life.

The Bree Collaborative's goal is that all Washingtonians are informed about their end-of-life options, communicate their preferences in actionable terms, and receive end-of-life care that is aligned with their wishes, goals, and values. These recommendations build off the work of many organizations and individuals dedicated to improving the care given to people at the end of life.

#### **Background**

In conversations between patients, their families, physicians, and trained facilitators, patients create their advance directives. The Patient Self-Determination Act (PSDA), passed by Congress in 1990, mandated that "hospitals, nursing facilities, skilled nursing facilities, providers of home health care or personal care services, hospice programs and managed care plans:"<sup>12,13</sup>

- Provide patients admitted to a health care institution with a written summary of their health care decision-making rights and the health care institution's policy about advance directives,
- Ask all patients on admission whether they have an advance directive and document their answers in the medical record,
- Educate staff and the community about advance directives, and
- Not deny care to any patient based on whether they do or do not have an advance directive.

The frequency of advance care planning conversations and advance directive documentation increased in the first years after the passage of the PSDA and currently the majority of people have some knowledge of the documents although many people remain confused about specific aspects. <sup>14,15</sup> Today, between 26% to slightly over a third of Americans have an advance directive, an increase from 16% in 1990. <sup>16,17,18</sup> However, definitions vary from study to study, between states, and between organizations limiting the accuracy of such estimations. The percent of individuals with a health care directive is most strongly associated with: older age; being white, non-Hispanic; higher education; and higher income. Those with a chronic disease and terminally ill patients are statistically more likely to have an advance directive. <sup>16,19</sup>

Although about 56% of Americans have heard about the durable power of attorney for health care, only about 33% of Americans over 35 years of age report create the document and designate a legal surrogate. An analysis of Health and Retirement Study data found that surrogates tend to be adult children (48.9%), followed by spouses (32.5%), or other relatives (13.5%). Of the deaths that occurred in the study, 42.5% required decision making by the surrogate and the designated surrogate was the decedent's actual decision maker 79.5% of the time. Having a durable power of attorney for health care is also associated with age but inconsistently with health status. 18

## **End-of-Life Care Goals**

The Bree Collaborative's End-of-Life Care Workgroup convened from January to October of 2014, and reviewed the available evidence on aligning patient wishes with the end-of-life care, available data, and existing efforts. In developing goals, the workgroup drew from and adapted five areas of quality improvement to drive system change:<sup>21</sup>

- Strong leadership and commitment
- Evidence-based or tested guidelines and protocols
- Data transparency
- Patient and family education
- Realignment of financial and non-financial incentives

The workgroup created the following model to better align end-of-life care with patient preference while taking into account how patients interact with the health care system, as shown in below:

Health care provider reimbursement for advance care planning

Provider education about conducting advance care planning with patients and families

Community engagement in advance care planning

Patient and family education and empowerment to engage in advance care planning

Writing wishes down as a result of advance care planning

Increasing availability of advance directives and POLST during time of crisis (e.g., registry) Implementation of protocols to increase the likelihood that patient's wishes are followed at the time of death

Based on these discussions, the workgroup recommended five focus areas that correspond to how an individual would ideally experience advance care planning for end of life. These focus areas work to empower patients to voice their wishes and make sure that the care that all Washingtonians receive at the end of life is the care that they want.

1. Increase awareness of advance care planning, advance directives, and POLST in Washington State

2. Increase the number of people who participate in advance care planning in the clinical and community settings

3. Increase the number of people who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by all readers including family members, friends, and health care providers; and can be acted upon in the health care setting

4. Increase the accessibility of completed advance directives and POLST for health systems and providers

5. Increase the likelihood that a patient's end-of-life care choices are honored

Each of the end-of-life care goals are supported by multi-stakeholder recommendations.

#### Recommendations

# 1. Increase awareness of advance care planning, advance directives, and POLST in Washington State

Promote community-wide discussions about how to have conversations regarding personal goals of care and the type of care desired at the end of life with family members, friends, and health care providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive

Many community groups are currently engaging their members in advance care planning. The Bree Collaborative recommends that communities currently engaged in this work continue to do so and encourages the spread of this engagement across Washington.

We encourage individuals, families, neighbors, health care facilities, community organizations, and religious groups to discuss planning for end-of-life care with people as early as they feel comfortable. Research shows that one of the primary benefits of end-of-life planning conversations is to prepare patients and their families for the decisions they will eventually have to make, even if not directly related to a treatment decision.<sup>22</sup> There are many successful examples of a community engaging its members in discussions about end-of-life care and end-of-life issues in Washington State.

While there is no single coordinating organization overseeing the work done by individual groups, Honoring Choices: Pacific Northwest,® a joint initiative of the Washington State Hospital Association (WSHA) and the Washington State Medical Association (WSMA), is developing a voluntary statewide community plan to promote advance care planning. Honoring Choice Pacific Northwest is a program that encourages early conversations about the type of care people would want if faced with a life threatening illness. It does this in two major ways. One, the program provides training and resources to hospitals and doctors to make sure they are prepared to discuss, record and honor people's wishes at the end of their life. Second, a public website offers individuals and families a place to learn about their choices and encourage conversations about their wishes ahead of time.

Honoring Choices: Pacific Northwest is adapted from Respecting Choices. Respecting Choices started in 1991 as a collaboration between leaders of the major health organizations in La Crosse, Wisconsin, led by the Gundersen Medical Foundation, the results of which are discussed later in this document. The program is designed as an "ongoing process of communication, integrated into the routine of patient-centered care" that incorporates "community engagement, professional education, and organization/standards of practice." Since 2000, Respecting Choices has worked with other organizations to spread the model. This has become Honoring Choices® Minnesota, an effort of the Twin Cities Medical Society, Honoring Choices® Wisconsin, an initiative of the Wisconsin Medical Society, and others. 24

There are many robust community programs working to engage their members across the state. Many programs run community workshops and train advance care planning facilitators who meet with community members. Workshops can include discussions on the importance of advance care planning, choosing a durable power of attorney for health care, how to talk to health care providers and loved ones about end-of-life care, and how to complete advance care planning paperwork.<sup>25</sup> Other programs offer training directly to health care providers and staff and often engage community churches or other organizations.

See the more detailed list of advance care planning programs and organizations on page 30. A non-exhaustive list of community engagement programs includes:

- The End of Life Choices program, an advance care planning process encouraging conversations about end-of-life planning organized by the Whatcom Alliance for Health Advancement (WAHA) and adapted from Respecting Choices. More information: http://whatcomalliance.org/end-of-life-care/
- The Death Cafe, also in Whatcom County, Washington, "provides an opportunity for people to come together to explore and share stories, experiences, ideas, and philosophical thoughts around death and dying." Whatcom Death Café "is a large group of people who gather monthly as their schedule allows." <sup>26</sup> More information: www.deathandcoffee.com
- The Snohomish County Health Leadership Coalition combines the resources of organizations including Verdant, the YMCA, Premera, and the Everett Clinic, among others. The goal of the coalition is to greatly increase the number of Snohomish County residents who have completed advance care plans. It offers training to healthcare providers and volunteer facilitators in a variety of culturally adapted advance care planning programs including Respecting Choices. More information: www.snocohealth.org
- Life Transitions, the End of Life Coalition of Southwest Washington is a county-wide effort that combines the efforts of Bridges Palliative Care Home Health and Hospice, Glenwood Place Senior Living, PeaceHealth Hospice Southwest, Southwest Washington Agency on Aging and Disabilities, and Fort Vancouver Convalescent Park Lido & Caretique. This program sponsors Respecting Choices® education for hospital and medical personnel as well as community presentations of the program upon request by churches and community groups and distributes advance directives as needed. For more information, email: swlifetransitions@gmail.com

As a result of the Patient Self-Determination Act, the health care facilities defined earlier are required to engage in public awareness campaigns. WSHA gives examples of types of campaigns that meet this requirement on their website, <a href="www.wsha.org/EOL.cfm">www.wsha.org/EOL.cfm</a>. Many health care facilities offer programs to their community promoting advance care planning around the state. The following are meant as examples and do not represent endorsement by the Bree Collaborative.

Swedish Edmonds Hospital offers free monthly workshops and individual counseling sessions
conducted by qualified living will facilitators. Services are offered to individuals and their surrogates
using the 6-Step Guide to create an advance care plan. Programs are offered in hospital facilities and
in venues in the community. At the conclusion of the workshop, the documents can be immediately
scanned in to participants' records if they receive care in the affiliated clinics or hospitals.

For more information, email: <u>AdvanceCarePlanning-EDM@swedish.org</u>

Group Health Cooperative offers a free two-hour community workshop titled, <u>Your Life Your Choices</u>.
 A facilitator leads participations through how to make informed end-of-life care decisions, how to have conversations with family members, friends, and loved ones, and how to document these wishes.<sup>27</sup> Over 6,000 people have attended these workshops in the past six years.

For more information, email: <a href="mailto:yourlifeyourchoices@ghc.org">yourlifeyourchoices@ghc.org</a>

The Bree Collaborative recommends that the State of Washington work to promote awareness and utilization of advance care planning at multiple levels of the health care delivery system and in communities across the state. This is especially important in communities lacking their own robust programs.

# 2. Increase the number of people who participate in advance care planning in clinical and community settings

As the body of research around advance care planning and public awareness grew after the Patient Self-Determination Act, interventions aimed at increasing advance care planning were increasingly successful in helping patients think through their goals and values and increasing the likelihood that wishes and goals of care were followed at the end of life.<sup>28</sup>

One of the largest and earliest interventions, the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT), involved a nurse educating patients, providers, and hospital staff about care outcomes and advance care planning. This intervention resulted in no improvement to patient-provider communication, increased provider knowledge about patient's end-of-life wishes, or an increased number of patients with do not resuscitate (DNR) orders.<sup>29</sup> More recent interventions focused on increasing the rate of advance care planning conversations in the clinical setting are associated with increased completion of advance directives and care that is aligned with the patient's goals and values.<sup>30</sup> A recent systematic review of advance care planning interventions found that more multifaceted interventions, those that allowed more in-person interaction between patients, family, friends, and health care providers, and those done over time, were more likely to be associated with patient wishes being followed at the time of death. Patients who received multifaceted interventions were also less likely to be hospitalized or receive care in an intensive care unit.<sup>10</sup>

Advance care planning has been shown to have many benefits. In a longitudinal study of cancer patients, discussions between patients and their health care providers about end-of-life wishes were associated with higher quality of death in the final week and lower total costs of care.<sup>31</sup> A patient's previous participation in advance care planning has been associated with lower stress, anxiety, and depression among surviving family members.<sup>32</sup> Familiarity with the preferences of loved ones has been shown to decrease stress among surrogate decision makers, indicating the importance of involving surrogate decision makers in the process of advance care planning and of designating a durable power of attorney for health care.<sup>33,34</sup>

Educate health care professionals on how to engage individuals and their families in advance care planning and how to refer to appropriate community-based advance care planning resources

Studies of communication between health care providers and patients, especially around end-of-life and advance care planning issues, have shown significant opportunities for improvement. A study of advance care planning discussions found that technical aspects of care receive great attention (e.g., in 96%, of cases physicians discussed treatment options, including cardiopulmonary resuscitation or mechanical ventilation in 88% of those cases, artificial nutrition or hydration in 25% of those cases, and admissions to an intensive care unit in 16% of those cases). However, only 34% of physicians elicited the patient's values, health care goals, and reasons for treatment. Other studies found that patients rated physicians' prediction of life expectancy, quality of life that may be expected as death approaches, the nature of the dying process, and a patient's spiritual or religious belief poorly but that patients felt positive about physicians listening to them, attending to their concerns, and answering their questions. The patients is a patient of the patients of the dying process of them.

There are many advance care planning educational resources for health care providers and staff including: Franciscan Palliative Care Academy, Swedish Edmonds Advance Care Planning Program, the University of Washington Palliative Care Center of Excellence, The Washington State Hospital Association, The Washington State Medical Association, and other appropriate resources

More information about Franciscan Palliative Care Academy: <a href="www.chifranciscan.org/Health-Care-Services/Hospice-and-Palliative-Care/">www.chifranciscan.org/Health-Care-Services/Hospice-and-Palliative-Care/</a>

More information on Swedish/Edmonds Advance Care Planning Program: <u>AdvanceCarePlanning-EDM@swedish.org</u>

More information about University of Washington Palliative Care Center of Excellence:

http://depts.washington.edu/pallcntr/

More information about Washington State Hospital Association: <a href="www.wsha.org/endoflife.cfm">www.wsha.org/endoflife.cfm</a> More information about Washington State Medical Association: <a href="www.wsma.org/end-of-life">www.wsma.org/end-of-life</a>

The Bree Collaborative recommends provider practices and other health care facilities educate health care providers and other staff how to engage their patients and the patient's family or friends in advance care planning. Training should incorporate cultural sensitivity and consideration for race, sexual orientation, language, and any other relevant considerations. Provider practices and other health care facilities should become familiar with advance care planning resources in their community and be able to appropriately refer their patients to these resources.

## Encourage the use of evidence-based advance care planning tools and programs

A review of decision aids for advance care planning found many available tools, but few that were freely available for public use.<sup>37</sup> The majority of the tools reviewed helped patients create a health care directive, designate a durable power of attorney for health care, included conversation prompts, and discussed whether the patient would want comfort care only. A smaller number of the tools addressed the patient's specific preference for life sustaining treatment, life support, treatment location, and comfort care. While more research is needed to compare the effectiveness of advance care planning programs and tools, many have been successfully used by different community groups in Washington to help patients and families think through the care they would like to receive.

Goals of care vary from person to person and within individual patients depending on severity and projected course of illness.<sup>38</sup> Preference for life sustaining treatment as compared to comfort care has been shown to change over time and is dependent on context.<sup>39,40</sup> Additionally, patients' preference for highly burdensome, life-sustaining treatment has been seen to decline along with declining health status.<sup>41</sup> In one

Successful advance care planning should:<sup>23</sup>

- 1. Assess readiness
- 2. Educate on health status
- 3.Help the patient choose a suitable surrogate and involve the designated surrogate in the conversation
- 4. Clarify the amount of leeway the surrogate should have in deviating from an advance care plan
- 5. Discuss and clarify values (e.g., If you were in X situation, what would be most important to you)
- 6.Document the advance care plan with an advance directive and POLST if appropriate
- 7.Be an ongoing process to account for changes in patient preference

study, when asked "If they had an incurable disease and were suffering a great deal of pain," 57% of adults would want treatment stopped. Other studies have found 80% of respondents wanting only comfort care in the case of a terminal illness. Trust and confidence in care providers and a preference for less invasive care when there is little hope of recovery have also been shown to be important to patients. Greater

uncertainty in advance treatment decisions is seen among non-white patients and among those with limited English literacy.<sup>44</sup>

Honoring Choices Pacific Northwest has also engaged Gunderson Health and Respecting Choices to develop a multi-year adaptable advance care planning resource for communities across Washington State. The First Steps® Design and Implementation strategy offers both an advance care planning curriculum and a customizable process for health care delivery systems, religious affiliations, consumer advocacy groups, and other community partners to promote advance care planning through conversation and stewardship of information. A critical aspect of the plan is to certify faculty, instructors, and facilitators in Washington State, which will ensure the sustainability of the program into the future.

The Respecting Choices® program, led by the Gundersen Medical Foundation, uses a mix of printed material, videos, and trained staff to discuss advance care planning. As a result of the use of these processes, 85% of those who died in the zip codes surrounding the Foundation had advance directives after two years with 95% of those advance directives in the medical record. The majority of decedents requested that treatment be forgone at the end of life and this was honored in 98% of the deaths. These numbers have increased to 90% of decedents having advance directives with 99.4% of those advance directives available in the medical record in the subsequent 10 years. The program is designed as an "ongoing process of communication, integrated into the routine of patient-centered care" that incorporates "community engagement, professional education, and organization/standards of practice."

The Bree Collaborative acknowledges that many advance care planning tools and programs are successfully being used within our State. Rather than recommending a specific tool, the Collaborative recommends use of advance care planning across health care settings that:

- Assesses patient readiness
- Educates the patient on their health status
- Helps the patient choose a suitable surrogate and involve the designated surrogate in the conversation
- Clarify the amount of leeway the patient would like the surrogate should have in deviating from an advance care plan
- Discuss and clarify values (e.g., If you were in X situation, what would be most important to you?)
- Document the advance care plan with an advance directive and POLST if appropriate
- Be an ongoing process to account for changes in patient preference

Encourage people and health care providers to involve family members and friends in advance care planning and designate a legal durable power of attorney for health care

Surrogate decision makers, legally designated with a durable power of attorney for health care form, are often asked to use the standard of substituted judgment, to make decisions reflective of what patients would have wanted had they been able to make the decision. When surrogates are not involved in the planning process, both they and health care providers have been shown to be inaccurate at predicting patients' wishes. 47,48 While surrogates tend to be more accurate than physicians at predicting patient treatment preference, they have been shown to be biased by their own beliefs in making decisions for others, tending

toward over-treatment.<sup>49</sup> Surrogates are more able to make judgments on behalf of patients and are less anxious when doing so when they have been involved with the advance care planning process. The amount of leeway people wish to give their chosen surrogates varies from person to person and is influenced by culture.<sup>50</sup> Successfully following a patient's wishes depends on surrogates having the opportunity to engage in decision-making conversations to increase their understanding of and commitment to the person's wishes.

The Bree Collaborative recommends encouraging all people to designate a durable power of attorney for health care as a surrogate decision maker and involve that surrogate and the person's family members and friends in advance care planning conversations.

#### Encourage appropriate timing of advance care planning conversations

"It's always too early until it's too late."

Appropriate timing of advance care planning conversations varies from person to person and is dependent on many factors including age, religion, health status, culture, emotional and social need, and other situational factors. However, the literature suggests that more general conversations that take place earlier on in a person's life may prepare them, their family members, and friends for the type of decisions they will need to make during future end-of-life care.<sup>22</sup> In this way, any end-of-life planning conversation will eventually be beneficial, even if not related to a specific treatment decision. Research suggests that more accurate prognosis would assist with determining appropriate timing for advance care planning conversations, with a change in prognosis triggering the need for a new conversation.<sup>51</sup> Separate care pathways depending on whether a patient has less or more than one year to live are also recommended to determine the type of advance care planning conversations to have and the type of documents to generate (e.g., advance directives vs POLST).<sup>52</sup>

The Bree Collaborative recommends health care providers, patients, family members, and friends to consider the following representation, Figure 2, of when to consider advance care planning, keeping in mind that end-of-life care discussions had before a crisis will help patients and families prepare for and feel more comfortable during physically and emotionally challenging future situations.

Hospice or Life-threatening illness or event with frail elderly **End of Life** Healthy unknown trajectory care Ongoing advance care planning and Reassessment of POLST in last year of creation of advance directive including advance care life planning and living will/health care directive, durable revision of advance power of attorney for health care, and a directive as needed written personal statement

Figure 2: Continuum of health states during which advance care planning should be considered.

Adapted from: Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision Aids for Advance Care Planning: An Overview of the State of the Science. *Ann Intern Med*. 2014 Jul 29.

Revise reimbursement policy to pay for advance care planning counseling and discussion with patients and their surrogate decision makers

The Affordable Care Act's first iteration in 2009 included Medicare reimbursement for health care providers to provide annual advance care planning consultation. This provision was subsequently withdrawn due to political opposition.

In the past five years, there has been growing support for a revision to national policy to allow Medicare to reimburse for advance care planning discussions and increased support within multiple states for revision to Medicaid policy to reimburse for advance care planning as well.<sup>53,54</sup> Private insurers across the country have also begun to reimburse for advance care planning conversations including Blue Cross Blue Shield of Michigan and New York and Cambia Health Solutions.<sup>55</sup> In August 2013, the state of Colorado began to reimburse providers for "end-of-life counseling by primary care providers and other specialty providers caring for clients with serious, chronic, or terminal illness relating to the MOST," a "medical order set defining client choices for certain life-sustaining treatments" similar to the Washington State POLST.<sup>56</sup> Reimbursement for a code specific to advance care planning is expected to increase the percentage of patients receiving advance care planning in the clinical setting.

The Bree Collaborative recommends that the Health Care Authority and private health plans revise their policy to reimburse for the use of HCPCS Code S0257 and other end-of-life care codes. These codes reimburse for counseling and discussion regarding advance directives or end-of-life care planning and decisions, with patients and their surrogate decision makers. To support increased advance care planning, the Bree Collaborative also recommends education for providers and health care facilities about how to appropriately bill for this code.

#### Promote awareness of the value of hospice and encourage appropriate hospice referrals

Hospice care is an interdisciplinary health care service aimed at supporting patients and their families in the last six months of life. A hospice team will work to manage pain and symptoms; assist with the emotional, psychosocial, and spiritual aspects of dying; provide medical supplies; coach the family and friends; and provide bereavement and counseling for surviving family and friends.<sup>57</sup>

Use of hospice care in the United States is increasing. In 2012, 1.5 to 1.6 million patients across the country received hospice care at the end of their lives.<sup>58</sup> The median length of hospice service in 2012 was 18.7 days, the average 71.8 days. The majority, 66%, of patients received hospice care in a private residence, nursing home, or residential facility; 27.4% received care in a hospice inpatient facility; and 6.6% in an acute care hospital. In Washington State among Medicare fee for service beneficiaries, the median hospice length of stay was 23 days and the mean 58.9 days in 2012.<sup>59</sup> Hospice length of stay in Washington State was similar in 2013 with a median of 23 days and mean of 57.5 days.

Many studies have shown increased patient, family, friend, and caregiver satisfaction and higher patient quality of life with hospice. <sup>60,61</sup> In one study, families of home hospice enrollees were more satisfied with the care received than family members of those who did not receive hospice services. <sup>62</sup> When compared to decedents not using hospice, significant Medicare cost savings are seen for patients enrolled for as few as one to seven days, and higher savings for longer enrollment periods. <sup>63</sup> Being referred to hospice later on in the illness trajectory is associated with greater unmet needs among family members, but is still associated with high quality of care. <sup>63</sup>

Learn more about hospice in Washington State: www.wshpco.org.

The Bree Collaborative recommends that health systems and individual providers educate their patients about the value of hospice; clarify any misunderstandings among patients, family, and friends; and work to facilitate appropriate hospice referrals.

#### Train qualified advance care planning facilitators

While the clinical setting is one of the best studied locations for initiating advance care planning conversations, including community-based advance care planning facilitators is important to supplement those efforts. Facilitators can be spiritual leaders, community leaders, retired health care professionals, or other community members interested in offering this service on a paid or voluntary basis. Planning sessions can be offered in health care facilities or in a variety of public and private venues in the communities at times that are compatible with the schedules of patients and their families, (e.g. evenings, weekends).

The WAHA's End of Life Choices program, the Swedish Edmonds Advance Care Planning Program, and Snohomish County Health Leadership Coalition currently train advance care planning facilitators and provide this service to their community members.

The Bree Collaborative recommends that health care and community organizations recruit and train a diverse group of advance care planning facilitators and look for opportunities for community collaboration

3. Increase the number of people who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by all readers including family members, friends, and health care providers; and can be acted upon in the health care setting

Encourage the documentation of advance care planning discussions with easily understandable and culturally appropriate advance directives that include: a living will (also called a health care directive) that stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and a written personal statement that articulates the patient's values and goals regarding end-of-life care

As independent documents, the quality advance directives may inconsistent. 64,65 Poorly executed advance directives have been criticized for: not accurately reflecting patients' wishes, partially due to patients not being able to accurately predict what they would want in an unknown future circumstance; not being interpretable by the surrogate or health care staff; and not leading to any change in patient care. 66,67 In a chart audit of internal medicine patient's advance directives, 28% of the documentation was of no clinical utility, indicating significant barriers to the utility of advance directives.<sup>68</sup> Other studies have shown significant issues with the applicability of patients' advance directives to endof-life care including failing to address

## Advance directives should be culturally appropriate and include:

## A living will/health care directive

- Consistent with section 030 of the Washington State Natural Death Act.
- Signed by the declarer in the presence of two witnesses
- Specify whether the declarer does or does not want to "have artificially provided nutrition and hydration" if the declarer is "diagnosed to be in a terminal condition or in a permanent unconscious condition"
- Stipulate other specific treatment preferences (if known and applicable to the situation)

#### • A durable power of attorney for health care

- Indicating the amount of leeway the surrogate should have in decision-making (e.g., "I want my surrogate to work with my doctors and to use her/his best judgment" vs "I want my surrogate to follow my health care choices on this form exactly.")<sup>80</sup>
- A written personal statement that articulates the patient's values and goals regarding end-of-life care

cardiopulmonary resuscitation, mechanical ventilation, or hemodialysis for heart failure patients.<sup>69</sup>

Other studies show that advance directives specifying end-of-life care limitations have many advantages. Advance directives have been associated with lower levels of Medicare cost due to fewer deaths in the hospital setting. There have been significant associations between subjects care as detailed in an advance directive and the actual care received, 97.1% of patients requesting comfort care only and 83.2% of patients requesting limited care received their requested level of care. Studies have shown patients having an advance directive to be less likely to have a feeding tube or a respirator in the last month of life, less likely to die in the hospital if they indicated a desire to not receive care in a hospital setting, and more likely to use hospice.

Racial disparities between those with and without an advance directive have been consistently found in the literature<sup>74,75,76</sup> but can be reduced through targeted patient education or when looking at specific populations such as hospitalized, seriously ill veterans.<sup>77,78</sup> Advance care planning conversations should be sensitive to the cultural and ethnic background of different groups and present alternative versions of advance directive and POLST if appropriate in many different languages and formats that are acceptable to a wide variety of groups.

The Bree Collaborative recommends that completion of advance directives be the result of ongoing, culturally-sensitive advance care planning conversations between patients, their health care providers, their surrogate(s), friends and family, and/or other community organizations or advance care planning facilitators. The Collaborative recommends that an advance directive include a living will (also known as a health care directive) that stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and a written personal statement that articulates the patient's values and goals regarding end-of-life care.

## Adopt resources designed to engage low-literacy patients in advance care planning and creation of advance directives

As discussed earlier, those who complete an advance directive are more likely to be white, have higher income, and have higher education. Reaching out to those of lower socioeconomic levels and with lower levels of health literacy is important to reduce the disparities inherent in who has access to advance care planning. The Bree Collaborative recommends respecting these groups by developing or adapting already existing approachable material in a variety of formats tailored to the perspectives of diverse cultures. As an example, Rebecca Sudore, MD, of the University of California at San Francisco has developed an advance directive at the fifth grade reading level with culturally appropriate graphics that is available in multiple languages.<sup>79,80</sup> Studies of this health literacy-adjusted advance directive have found it to be preferred over the standard advance directive in California and to significantly increase completion rates.<sup>81</sup>

The advance directives are currently only legally binding in California and are available, here: www.iha4health.org/our-services/advance-directive/.

In support of a shift away from a focus on advance directives and toward an orientation of preparing for future end-of-life decision-making,<sup>22</sup> Dr. Sudore and the University of California at San Francisco developed the Prepare for Your Care website, "designed to help people and their loved ones prepare for medical decision making," which begins with a lesson on how to use a computer then allows the user to navigate through the website as (1) as a movie or (2) as an interactive website. Users are taken through five steps: 82

- Choosing a medical decision maker
- 2. Deciding what matters most in life
- Choosing flexibility for the decision maker
- 4. Telling others about their wishes, and
- 5. Asking doctors the right questions.

Each step contains a statement of importance and explains what the user as a consumer needs to do and how to do or say it. When users have completed all the steps on the website, an action plan is generated that can then be used to create an advance directive, but that is not itself an advance directive. The website was developed using social cognitive theory with focus groups and cognitive interviews. Pilot studies of the website have shown significant increases in knowledge, contemplation, self-efficacy, and readiness after one week of use in a sample of 65% non-white participants.

The website is available, here: www.prepareforyourcare.org

The Bree Collaborative recommends that the California low-literacy advance directive as described above be adapted for Washington State and made available for wide, free use as one of a number of innovative approaches to broaden the reach of advance directives.

# 4. Increase the accessibility of completed advance directives and POLST for health systems and providers

One of the primary barriers identified by the Bree Collaborative End-of-Life Care workgroup, was that completed advance directives and POLST are often not available when needed in a health care setting or by family and friends and that health care providers, family members, and friends were unaware that patients had completed an advance directive. One study of emergency medical technician responders found that POLST changed treatment for 45% of patients when present.<sup>84</sup>

#### Contract with an existing registry to store and make accessible advance directives and POLST

There is a growing movement within multiple states to build registries dedicated to increasing the accessibility of POLST and advance directives, accessed electronically or via phone from a central registry. Previously, the Washington State Department of Health managed a living will registry that was eliminated due to lack of funding in 2011.

Information about this registry can be found, here:

www.doh.wa.gov/AboutUs/ProgramsandServices/DiseaseControlandHealthStatistics/CenterforHealthStatistics/LivingWillRegistry/

The Bree Collaborative acknowledges that this registry was under-utilized and recommends that the State of Washington both contract with an existing registry in use by another state and promote the registry to health systems, providers, and the people of Washington State to facilitate widespread use.

While this is not an exhaustive list, Oregon, New York, Virginia, and Utah have either advance directive or POLST registries and are profiled as examples:

### Oregon POLST Registry<sup>85</sup>

- After design and systems training phases, the Oregon POLST registry began as a single county pilot project in 2009. Legislation, Senate Bill 329, created a partnership between the Department of Human Services and the Oregon Health Authority to allow for statewide expansion and to address HIPAA requirements. The registry has been available statewide since December 2009. Physicians fill out POLST with patients and submit the orders to the registry unless the patient opts out. A patient's POLST is available to health care providers via a 24/7 call center.<sup>86</sup>
- Recent analysis of death records in 2010 and 2011 found a significant association between decedents having a POLST order indicating comfort measures only and avoidance of hospitalization as compared to decedents with POLST indicating full treatment.<sup>87</sup>
- More information: www.orpolstregistry.org

## New York eMOLST Registry<sup>88</sup>

- New York's eMOLST Registry, organized by Compassion and Support and Excellus Blue Cross Blue Shield, allows users to electronically access patient orders 24/7. Forms are completed electronically, reducing the occurrence of errors or of orders that do not make sense together. MOLST forms are completed as part of conversations between patients, surrogates (if available), and a trained health care professional to "ensure shared, informed medical decision-making."
- More information: <u>www.compassionandsupport.org</u>

#### • Virginia Advance Directive Registry<sup>89</sup>

- The Commonwealth of Virginia established an advance health care directive registry through § 54.1-2994. The registry allows residents to "store their Advanced Health Care Directive, Health Care Power of Attorney, Declaration of Anatomical Gift, and other documents so that medical providers, emergency responders, family members, friends, and anyone else they grant access will honor their wishes." This registry is hosted via Unival, Inc and the Virginia Department of Health, is connected to the statewide health information exchange, and is accessible 24/7 by health care providers, patients, and their designated family and/or other individuals.
- o More information: www.virginiaregistry.org

#### • Utah ePOLST Registry<sup>90</sup>

- O The Utah ePOLST Registry is an electronic registry maintained by the Bureau of Health Facility Licensing Certification and Resident Assessment. The registry began as an agreement between HealthInsight and the Office of the National Coordinator for Health Information Technology, Utah Department of Health and "allows authorized users to store and retrieve information pertaining to patients' [end-of-life] care preferences." Important elements during the creation of the registry included: integration with Utah's electronic death entry network, secure user authentication, deactivation of an old POLST form if the patient makes any changes, identification of duplicate patient records, accessibility to emergency medical service providers (the primary users) via mobile devices, organization of patients by physician license number, and digital physician and patient signatures. 91
- More information: https://health.utah.gov/ems/polst/

Work with the Department of Motor Vehicles to add text indicating the presence of an advance directive on the Washington State driver's license with the additional option of putting a QR code on the back of the driver's license to gain direct access to the registry

The state of Hawaii currently allows residents to indicate the presence of an advance directive on their driver's license. A Robert Wood Johnson grant allowed Kokua Mau, Hawaii's Hospice and Palliative Care Organization, to develop a public awareness campaign about advance directives and encourage residents to add AHCD, or advance health care directive, to their driver's license between 1999 and 2002. 92,93 In 2001, 21% of "renewed Hawaiian driver's licenses carried AHCD," and hospice referrals also increased. The statewide adoption of an advance directive designator was assisted by a new state law in 2000 that "ended the use of social security numbers as identifiers on driver's licenses and state civil identification [and] adults in the state had to obtain a new driver's license or identification." Hawaii's Office on Aging worked with the Division of Motor Vehicles and Civil Identification Branch to add AHCD to identification and supply advance directives and distribute educational material to Hawaiian citizens.

More information: www.dmv.org/hi-hawaii/organ-donor.php

When the QR code is scanned, users would be directed to instructions on how to obtain a copy of the patient's advance directive and/or POLST from the state registry noted in the recommendation above.

The Bree Collaborative recommends that the State of Washington work with the Department of Motor Vehicles to add text indicating the presence of an advance directive on the Washington State driver's license with the additional option of putting a QR code on the back of the driver's license to gain direct access to the registry.

#### 5. Increase the likelihood that a patient's end of life care choices are honored

The Bree Collaborative acknowledges that there may be occasions when it is medically or ethically inadvisable to honor the terms of a patient's advance directive or POLST. This may occur because the document was poorly executed (e.g., illegible, nonspecific, executed when the patient lacked capacity, not witnessed) or because the patient's condition followed a trajectory that could not have been anticipated when the document was created or because in the provider's opinion, the requested intervention is either futile or has the potential to worsen rather than improve the patient's condition. When providers decide not to honor an advance directive for any of the foregoing reasons, this decision should be discussed with the patient's healthcare representative and, if necessary, presented for consultation with the organization's ethics committee.

The Bree Collaborative encourages providers and health care staff to take time and explain all the terms on an advance directive and POLST to family and friends at the end of a patient's life and support the patient, family, and friends during a time of crisis.

Implement quality improvement programs within hospitals, nursing homes, and other settings to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation

Some nursing home and hospital quality improvement programs have incorporated elements of advance care planning or accurate information transfer of POLST into their standard practice. Interventions to Reduce Acute Care Transfers (INTERACT®) uses advance care planning tools including:94

- A tracking tool to indicate when advance care planning discussions have occurred between patients and social workers, licensed nurses, primary care clinicians, clergy, and patients.
- Advance care planning communication guide.
- List of criteria for identifying appropriate residents for hospice or comfort care.
- Educational information for residents and families about POLST, do not resuscitate orders, and feeding tubes.

Qualis Health, the Quality Improvement Organization for the states of Washington and Idaho, facilitates community building and engages in direct one-to-one technical assistance through evidence based models including the INTERACT® Program. Qualis Health provides quarterly data reports at the community, hospital, skilled nursing facility, and home health agency level. Data is used as a prompt to do further local analysis, identify risk, and other quality improvement activities.

More information: www.qualishealth.org

The Bree Collaborative recommends that facilities providing care to patients and their families at the end of life (e.g., hospitals, nursing homes) implement quality improvement programs to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation.

Encourage providers and facilities to measure family and friend satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies

The Medicare program is replacing the longstanding Family Evaluation of Hospice Care (FEHC) survey with a new Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice survey beginning April 2015. The new survey is more focused on service quality issues and less focused on questions of whether the care patients received met goals of care. The new survey is focused on satisfaction with Hospice services rather than satisfaction with overall end-of-life process.

The FEHC survey is available here: <a href="www.nhpco.org/fehc-survey-materials">www.nhpco.org/fehc-survey-materials</a>

The new CAHPS hospice survey is available here: <a href="https://www.hospicecahpssurvey.org/content/SurveyInstruments.aspx">www.hospicecahpssurvey.org/content/SurveyInstruments.aspx</a>

The Bree Collaborative recommends that facilities providing care to patients and their families at the end of life (e.g., hospitals, nursing homes) survey surviving family members and friends with brief surveys of pertinent and validated questions assessing quality of care.

Enact legislation providing legal immunity to health care providers who honor a patient's POLST, comparable to existing protections for providers who honor a patient's advance directive

For over forty years, Washington's Natural Death Act has provided legal immunity from civil or criminal lawsuits and professional discipline for providers who honor a patient's advance directive. While all other states with POLST programs (more than twenty) provide legal immunity to providers who honor a POLST, Washington alone has not enacted legislation to protect providers. This has led to reluctance by some providers and hospitals to honor POLST orders. Fear of liability has led some long term care facilities to have policies requiring resuscitation of all residents, even those with POLST orders stating they do not want CPR. The lack of immunity protection is a barrier for families and providers who want to follow advance care plans. In some cases, patient's plans have been disregarded and patients have received unwanted resuscitation-despite having a valid POLST order. Providing immunity protection will help assure providers and facilities feel safe in honoring patients' wishes expressed in POLST orders.

The Bree Collaborative recommends that the Washington State Legislature pass legislation protecting healthcare providers and caregivers who honor a patient's POLST from civil, criminal and professional liability, similar to the protection currently provided for those honoring an advance directive.

#### Measurement

The Bree Collaborative acknowledges that many of the measures needed to show community baseline status and subsequent improvement on several of the recommendations made here do not exist at this time. Some require the creation of simple surveys of the preferences, knowledge, and actions of individuals, their surrogates, and their family members. Others require the collection of data from providers. The most challenging data collection requires access to patients' EMRs, (e.g. coding preferences, coding the type of care delivered, assessing the congruence between the type of care delivered and received.) The creation of data in the categories below is needed as a way to quantify the need for advance care planning and the effectiveness of the types of intervention being used to be sure that all Washingtonians are informed about their end-of-life options, communicate their preferences in actionable terms, and receive end-of-life care that is aligned with their wishes, goals, and values.

The sequence to develop measurable end-of-life care outcomes is:

- 1. People are aware of the need for advance care planning.
- 2. People understand the terminology and options that are discussed in advance care planning and written in advance directives.
- 3. Advance care planning is completed and understood by the person and his or her surrogate.
- 4. Advance directives are completed including a durable power of attorney for health care, a health care directive/living will, and a written personal statement.
- 5. POLST is discussed with a physician and completed when appropriate.
- 6. Completed advance directives are discussed, reviewed, and understood by the person's designated durable power of attorney for health care, or surrogate.
- 7. Completed advance directives are discussed with family members and friends.
- 8. Completed advance directives are discussed with health care providers.
- 9. Advance directives and POLST, if relevant, are entered into the patient's record.
- 10. Advance directives including durable power of attorney are consulted by health care providers when needed such as during a time of crisis.
- 11. The setting in which patients spend the end of their life.
- 12. The number of patients on hospice at the end of their life.
- 13. The number of hospice days for each patient.
- 14. The patient receives care that is aligned with his or her wishes, goals, and values.
- 15. Family are satisfied with the care that the patient received at his or her end of life.

## Stakeholder-Specific Recommendations

#### **Provider Practices**

- Educate health care providers and staff on:
  - How to have empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversations
  - How to be reimbursed for these conversations.
  - The difference between an advance directive and POLST, and patients for whom each would be acceptable.
  - How to refer patients to community-based advance care planning resources if appropriate.
- Encourage all patients over the age of 18 to consider having a conversation about advance care
  planning with the content of those conversations appropriate to the patient's age, health status,
  literacy level, and readiness.
- Adopt an advance care planning tool(s) or program(s) and standardize its use across your clinic or health care system. Possible examples include Honoring Choices: Pacific Northwest or the Institute for Health Care Improvement's Conversation Ready.
- Document in the medical record that the provider has used a standardized advance care planning tool.
- Document the results of advance care planning discussions with easily understandable and culturally
  appropriate advance directives that include: a living will (also called a health care directive) that
  stipulates specific treatment preferences (if known and applicable to the situation), a durable power
  of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate
  should have in decision-making, a written personal statement that articulates the patient's values
  and goals regarding end-of-life care, and POLST, if appropriate.
- Develop standardized protocols on how to transfer information contained in the advance directive or POLST to hospitals in your community such as through the advance directive/POLST registry, if in existence.
- Support patients as they navigate care between different health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.
- Promote awareness of the value of hospice and encourage appropriate hospice referrals.

#### **Hospitals**

- Educate health care providers and staff on:
  - How to have empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversations
  - How to be reimbursed for these conversations.
  - The difference between an advance directive and POLST, and patients for whom each would be acceptable.
  - How to refer patients to community-based advance care planning resources if appropriate.
  - Explaining the terms on an advance directive and POLST to family and friends at the end of a patient's life
  - Supporting the patient, family, and friends during a time of crisis.
- Work with your community's organizations (e.g., churches, non-profits focused on end-of-life care)
   to promote community-wide discussions about how to have conversations regarding personal goals
   of care and the type of care desired at the end of life with family members, friends, health care

- providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive.
- Review your facility's protocols around asking about and honoring advance directives to decrease barriers to patients' wishes being honored at the end of life.
- Adopt an advance care planning tool or program and standardize its use across your system. Possible examples include Honoring Choices Pacific Northwest or the Institute for Health Care Improvement's Conversation Ready.
- Enter advance directives and/or POLST into the patient's medical record once completed and communicate with the patient and his or her primary care provider as to whether the patient has advance directives and/or a POLST in his or her medical record.
- Promote awareness of the value of hospice, encourage appropriate hospice referrals, and be sure to communicate any referrals back to the patient's primary care provider.
- Implement a quality improvement program to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation
- Measure family and friend satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies.
- Support patients as they navigate care between different health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.

## **Skilled Nursing Facilities**

- Educate health care providers and staff on:
  - How to have empathetic, realistic, and patient- and family-centered (e.g., using lower literacy materials if appropriate) advance care planning conversations
  - How to be reimbursed for these conversations.
  - The difference between an advance directive and POLST, and patients for whom each would be acceptable.
  - How to refer patients to community-based advance care planning resources if appropriate.
  - Explaining the terms on an advance directive and POLST to family and friends at the end of a patient's life
  - Supporting the patient, family, and friends during a time of crisis.
- Work to promote discussions with residents about how to have conversations regarding personal
  goals of care and the type of care desired at the end of life with family members, friends, and health
  care providers; the importance of having an advance directive that includes a living will (also known
  as a health care directive), a durable power of attorney for health care, and a written personal
  statement about health care goals and values; and the difference between POLST and an advance
  directive.
- Enter advance directives and/or POLST into the patient's medical record once completed and communicate with the patient and his or her primary care provider as to whether the patient has advance directives and/or a POLST in his or her medical record.
- Promote awareness of the value of hospice and encourage appropriate hospice referrals.
- Implement a quality improvement program to encourage greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation.
- Measure family satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies.

• Support patients as they navigate care between different health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.

#### **Health Plans**

- Revise reimbursement policy to include use of HCPCS Code S0257 and other end-of-life care codes, counseling and discussion regarding advance directives or end-of-life care planning and decisions, with patients and their surrogate decision makers.
- Educate providers and health care facilities how to appropriately bill for this code.
- Encourage hospitals, nursing homes, and other applicable settings to implement a quality improvement program focused on greater adherence to patients' requests as outlined in advance directives and POLST if accurate and applicable to the current situation
- Measure family and friend satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies.
- Develop inclusive and comprehensive benefits for care of patients with serious illness at the end of life allowing them to receive care consistent with their wishes and goals even if not eligible for hospice.
- Support patients as they navigate care between separate health care facilities and systems including facilitation of information sharing and patient and family outreach during times of crisis.

## **Employers/Purchasers**

- Purchase health plans that honor a patient's choices at the end-of-life through providing reimbursement for advance care planning conversations with patients and their surrogate decision makers.
- Educate your employees about how to have conversations regarding personal goals of care and the type of care desired at the end of life with family members, friend, and health care providers; the importance of having an advance directive that includes a living will (also known as a health care directive), a durable power of attorney for health care, and a written personal statement about health care goals and values; and the difference between POLST and an advance directive.

## The State of Washington

- Revise reimbursement policy to include use of HCPCS Code S0257 and other end-of-life care codes, counseling and discussion regarding advance directives or end-of-life care planning and decisions, with patients and their surrogate decision makers.
- Educate providers and health care facilities how to appropriately bill for this code.
- Contract with an existing state registry for advance directives and POLST and promote use of the registry to health systems, providers, and the people of Washington State to facilitate widespread use.
- Work with the Department of Motor Vehicles to add text indicating the presence of an advance directive on the Washington State driver's license with the additional option of putting a QR code on the back of the driver's license to gain direct access to the registry.
- Promote awareness and utilization of advance care planning at multiple levels of health care delivery systems.
- Promote legislation and regulatory changes to promote the detailed recommendations in this report
  including legislation protecting healthcare providers and caregivers who honor a patient's POLST
  from civil, criminal and professional liability, similar to the protection currently provided for those
  honoring an advance directive.

The Bree Collaborative's options, communicate th is aligned with their wish	eir preferences in a	ctionable terms, ar	

## **End-of-Life Care Improvement Efforts in Washington State**

Many organizations and programs are dedicated to promoting advance care planning in Washington State and across the country. Our recommendations draw from the work of the efforts profiled below as well as others, seek to empower Washington State residents, and work to align end-of-life care with patient's wishes, goals, and values.

This is not an exhaustive list and does not represent endorsement by the Bree Collaborative.

## **Compassion and Choices of Washington**

Compassion and Choices of Washington serves as an advocate for terminally ill patients and their family through facilitating conversations about end-of-life choices, educating the public and health care professionals, and promoting the use of advance directives, among other endeavors. Compassion and Choices provides end-of-life counseling and client support services for patients and families.

More information: compassionwa.org

## **Conversation Ready Project**

The Conversation Ready Project is a national initiative of the Institute for Healthcare Improvement. The one-year project is meant to introduce new processes within multiple health care systems "to reframe patient-provider relationships around the question, *What matters most to you*?" Virginia Mason Medical Center in Seattle, Washington is part of the Conversation Ready Project.

More information:

www.ihi.org/Engage/Initiatives/ConversationProject/Pages/ConversationReady.aspx

More information: theconversationproject.org

#### **Death Over Dinner**

Death Over Dinner is an online project from the University of Washington's Masters in Communication Leadership program to address the disparity between desired and actual end-of-life care. The website offers conversation prompts and resources to start the conversation about end-of-life care for a wide audience.

More information: deathoverdinner.org

#### Franciscan Hospice and Palliative Care Academy

The Franciscan Hospice and Palliative Care Academy trains physicians, nurse practitioners, and physician assistants to enhance "ability to provide excellent symptom management" and teach "the communication skills needed to break bad news, prognosticate and match medical treatments to patient preferences."

More information: <a href="https://www.chifranciscan.org/Health-Care-Services/Palliative-Care/Palliative-Care-

#### Kitsap County Cross Continuum Care Transitions Project (KC4TP) Palliative Care Committee

The Kitsap County Cross Continuum Care Transitions Project (KC4TP) began in 2012 as a collaboration between Harrison Medical Center, regional skilled nursing facilities, hospice and palliative care facilities, specialty and primary care clinics, and other community health care support agencies to address rehospitalization.

More information: www.harrisonmedical.org/home/kc4tp

## Honoring Choices Pacific Northwest®

Honoring Choices Pacific Northwest, a joint initiative of the Washington State Hospital Association and the Washington State Medical Association, is a program that encourages early conversations about the type of care people would want if faced with a life threatening illness. It does this in two major ways. One, the program provides training and resources to hospitals and doctors to make sure they are prepared to discuss, record and honor people's wishes at the end of their life. Second, a public website offers a place for individuals and families to learn about their choices and encourage conversations about their wishes

#### **Know Your Choices - Ask Your Doctor**

The Know Your Choices - Ask Your Doctor campaign is organized by the WSMA and promotes "patient-centered health initiatives to enhance the relationship between patient and physician." End-of-life resources are a part of the Know Your Choices - Ask Your Doctor campaign. The WSMA has served as a state resource for advance directives and end-of-life planning since the early 1990s. This work started with the brochure "Who Will Decide If You Can't" containing the Washington State health care directive and durable power of attorney for health care form. Today, the advance directive brochure is the most popular patient resource and is distributed across hospitals, clinics, and health systems across the state.

More information: <a href="https://www.wsma.org/know-your-choices">www.wsma.org/know-your-choices</a> More Information: <a href="https://www.wsma.org/advance-directives">www.wsma.org/know-your-choices</a>

## Life Transitions, the End of Life Coalition of Southwest Washington

This is a county-wide effort that combines the efforts of Bridges Palliative Care Home Health and Hospice, Glenwood Place Senior Living, PeaceHealth Hospice Southwest, Southwest Washington Agency on Aging and Disabilities, and Fort Vancouver Convalescent Park Lido & Caretique. This program sponsors Respecting Choices education for hospital and medical personnel as well as community presentations of the program upon request by churches and community groups and distributes advance directives as needed.

For more information, email: <a href="mailto:swlifetransitions@gmail.com">swlifetransitions@gmail.com</a>

#### **Palliative Care Initiative**

The Palliative Care Initiative is a regional partnership between Community Organized Group for Health, Peace Health Hospice, Peace Health Palliative Care, Western Washington University, Whatcom Alliance for Health Advancement, and Whatcom Family and Community Network. The Initiative puts on various training events for providers such as the Palliative Care Summer Institute, hosts national speakers, and works to "create a space where people with serious illnesses don't have to be cured to heal."

More information: <a href="https://www.wwu.edu/ee/bsn/palliative.shtml">www.wwu.edu/ee/bsn/palliative.shtml</a>

### 6-Steps Swedish Advance Care Planning Program

Swedish Edmonds Hospital offers free monthly workshops and individual counseling sessions conducted by qualified living will facilitators. Services are offered to individuals and their surrogates using the 6-Step Guide to create of an advance care plan. Programs are offered in hospital facilities and in venues in the community.

For more information, email: <a href="mailto:AdvanceCarePlanning-EDM@swedish.org">AdvanceCarePlanning-EDM@swedish.org</a>

#### **Snohomish County Health Leadership Coalition Advance Care Planning Initiative**

The Snohomish County Health Leadership Coalition combines the resources of organizations including Verdant, the YMCA, Premera, and the Everett Clinic, among others. The goal of the coalition is to greatly increase the number of Snohomish County residents who have completed advance care plans. It offers training to healthcare providers and volunteer facilitators in a variety of culturally adapted advance care planning programs including Respecting Choices.

More information: www.snocohealth.org

#### **Supportive Care Coalition**

Providence Health and Services, PeaceHealth, and Catholic Health Initiatives founded the Coalition in 1994 and has expanded since to a membership of 22 Catholic health care organizations in 42 states. Much of the Coalition's work is focused on increasing palliative care quality and accessibility.

More information: <a href="mailto:supportivecarecoalition.org/index.php">supportivecarecoalition.org/index.php</a>

## **Washington State End-of-Life Coalition**

The Washington State End-of-Life Consensus Coalition was created by the WSMA in 1997 to promote conversations between patients and their providers about "living and dying well within all communities across Washington." Members are from a diverse array of organizations across Washington State and convene once a year at an annual conference.

More information: <a href="https://www.wsma.org/weolcc">www.wsma.org/weolcc</a>

#### Washington Physician Orders for Life Sustaining Treatment (POLST) Task Force

The WSMA coordinates the Washington POLST Task Force with the Washington State Department of Health. POLST was piloted in Oregon in 1995 and the National POLST Paradigm Taskforce was established from early-adopter states in 2004. The National POLST Paradigm is an approach to end-of-life planning that emphasizes, "advance care planning conversations between patients, health care professionals and loved ones; shared decision-making between a patient and his/her health care professional about the care the patient would like to receive at the end of his/her life; and ensuring patient wishes are honored." States or regions implement their own POLST programs represent the National POLST Paradigm after being endorsed by the program. The WSMA offers up-to-date POLST forms, frequently asked questions, and provides resources to providers and patients about the legality of and operational uses of POLST.

More Information: <a href="https://www.polst.org">www.polst.org</a> More Information: <a href="https://www.wsma.org/polst">www.wsma.org/polst</a>

## **University of Washington Palliative Care Center of Excellence**

The University of Washington's (UW) Palliative Care Center of Excellence (PCCE) was launched in October of 2012 with the mission to improve the palliative care received by patients with life-threatening illness and their families in the UW system and to provide new knowledge and educational and clinical resources to improve palliative care regionally, nationally, and globally. The PCCE strives to accomplish this mission by enhancing research, education, and clinical services in palliative care at the University of Washington, the Seattle region and throughout the Northwest. The PCCE has also launched the UW Palliative Care Training Center that is developing a program funded by the Cambia Health Foundation to provide specialty-level training and on-boarding for palliative care providers including physicians, nurses, social workers, spiritual care providers, and others throughout the region.

More information: www.uwpalliativecarecenter.com

#### University of Washington School of Medicine End-of-Life Care Research Program

The University of Washington, School of Medicine, End-of-Life Care Research Program started in 1998 is housed and supported by Harborview Medical Center and funded by various grants from the National Institutes of Health and the National Palliative Care Research Center. The Research Program develops patient-provider communication tools, instruments, and interview guides, and conducts research on aspects of end-of-life care including improving physician communication skills, supporting families in the intensive care unit, and patient expectations.

More information: <a href="mailto:depts.washington.edu/eolcare/">depts.washington.edu/eolcare/</a>

#### References

<sup>1</sup> Barnato AE, Herndon MB, Anthony DL, Gallagher PM, Skinner JS, Bynum JP, Fisher ES. Are regional variations in end of life care intensity explained by patient preferences?: A Study of the US Medicare population. *Med Care*. 2007 May;45(5):386-93.

<sup>2</sup> Goodman DC, Esty AR, Fisher ES, Chang CH. Trends and Variation in End of life Care for Medicare Beneficiaries with Severe Chronic Illness. The Dartmouth Atlas Project. April 12, 2011. Accessed: July 2014. Available: www.dartmouthatlas.org/downloads/reports/EOL Trend Report 0411.pdf

- <sup>3</sup> Raphael C, Ahrens J, Fowler N. Financing end of life care in the USA. J R Soc Med. 2001 September; 94(9): 458–461.
- <sup>4</sup> End of life Care. Dartmouth Atlas of Health Care. Accessed: July 2014. Available: www.dartmouthatlas.org/data/topic/topic.aspx?cat=18.
- <sup>5</sup> Center for Health Statistics. Death Data: Table A11 Place Where Death Occurred by County of Occurrence. Washington State Department of Health. 1980-2013. Accessed: August 2014. Available: www.doh.wa.gov/DataandStatisticalReports/VitalStatisticsData/DeathData/DeathTablesbyTopic.
- <sup>6</sup> Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med*. 1997 Jan 15;126(2):97-106.
- <sup>7</sup>Collins LG, Parks SM, Winter L. The state of advance care planning: one decade after SUPPORT. *Am J Hosp Palliat Care*. 2006 Oct-Nov;23(5):378-84.
- <sup>8</sup> Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B; FAMIREA Study Group. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med*. 2005 May 1;171(9):987-94.
- <sup>9</sup> Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and utility of advance care planning in a county that implemented an advance care planning microsystem. *JAGS*. 2010;58:1249-1255.
- <sup>10</sup> Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end of life care: A systematic review. *Palliat Med*. 2014 Sep;28(8):1000-1025.
- <sup>11</sup> Jackson JM, Rolnick SJ, Asche SE, Heinrich RL. Knowledge, attitudes, and preferences regarding advance directives among patients of a managed care organization. *Am J Manag Care*. 2009 Mar;15(3):177-86.
- <sup>12</sup> Washington State Hospital Association. End of life Care Manual. Accessed: August 2014. Available: www.wsha.org/EOL-Statutes-SDAct.cfm.
- <sup>13</sup> American Bar Association. Law for Older Americans: Health Care Advance Directives. Accessed: August 2014. Available:
  - www.americanbar.org/groups/public education/resources/law issues for consumers/patient self determination act.html.
- <sup>14</sup> Teno J, Lynn J, Wenger N, Phillips RS, Murphy DP, Connors AF Jr, Desbiens N, Fulkerson W, Bellamy P, Knaus WA. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc. 1997 Apr;45(4):500-7.
- <sup>15</sup> Joos SK, Reuler JB, Powell JL, Hickam DH. Outpatients' attitudes and understanding regarding living wills. *J Gen Intern Med*. 1993 May;8(5):259-63
- <sup>16</sup> Rao JK, Anderson LA, Lin FC, Laux JP. Completion of Advance Directives Among U.S. Consumers. *Am J Prev Med*. 2014 Jan;46(1):65-70.
- <sup>17</sup> Pew Research Center. November 2013. Views on End of life Medical Treatments. Accessed: May 2014. Available: <a href="https://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/">www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/</a>
- <sup>18</sup> American Association of Retired Persons (AARP). 2008. AARP Bulletin Poll "Getting Ready to Go" Executive Summary. AARP.org, Surveys and Statistics. Washington, DC. 2008.
- <sup>19</sup> Tung EE, Wieland ML, Verdoorn BP, Mauck KF, Post JA, Thomas MR, Bundrick JB, Jaeger TM, Cha SS, Thomas KG. Improved resident physician confidence with advance care planning after an ambulatory clinic intervention. *Am J Hosp Palliat Care*. 2014 May;31(3):275-80.

<sup>20</sup> Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010 Apr 1;362(13):1211-8.

- <sup>21</sup> Shojania KG, Grimshaw JM. Evidence-based quality improvement: the state of the science. *Health Aff (Millwood)*. 2005 Jan-Feb;24(1):138-50.
- <sup>22</sup> Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end of life decision making. *Ann Intern Med.* 2010 Aug 17;153(4):256-61.
- <sup>23</sup> Gunderson Health System. Respecting Choices Advance Care Planning. Accessed: August 2014. Available: www.gundersenhealth.org/respecting-choices.
- Wisconsin Medical Society. Honoring Choices Wisconsin. Accessed: August 2014. Available: www.wisconsinmedicalsociety.org/professional/orphan/honoring-choices-wisconsin-executive-summary.
- <sup>25</sup> Whatcom Alliance for Health Advancement. End of Life Choices. Accessed: August 2014. Available: http://whatcomalliance.org/end-of-life-care/.
- <sup>26</sup> Death Cafe in Whatcom County. Accessed: April 2014. Available: <a href="www.deathandcoffee.com">www.deathandcoffee.com</a>.
- <sup>27</sup> Group Health Cooperative. Advance Directives and End of life Decisions. Updated: March 1, 2014. Accessed: August 2014. Available: <a href="https://www.ghc.org/healthAndWellness/?item=/common/healthAndWellness/careDecisions/carePlanning/advancedDirectives.html">www.ghc.org/healthAndWellness/?item=/common/healthAndWellness/careDecisions/carePlanning/advancedDirectives.html</a>.
- <sup>28</sup> Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010 Mar 23;340:c1345
- <sup>29</sup> Connors AF, Dawson NV, Desbiens NA, Fulkerson WJ, Goldman L, Knaus WA, Lynn J. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA*. 1995 Nov 22-29;274(20):1591-8.
- <sup>30</sup> Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ4. Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis. *J Am Med Dir Assoc*. 2014 Jul;15(7):477-489.
- <sup>31</sup> Zhang B1, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end of life conversations. *Arch Intern Med*. 2009 Mar 9;169(5):480-8.
- <sup>32</sup> Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010 Mar 23;340:c1345
- <sup>33</sup> Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001 Jan;29(1):197-201.
- <sup>34</sup> Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med*. 2007 Sep;22(9):1274-9.
- <sup>35</sup> Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med*. 1998 Sep 15;129(6):441-9.
- <sup>36</sup> Curtis JR, Engelberg RA, Nielsen EL, Au DH, Patrick DL. Patient-physician communication about end of life care for patients with severe COPD. *Eur Respir J.* 2004 Aug;24(2):200-5.
- <sup>37</sup> Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision Aids for Advance Care Planning: An Overview of the State of the Science. *Ann Intern Med*. 2014 Jul 29.
- <sup>38</sup> Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, Shortt S, Tranmer J, Lazar N, Kutsogiannis J, Lam M; Canadian Researchers End of life Network(CARENET). What matters most in end of life care: perceptions of seriously ill patients and their family members. *CMAJ*. 2006 Feb 28;174(5):627-33.
- <sup>39</sup> Lockhart LK, Ditto PH, Danks JH, Coppola KM, Smucker WD. The stability of older adults' judgments of fates better and worse than death. *Death Stud*. 2001 Jun;25(4):299-317.
- <sup>40</sup>Ditto PH, Jacobson JA, Smucker WD, Danks JH, Fagerlin A. Context changes choices: A prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making*. Jul-Aug 2006;26(4):313-322.
- <sup>41</sup> Fried TR, O'Leary J, Van Ness P, Fraenkel L. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *J Am Geriatr Soc.* 2007 Jul;55(7):1007-14.
- <sup>42</sup> Schiff R, Rajkumar C, Bulpitt C. Views of elderly people on living wills: interview study. *BMJ*. 2000 Jun 17;320(7250):1640-1.
- <sup>43</sup> Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, Shortt S, Tranmer J, Lazar N, Kutsogiannis J, Lam M; Canadian Researchers End of life Network(CARENET). What matters most in end of life care: perceptions of seriously ill patients and their family members. CMAJ. 2006 Feb 28;174(5):627-33.
  Page 35 of 38

<sup>44</sup> Sudore RL, Schillinger D, Knight SJ, Fried TR. Uncertainty about advance care planning treatment preferences among diverse older adults. *J Health Commun*. 2010;15 Suppl 2:159-71

<sup>45</sup> Hammes BJ, Rooney BL. Death and end of life planning in one midwestern community. *Arch Intern Med.* 1998 Feb 23;158(4):383-90.

- <sup>46</sup> Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc.* 2010 Jul;58(7):1249-55.
- <sup>47</sup> Seckler AB, Meier DE, Mulvihill M, Paris BE. Substituted judgment: how accurate are proxy predictions? *Ann Intern Med*. 1991 Jul 15;115(2):92-8.
- <sup>48</sup> Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med*. 2006 Mar 13;166(5):493-7.
- <sup>49</sup> Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol*. 2001 May;20(3):166-75.
- <sup>50</sup> Kelley AS, Wenger NS, Sarkisian CA. Opiniones: end of life care preferences and planning of older Latinos. *J Am Geriatr Soc.* 2010 Jun;58(6):1109-16
- <sup>51</sup> Billings JA, Bernacki R. Strategic targeting of advance care planning interventions: the goldilocks phenomenon. *JAMA Intern Med.* 2014 Apr;174(4):620-4.
- <sup>52</sup> Bomba PA, Vermilyea D. Integrating POLST into palliative care guidelines: a paradigm shift in advance care planning in oncology. *J Natl Compr Canc Netw.* 2006 Sep;4(8):819-29. Available: <a href="https://www.compassionandsupport.org/pdfs/professionals/training/Integrating">www.compassionandsupport.org/pdfs/professionals/training/Integrating</a> POLST into PC Guidelines.pdf
- <sup>53</sup> The Advisory Board Company. Medicare May Reimburse Docs for End of life Care. Accessed: August 2014. Available: http://www.advisory.com/daily-briefing/2014/06/04/medicare-may-reimburse-docs-for-end-of-life-care
- <sup>54</sup> Curtis JR. Reimbursement for advance care planning: why should intensivists care? *Am J Respir Crit Care Med*. 2011 Aug 15;184(4):387-8.
- <sup>55</sup> Belluck P. Coverage for End of life Talks Gaining Ground. The New York Times. August 30, 2014. Accessed August 2014. Available: <a href="http://www.nytimes.com/2014/08/31/health/end">http://www.nytimes.com/2014/08/31/health/end of life-talks-may-finally-overcome-politics.html?smid=tw-nytimeshealth&seid=auto& r=2</a>
- <sup>56</sup> Colorado Department of Health Care Policy and Financing. Provider Bulletin January 2014. January 2014. Accessed: July 2014. Available: <a href="https://www.colorado.gov/pacific/sites/default/files/Bulletin\_0114\_B1400346.pdf">https://www.colorado.gov/pacific/sites/default/files/Bulletin\_0114\_B1400346.pdf</a>
- <sup>57</sup> National Hospice and Palliative Care Organization. Hospice Care. Accessed: August 2014. Accessed: August 2014. Available: <a href="https://www.nhpco.org/about/hospice-care">www.nhpco.org/about/hospice-care</a>
- National Hospice and Palliative Care Organization. NHPCO's Facts and Figures: Hospice Care in America. 2013. Accessed: August 2014. Available: <a href="https://www.nhpco.org/sites/default/files/public/Statistics">www.nhpco.org/sites/default/files/public/Statistics</a> Research/2013 Facts Figures.pdf
- <sup>59</sup> Hospice length of stay data from Medicare only fee for service. Qualis Health. Received: November 2014.
- <sup>60</sup> Teno JM, Shu JE, Casarett D, Spence C, Rhodes R, Connor S. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007 Aug;34(2):120-5.
- <sup>61</sup> Earle CC, Landrum MB, Souza JM, Neville BA, Weeks JC, Ayanian JZ. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol*. 2008 Aug 10;26(23):3860-6
- <sup>62</sup> Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end of life care at the last place of care. *JAMA*. 2004 Jan 7;291(1):88-93.
- <sup>63</sup> Kelley AS, Deb P, Du Q, Aldridge Carlson MD, Morrison RS. Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. *Health Aff (Millwood)*. 2013 Mar;32(3):552-61.
- <sup>64</sup> Tan TS, Jatoi A. End of life hospital costs in cancer patients: do advance directives or routes of hospital admission make a difference? *Oncology*. 2011;80(1-2):118-22
- <sup>65</sup> Silveira MJ, Wiitala W, Piette J. Advance directive completion by elderly Americans: a decade of change. *J Am Geriatr Soc.* 2014 Apr;62(4):706-10.
- <sup>66</sup> Nauck F, Becker M, King C, Radbruch L, Voltz R, Jaspers B. To what extent are the wishes of a signatory reflected in their advance directive: a qualitative analysis. *BMC Med Ethics*. 2014 Jun 30;15:52.
- <sup>67</sup> Fagerlin A, Schneider CE. Enough: The Failure of the Living Will. Hastings Center Report 34, no. 2 (2004): 30-42.
- <sup>68</sup> Tung EE, Wieland ML, Verdoorn BP, Mauck KF, Post JA, Thomas MR, Bundrick JB, Jaeger TM, Cha SS, Thomas KG. Improved resident physician confidence with advance care planning after an ambulatory clinic intervention. *Am J Hosp Palliat Care*. 2014 May;31(3):275-80.
  Page 36 of 38

<sup>69</sup> Dunlay SM, Swetz KM, Mueller PS, Roger VL. Advance directives in community patients with heart failure. *Circ Cardiovasc Qual Outcomes*. 2012 May;5(3):283-9.

- <sup>70</sup> Nicholas LH, Langa KM, Iwashyna TJ, Weir DR. Regional variation in the association between advance directives and end of life Medicare expenditures. *JAMA*. 2011 Oct 5;306(13):1447-53.
- <sup>71</sup> Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010 Apr 1;362(13):1211-8.
- <sup>72</sup> Bischoff KE, Sudore R, Miao Y, Boscardin WJ, Smith AK. Advance care planning and the quality of end of life care in older adults. *J Am Geriatr Soc.* 2013 Feb;61(2):209-14.
- <sup>73</sup> Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end of life care: a national study. *J Am Geriatr Soc.* 2007 Feb;55(2):189-94.
- Wagner GJ, Riopelle D, Steckart J, Lorenz KA, Rosenfeld KE. Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *J Pain Symptom Manage*. 2010 Mar;39(3):527-34.
- <sup>75</sup> Phipps E, True G, Harris D, Chong U, Tester W, Chavin SI, Braitman LE. Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *J Clin Oncol*. 2003 Feb 1;21(3):549-54.
- <sup>76</sup> Hopp FP. Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: results from a national study. *Gerontologist*. 2000 Aug;40(4):449-57.
- <sup>77</sup> Zaide GB, Pekmezaris R, Nouryan CN, Mir TP, Sison CP, Liberman T, Lesser ML, Cooper LB, Wolf-Klein GP. Ethnicity, race, and advance directives in an inpatient palliative care consultation service. *Palliat Support Care*. 2013 Feb;11(1):5-11
- <sup>78</sup> Fischer SM, Kutner JS, Sauaia A, Kramer A. Lack of ethnic differences in end of life care in the Veterans Health Administration. *Am J Hosp Palliat Care*. 2007 Aug-Sep;24(4):277-83.
- <sup>79</sup> Sudore, R. Presentation to the End of life Workgroup. April 2014.
- <sup>80</sup> Sudore R, Papartassee M. California Advance Health Care Directive. San Francisco Department of Public Health. Available: www.iha4health.org/wp-content/uploads/2014/03/CAHCD\_English\_no\_Script\_3.14.13.pdf
- <sup>81</sup> Sudore RL, Landefeld CS, Barnes DE, Lindquist K, Williams BA, Brody R, Schillinger D. An advance directive redesigned to meet the literacy level of most adults: a randomized trial. *Patient Educ Couns*. 2007 Dec;69(1-3):165-95.
- <sup>82</sup> The Regents of the University of California. Prepare for your Care. 2013. Accessed: August 2014. Available: <a href="https://www.prepareforyourcare.org">www.prepareforyourcare.org</a>
- <sup>83</sup> Sudore RL, Knight SJ, McMahan RD, Feuz M, Farrell D, Miao Y, Barnes DE. A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study. *J Pain Symptom Manage*. 2014 Apr;47(4):674-86.
- <sup>84</sup> Schmidt TA, Hickman SE, Tolle SW, Brooks HS. The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes. *J Am Geriatr Soc.* 2004 Sep;52(9):1430-4.
- 85 Oregon POLST Registry. History of the Oregon POLST Registry. Accessed: August 2014. Available: www.orpolstregistry.org/oregon-polst-registry/about-opr/
- <sup>86</sup> Schmidt TA, Zive D, Fromme EK, Cook JN, Tolle SW. Physician orders for life-sustaining treatment (POLST): lessons learned from analysis of the Oregon POLST Registry. *Resuscitation*. 2014 Apr;85(4):480-5.
- <sup>87</sup> Fromme EK, Zive D, Schmidt TA, Cook JN, Tolle SW. Association between physician orders for life-sustaining treatment for scope of treatment and in-hospital death in Oregon. *J Am Geriatr Soc.* 2014 Jul;62(7):1246-51.
- 88 Compassion and Choices. Electronic Medical Orders for Life-Sustaining Treatment in New York State. Accessed: August 2014. Available:
  - www.compassionandsupport.org/index.php/for professionals/molst training center/emolst
- <sup>89</sup> Virginia Department of Health. Advance Health Care Directive Registry. Accessed: August 2014. Available: <a href="https://www.virginiaregistry.org">www.virginiaregistry.org</a>
- <sup>90</sup> Bureau of Emergency Medical Services. Life with Dignity/POLST/DNR. Accessed: August 2014. Available: <a href="health.utah.gov/ems/polst/">health.utah.gov/ems/polst/</a>
- <sup>91</sup> Duncan J, Taillac P, Nangle B, Henry M, Houston J, Talebreza S, Finch L, Brunker C, Rajeev D, Smith HJ6, North C. Electronic End of life Care Registry: the Utah ePOLST Initiative. *AMIA Annu Symp Proc.* 2013 Nov 16;2013:345-53.
- <sup>92</sup> Robert Wood Johnson Foundation. Hawaii Overcomes Cultural Barriers to End of life Care: Establishment of a statewide collaborative program to improve end of life care. Updated: September 2016. Accessed: August 2014.
   Available: <a href="https://www.rwjf.org/content/dam/farm/reports/program\_results\_reports/2006/rwjf16950">www.rwjf.org/content/dam/farm/reports/program\_results\_reports/2006/rwjf16950</a>
   Page 37 of 38

<sup>&</sup>lt;sup>93</sup> Kokua Mau: Hawai'i and Palliative Care Organization. Welcome to Kokua Mau. Accessed: August 2014. Available: <a href="https://www.kokuamau.org">www.kokuamau.org</a>

<sup>94</sup> INTERACT. INTERACT Version 3.0 Tools. © 2011 Florida Atlantic University. Accessed: August 2014. Available: www.interact2.net/docs/INTERACT%20Version%203.0%20Tools/Overview%20of%20the%20INTERACT%20Quality %20Improvement%20Program/INTERACT%20Table%20of%20Tools%20Dec%2029%202012.pdf

# **Appendix A: Bree Collaborative Members**

Member	Title	Organization		
Susie Dade MS	Deputy Director	Washington Health Alliance		
John Espinola MD, MPH	Vice President, Quality and Medical Management and Provider Engagement	Premera Blue Cross		
Gary Franklin MD, MPH	Medical Director	Washington State Department of Labor and Industries		
Stuart Freed MD	Medical Director	Wenatchee Valley Medical Center		
Tom Fritz	Chief Executive Officer	Inland Northwest Health Services, Spokane		
Joe Gifford MD	Chief Executive, ACO of Washington	Providence Health and Services		
Richard Goss MD	Medical Director	Harborview Medical Center – University of Washington		
Steve Hill (Chair)	Retired	Previously Director, Department of Retirement Systems, and Chair, Puget Sound Health Alliance		
Christopher Kodama MD	Medical Vice President, Clinical Operations	MultiCare Health System		
MaryAnne Lindeblad RN, MPH	Director, Medicaid Program	Health Care Authority		
Greg Marchand	Director, Benefits & Policy and Strategy	The Boeing Company		
Robert Mecklenburg MD	Medical Director, Center for Health Care Solutions	Virginia Mason Medical Center		
Kimberly Moore MD	Associate Chief Medical Officer	Franciscan Health System		
Carl Olden MD	Family Physician	Pacific Crest Family Medicine, Yakima		
Mary Kay O'Neill MD, MBA	Executive Medical Director	Regence Blue Shield		
John Robinson MD, SM	Chief Medical Officer	First Choice Health		
Terry Rogers MD (Vice Chair)	Chief Executive Officer	Foundation for Health Care Quality		
Jeanne Rupert DO, PhD	Director of Medical Education	Skagit Valley Hospital		
Kerry Schaefer	Strategic Planner for Employee Health	King County		
Bruce Smith MD	Associate Medical Director, Strategy Deployment	Group Health Physicians		
Lani Spencer RN, MHA	Vice President, Health Care Management Services	Amerigroup		
Jay Tihinen	Assistant Vice President Benefits	Costco Wholesale		
Carol Wagner RN, MBA	Senior Vice President for Patient Safety	The Washington State Hospital Association		
Shawn West MD				

Appendix Page 1 of 9

# Appendix B: End of Life/Advance Directives Workgroup Charter

### **Problem Statement**

End of life (EOL) care in the United States is strikingly variable and often misaligned with patient preference. While the majority of patients report wanting to spend the last part of their lives at home, in reality this time is spent in a hospital or nursing home. Unnecessarily aggressive care to prolong life can negatively impact quality of life, increase cost, and seriously overburden the health care system. Appropriately timed EOL conversations between provider and patient and use of advance directives can increase patient confidence, sense of dignity, and the probability that patient wishes are honored at time of death. However, despite their indisputable value in principle, only a small fraction of adults discuss EOL care with their providers and family or complete advance directives.

### Aim

To improve quality of life and reduce unnecessary costs of care delivered at the end of life in Washington State and to empower patients to work with their physicians and others participating in their care to develop advance directives in accordance with their preferences.

### **Purpose**

The purpose of the End of Life/Advance Directives (EOL) workgroup is to propose recommendations to the full Bree Collaborative on how to improve care, improve quality, and reduce unnecessary variation at the end of a patient's life through greater utilization of Advance Directives.

- 1. <u>Focus initially on end-of-life planning discussions</u>. Target the initiation of end-of-life planning discussions between physicians, other members of the health-care delivery team, patients, their surrogates, and family members with a focus on patient preference and a goal of completing an advance directive. Clear jargon-free language with a focus on appropriate palliative care is imperative.
- 2. <u>Encourage widespread adoption of advance directives</u>. Gather evidence-based guidelines and identify opportunities for the Bree Collaborative to endorse and otherwise support broader adoption of successful evidence-based programs, such as approaches focused on appropriate code status discussion. Mindful of the pragmatics of end-of-life care, this will include innovative recommendations to staff and how to fund advanced care planning.
- 3. <u>Increase measurement and reporting of advance directives</u>. Promote the collection of process and outcome measures for end of life care, including congruence with the patients' advance directives instructions, code status discussion, palliative care, and hospice care including facility-based and home-based.

### **Duties & Functions**

The EOL workgroup shall:

- Coordinate with members of WSHA, WSMA, other stakeholder organizations and subject matter experts to maximize impact.
- Present findings and recommendations in a report.
- Provide updates at Bree Collaborative meetings.
- Research evidence-based guidelines, emerging best practices, and current initiatives to improve patient quality of life and/or reduce health care costs for end of life care.
- Create and oversee subsequent subgroups to help carry out the work, as needed.
- Post draft report on the Bree Collaborative website for public comment prior to sending report to the Bree Collaborative for approval and adoption.

#### Structure

The EOL workgroup will consist of individuals appointed by the chair of the Bree Collaborative, and confirmed by the Bree Collaborative steering committee.

The chair of the EOL workgroup will be appointed by the chair of the Bree Collaborative. The Bree Collaborative project director will staff and provide management and support services for the EOL workgroup.

Less than the full EOL workgroup may convene to: gather and discuss information; conduct research; analyze relevant issues and facts; or draft recommendations for the deliberation of the full workgroup. A quorum shall be a simple majority and shall be required to accept and approve recommendations to the Bree Collaborative.

### **Meetings**

The EOL workgroup will hold meetings as needed.

The EOL workgroup chair will conduct meetings. Committee staff will arrange for the recording of each meeting and distribute meeting agendas and other materials prior to each meeting.

### **EOL Workgroup Members**

Name	Title	Organization
John Robinson, MD	Chief Medical Officer	First Choice Health
(Chair)		
Bruce Smith, MD	Medical Director, Government	
(Vice Chair)	Programs	Group Health Cooperative
Anna Ahrens	Director of Patient and Family	MultiCare Health System
	Support Services	
J. Randall Curtis, MD	Professor of Medicine	UW Palliative Care Center of Excellence
		Section Head
Trudy James	Chaplain	Heartwork
Bree Johnston, MD	Medical Director, Palliative Care	PeaceHealth
Abbi Kaplan	Principal	Abbi Kaplan Company
Timothy Melhorn, MD	Internist	Yakima Valley Memorial Hospital and
		the Memorial Foundation
Joanne Roberts, MD	Chief Medical Officer	Providence Regional Medical Center
		Everett
Richard Stuart, DSW	Clinical Professor Emeritus,	University of Washington
	Psychiatry	
Observers		
Tanya Carroccio	Director, Quality & Performance	Washington State Hospital Association
	Improvement	
Jessica Martinson	Director, Clinical Education and	Washington State Medical Association
	Professional Development	
Committee Staff		
Steve Hill	Chair	Bree Collaborative
Ginny Weir	Project Director	Bree Collaborative

<sup>&</sup>lt;sup>1</sup> Raphael C, Ahrens J, Fowler N. Financing end-of-life care in the USA. J R Soc Med. 2001 September; 94(9): 458–461.

Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and utility of advance care planning in a county that implemented an advance care planning microsystem. JAGS. 2010;58:1249-1255.

# DURABLE POWER OF ATTORNEY FOR HEALTH CARE

# **Notice to Person Executing This Document**

#### This is an important legal document. Before executing this document you should know these facts:

- This document gives the person you designate as your Health Care Agent the power to make MOST health care decisions for you if you lose the capability to make informed health care decisions for yourself. This power is effective only when you lose the capacity to make informed health care decisions for yourself. As long as you have the capacity to make informed health care decisions for yourself, you retain the right to make all medical and other health care decisions.
- You may include specific limitations in this document on the authority of the Health Care Agent to make health care decisions for you.
- Subject to any specific limitations you include in this document, if you do lose the capacity to make an informed decision on a health care matter, the Health Care Agent GENERALLY will be authorized by this document to make health care decisions for you to the same extent as you could make those decisions yourself, if you had the capacity to do so. The authority of the Health Care Agent to make health care decisions for you GENERALLY will include the authority to give informed consent, to refuse to give informed consent, or to withdraw informed consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition. You can limit that right in this document if you choose.
- When exercising his or her authority to make health care decisions for you when deciding on your behalf, the Health Care Agent will have to act consistent with your wishes, or if they are unknown, in your best interest. You may make your wishes known to the Health Care Agent by including them in this document or by making them known in another manner.
- When acting under this document the Health Care Agent GENERALLY will have the same rights that you have to receive information about proposed health care, to review health care records, and to consent to the disclosure of health care records.

# 1. Creation of Durable Power of Attorney for Health Care

I intend to create a power of attorney (Health Care Agent) by appointing the person or persons designated herein to make health care decisions for me to the same extent that I could make such decisions for myself if I was capable of doing so, as recognized by RCW 11.94.010. This designation becomes effective when I cannot make health care decisions for myself as determined by my attending physician or designee, such as if I am unconscious, or if I am otherwise temporarily or permanently incapable of making health care decisions. The Health Care Agent's power shall cease if and when I regain my capacity to make health care decisions.

# 2. Designation of Health Care Agent and Alternate Agents

			able of giving informed consent	to health
care, I		, designate	and appoint:	
Name		Address		
City	State	Zip	Phone	
authorize her or him to consult with	- ,	of my regaining the	ney for Health Care recognized in RC\ capacity to make treatment decisions nel.	
In the event that		is unable o	unwilling to serve, I grant these pow	ers to
Name		Address		
City	State	Zip	Phone	
In the event that both		and		
are unable or unwilling to serve, I gr	ant these powers to			
Name		Address		
City	State	Zip	Phone	

Appendix Page 4 of 9

Your name (print)	
-------------------	--

# 3. General Statement of Authority Granted.

My Health Care Agent is specifically authorized to give informed consent for health care treatment when I am not capable of doing so. This includes but is not limited to consent to initiate, continue, discontinue, or forgo medical care and treatment including artificially supplied nutrition and hydration, following and interpreting my instructions for the provision, withholding, or withdrawing of life-sustaining treatment, which are contained in any Health Care Directive or other form of "living will" I may have executed or elsewhere, and to receive and consent to the release of medical information. When the Health Care Agent does not have any stated desires or instructions from me to follow, he or she shall act in my best interest in making health care decisions.

The above authorization to make health care decisions does not include the following absent a court order:

- (1) Therapy or other procedure given for the purpose of inducing convulsion;
- (2) Surgery solely for the purpose of psychosurgery;
- (3) Commitment to or placement in a treatment facility for the mentally ill, except pursuant to the provisions of Chapter 71.05 RCW;
- (4) Sterilization.

I hereby revoke any prior grants of durable power of attorney for health care.

4. Special Provisions	<b>.</b>						
DATED this	day of	, (Year)					
		GRANTOR					
	)	)ss.					
COUNTY OF							
		e GRANTOR,					
DATED this	day of	, (Year)					
	NOTARY PUBL	NOTARY PUBLIC in and for the State of Washington,					
	residing at						
	My commission	on expires					

NOTE: Washington state does not require this directive to be notarized or witnessed. Since some states do require it to be notarized; you may want to do so in the event you travel out-of-state.

Appendix Page 5 of 9

# **HEALTH CARE DIRECTIVE**

Dire	ective made this	day of	,·
I.			(Year)being of sound mind, willfully, and voluntarily make known my
			nces set forth below, and do hereby declare that:
	If at any time I should have an i tending physician, and where th process of my dying, I direct tha I understand "terminal conditio	incurable and irreversible contents application of life-sustaint such treatment be withhom? means an incurable and	ondition certified to be a terminal condition by my atning treatment would serve only to artificially prolong the eld or withdrawn, and that I be permitted to die naturally. irreversible condition caused by injury, disease or illness ath within a reasonable period of time in accordance with
(B)		from which those physicia	ve state, or other permanent unconscious condition as ns believe that I have no reasonable probability of recovery, lrawn.
(C)	) If I am diagnosed to be in a term		
	ing treatment. I understand artis	n and hydration to be with ficially administered nutrit	ndrawn or withheld the same as other forms of life-sustainion and hydration is a form of life-sustaining treatment in ho care for me to honor this directive.
(D)	that this directive shall be honor of my fundamental right to refu	red by my family, physiciar ise medical or surgical treat	e use of such life-sustaining procedures, it is my intention as and other health care providers as the final expression ment, and also honored by any person appointed to make any or otherwise. I accept the consequences of such refusal.
(E)	If I have been diagnosed as preg effect during the course of my p		known to my physician, this directive shall have no force or
(F)	I understand the full import of also understand that I may ame		otionally and mentally competent to make this directive. I at any time.
(G)	) I make the following additional	directions regarding my ca	ire:
	Signed:		
	not the attending physician	, an employee of the attend who has a claim against any	believe him or her to be of sound mind. In addition, I ameling physician or health care facility in which the declarer portion of the estate of the declarer upon the declarer's
			Witness:
			Witness:

Appendix Page 6 of 9

# **What To Do With These Forms**

The attached Health Care Directive and Durable Power of Attorney for Health Care forms are all legal documents once they are completely filled out and signed with the appropriate signatures. Signed copies of the completed directives should be included in your medical record, given to any person to whom you give your durable power of attorney—including any alternate people you may have named—and to your personal attorney. Originals should be kept by someone you trust and who can obtain them in an emergency.

### **For Further Information**

These forms have been provided as a public service by the Washington State Medical Association. You are encouraged to discuss the directives with your physician. Any legal questions you may have about the use and effect of these directives may be answered by an attorney.

Appendix Page 7 of 9

	HIPAA PERMITS DISCLOSURE OF	POLST '	TO OTHER HEALTH CARE PROVIDERS AS	NECESSARY	
	Physician O	)rde	<b>rs</b> for Life-Sustaining Treatment		
	Name - First Name - Middle Initial		FIRST follow these orders, THEN contact physician, nurse practitioner or PA-C. The POLST form is always voluntary. The POLST is a set of medical orders intended to guide medical treatment based on a person's current medical condition and goals. Any section not		
Date	e of Birth Last 4 #SSN G	iender /I F	completed implies full treatment for that section. treated with dignity and respect.		
Med	ical Conditions/Patient Goals:		Agency Info/Sticker		
A Check		=	<b>PR):</b> Person has no pulse and is not breathing  Do Not Attempt Resuscitation (Allow Natural		
One	_ : _	priate c	omfort measures and may still include the	•	
В	MEDICAL INTERVENTIONS: Person	has puls	e and/or is breathing.		
Check One  Composition of the co					
	LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, IV fluids an cardiac monitor as indicated. Do not use intubation or mechanical ventilation. May use less invasive air way support (e.g. CPAP, BiPAP).  Transfer to hospital if indicated. Avoid intensive care if possible.				
	FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.  Transfer to hospital if indicated. Includes intensive care.  Additional Orders: (e.g. dialysis, etc.)				
C	SIGNATURES: The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by a surrogate, the patient must be decisionally incapacitated and the person signing is the legal surrogate.				
	Discussed with:  Patient Parent of Minor Guardian with Health Care Authority	PRINT	— Physician/ARNP/PA-C Name	Phone Number	
	Spouse/Other as authorized by RCW 7.70.065 Health Care Agent (DPOAHC)	<b>X</b> P	Physician/ARNP/PA-C Signature ( <i>mandatory)</i>	Date (mandatory)	
	<u>PRINT</u> — Patient or Legal Surrogate Name	·		Phone Number	
	Patient or Legal Surrogate Signature	Date (mandatory)			
	Person has: Health Care Directive (liv	_		ndvance care planning accompany POLST	

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Photocopies and faxes of signed POLST forms are legal and valid. May make copies for records. For more information on POLST visit www.wsma.org/polst.



Revised 4/2014



HIPAA PERMITS DISCLO	SURE OF POLST	ΤΟ ΟΤΙ	HER HEALTH C	ARE PROVIDE	RS AS NEC	ESSARY
Other Contact Information	(Optional)					
Name of Guardian, Surrogate or otl	ner Contact Person	Relation	ionship Phone Number			
Name of Health Care Professional P	reparing Form	Preparer	Title	Phone Nu	mber	Date Prepared
D Non-Emergency Mei	DICAL TREATMEN	IT PREF	ERENCES			
ANTIBIOTICS:  No antibiotics. Use other modernine use or limitation				entibiotics if life a comfort as goa	-	longed.
Always offer food and liquids by	MEDICALLY Assisted Nutrition:  Always offer food and liquids by mouth if feasible.  No medically assisted nutrition by tube.  Trial period of medically assisted nutrition by tube.  (Goal:					
ADDITIONAL ORDERS: (e.g.	dialysis, blood produ	cts, impla	nted cardiac device	es, etc. Attach add	litional order	s if necessary.)
Physician/ARNP/PA-C Signature					Date	
Patient or Legal Surrogate Sig	nature			Date		
Completing POLST  The POLST is usually for persons with ser  Completing a POLST form is always voluth  The POLST must be completed by a heal patient's preferences and medical conditions are sufficiently preferences and medical conditions.  POLST must be signed by a physician/AF surrogate, to be valid. Verbal orders are a by physician/ARNP/PA-C in accordance with the process of the process of the previous orders.  This POLST is valid in all care settings inclined physician's orders.  The POLST is a set of medical orders. The previous orders.  The POLST does not replace an advance of is encouraged for all competent adults rean advance directive allows a person to dhealth care instructions and/or name a suon his/her behalf. When available, all doct to ensure consistency, and the forms updany conflicts.	heir signature olicy.  laced by aces all ective tatus. r future to speak yed	tempt Resuscitation SECTION B:  • When comfort can ing someone with setting able to proceed to a not the setting able to a not the	ould be used on a person."  not be achieved in the "Comfort Measures Or vide comfort (e.g., treato enhance comfort mort Measures Only."  rdration is a measure vids should indicate al Interventions" or "Fuirtion must always be considered to the person of	current setting, nly," should be to atment of a hip ay be appropriately be appropriately that may protect the setting of the statement.  If the setting or care as son's health statement, cian Orders" and	the person, includ- ransferred to a fracture). te for a person who ong life. A person ally feasible.	
Review of this POLST Form	La cation of David			D. C. O. Lawren		
Review Date Reviewer	Location of Revi	ew		Review Outcome  No Change Form Voided  No Change Form Voided	New	form completed
SEND ORIGINAL F	ORM WITH PERS	ON WH	ENEVER TRAN	SEERRED OR I	DISCHARG	ED