

An Educational Intervention to Increase Advance Directive Completion in the Medical/Surgical  
Pulmonary Stepdown Unit

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### **Abstract**

Advance care planning (ACP) enables and empowers individuals to drive their medical care, especially once they become incapacitated by disease or terminal illness. Advance directives (ADs) have proven to decrease end-of-life expenditures by Medicare. In addition, completion of an AD increases the probability of medical care that coincides with the patient's wishes and decreases decision-making burden for the family and physicians.

### **Purpose**

The purpose of this quality improvement project is to assess the effectiveness in increasing advance directive completion rates by offering an educational intervention for healthcare providers about advance care planning.

### **Methodology**

This quality improvement project was designed with implementation of a pre- and post-test survey design to measure healthcare provider knowledge on proper ACP approaches. Thirty healthcare providers (internal medicine residents and advanced nurse practitioners) that rotate through the medical/surgical pulmonary stepdown unit (PSDU) were offered education on advance care planning utilizing conversation guides and a presentation developed by the head of palliative care at Johns Hopkins Hospital. The number of ADs on file in the PSDU pre-implementation and post-implementation was evaluated by counting the number of ADs on file 3 months prior to implementation compared to the number of ADs on file over a 3-month period after implementation.

### **Results**

A paired-samples *t*-test was used to compare the pre- and post-test survey results in order to determine the association between reinforced healthcare education and AD completion over a

6-month period. The findings revealed a statistically significant difference in the pre- and post-test scores, with an overall increase in scores post educational sessions. The paired-samples *t*-test indicated that scores were significantly higher post-implementation ( $M = 39.5, SD = 7.5$ ) than pre-implementation ( $M = 30.5, SD = 5.8$ ),  $t(29) = -6.8, p < .05, d = 1.34$ . According to the Chi-squared test, there was no association between reinforced education and AD completion rates (Chi-square = .029,  $p = .865$ ), which is a reflection of the limited number of cases used for data extraction. The number of completed ADs on file post implementation increased from 6 to 15.

### **Implications for Practice**

Based on the findings of this project, interventions to inform healthcare providers about the ACP process should be considered as part of clinical practice. It is strongly suggested that healthcare providers receive periodic updates regarding the ACP process in addition to receiving conversation tools for guidance. If the findings of this intervention could be applied to the overall hospital population, then this simple intervention would likely result in a significant increase in completed ADs overall. Thus, the objective of providing medical care that coincides with ones' wishes and improved outcomes at the end of life would be a closer reality.

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## **Introduction**

Many individuals are unaware of the options they have regarding their medical care now and in the future. Advanced care planning (ACP) is a process that enables and empowers individuals' medical care decisions, both currently and in the future when they become incapacitated by disease or terminal illness. Healthcare providers should be adequately educated about advance care planning, in order to properly navigate the conversation. Healthcare providers may be unaware of the all options a patient may have and/or the proper protocol to ascertain their choices. Advance care planning will allow the patients to understand their options and to be better equipped to make educated medical care decisions. Advance care planning may decrease unwanted medical procedures or treatments that ultimately prolong the inevitable. In turn proper education provided to the healthcare providers might lead to an increase in advance directives.

## **Background and Significance**

Over a million individuals are hospitalized all over the United States on a yearly basis, especially the elderly, those who suffer from chronic comorbidities and terminal illnesses. Their illness is prone to progressing and their health to deteriorate, which would entail life sustaining measures to take place. People are living longer, and chronic conditions grow more complex each day, which entails a rise in the cost of healthcare and coincides with an increase in Medicare enrollment (Mullaney, Devereaux, Lee, & MacArthur, 2015). On the other hand, all individuals face the risk of hospitalization, resulting from a stroke, traumatic injury, cancer, and chronic or life threatening conditions. Sadly, any individual, despite their health status is at risk; therefore, each individual needs to plan ahead and discuss their wishes with their family and/or healthcare providers. Unfortunately, this discussion rarely takes place and ultimately, the next of

kin is responsible for making medical decisions and may feel a sense of burden or guilt. This can result in the patient enduring unwanted medical procedures or treatments that ultimately prolong the inevitable and subject them to a poor quality of life. A poor quality of life may include being attached to a ventilator for the rest of their life, requiring a feeding tube for nutrition, and may endure painful pressure sores. In turn, this may cause a rise in medical expenses and Medicare enrollment.

The utilization of an ACP allows individuals to discuss and document their wishes, should anything expected or unexpected occur. ACP is a process that is used to facilitate autonomy in the event the patient is rendered incapacitated and aims to support an individual's goals, values, and preferences at any age and health status (Sudore et al., 2017). ACP can lead to an advance directive (AD), if the patient chooses to do so. AD is the result of the patient and consumer rights movement of the 60's and 70's. An AD is a legal document which is completed when the patient still possesses his/her decision-making capacity regarding their health decisions in the future in the event they become incapacitated (Detering, & Silveira, 2018). End of life (EOL) decisions revolve around autonomy, quality of life, and life-sustaining measures, which has been the topic of debate for many years. Providers, policy makers, legislators, and the public have their own perspective on the topic but may not know all the facts. As technology has improved over the years, so has medicine and people have been able to prolong the inevitable through life-sustaining measures. EOL decisions need to be discussed to respectfully carryout the individuals wishes and to prevent unwanted medical management.

The Patient Self-Determination Act (PSDA) was established in 1990, to give individuals the right to accept or reject medical care legally, based on their wishes despite their physical state (Goodwin, Kiehl, & Peterson, 2002). PSDA is the first policy created to inform patients of their

medical treatment rights and it is the responsibility of the healthcare professionals to make the patients aware of their rights (Goodwin et al., 2002). According to the PSDA, institutions must inform patients of their right to participate in and direct their own health care decision, refuse medical or surgical treatment, prepare an AD, and to review information on the institutional policies governing these rights (Detering, & Silveira, 2018). Since this act has been passed little has been accomplished in the United States. A systematic review analyzing 150 studies from 2011 through 2016 in the US concluded that about 37% of individuals have completed an AD (Detering, & Silveira, 2018). Now regulatory agencies, such as the Joint Commission and Centers for Medicare and Medicaid Services (CMS), are requiring facilities and organizations to properly educate healthcare providers, so they are prepared to discuss AD with their patients (Donahue, 2013). ACP helps to put things into perspective for the patient and their family, which entails an understanding of what exactly the patient wants done when he or she is deemed incapacitated or requiring life sustaining measures. ACP can decrease hospitalization rates, unwarranted medical expenses; in addition, providing autonomy to the patient, and ease of family burden.

Traditionally healthcare providers made medical decisions based on beneficence in the hopes of comforting or curing their patients; therefore, they mostly made all the decisions. However, if the patient's condition takes a turn for the worse then so does the providers' mindset to sustain life by any measure. Just like the medical world has changed so should the thought process of the providers. Many physicians, nurse practitioners, patients, as well as their families express a sense of hardship, and morbid feelings when it comes to discussing EOL decisions. Most healthcare professionals were not properly educated on the concept of ACP, which may be the reason why this topic is misunderstood (Splendore, & Grant, 2017). Some barriers of ACP

discussion are family burden, assuming their families already know their wishes, but the number one reason is the lack of awareness that ACP exists (Splendore, & Grant, 2017). Chronic comorbidities grow more complex with each passing day causing a rise in healthcare costs. It requires longer, more frequent hospitalizations, and coincides with an increase in Medicaid and Medicare enrollments (Mullaney, Devereaux, Lee, & MacArthur, 2015). Family members are advised to apply for Medicaid and/or Medicare depending on the patient's age for health coverage and assistance based on the patient's needs. Family members want their loved ones to live on, which may cause them to agree to all life-sustaining measures that are available which may be aggressive and expensive; however, they may not consider the wishes of their loved one or their perception of quality of life. Advancements in medical technology and the availability of different treatment options allow the dying process to become modified for each individual. All these factors contribute to the loss of control over the dying process (Vearrier, 2016). In order to improve EOL care, the CMS will reimburse healthcare professionals for discussing ACP with their patients (Halpern, 2015).

Burden on the patient's families and healthcare provider regarding decision-making is greatly decreased, when an AD is completed, according to recent studies (Portanova, Ailshire, Perez, Rahman, & Enguidanos, 2017). Unfortunately, 76 percent of patients are unable to express their preferences impacting their EOL choices (Sudore & Sudore, 2010). A terminal illness is not the basis of an ACP because chronic conditions can change in the blink of an eye. Chronic conditions through medications and proper treatment are considered stable because they are maintained. Unfortunately, a stable condition could take a turn for the worst and suddenly become terminal; thus, an ACP discussion could avoid confusion and allows everyone to be prepared (Mullick, Martin, & Sallnow, 2013). Consequently, without these discussions to

determine EOL choices and/or to create ADs, both the patients and their family members suffer both physically and emotionally. The lack of these discussion leads to an increase in hospice referrals and medical care costs (Harlow, 2017). In theory there is an increase in hospice referral, but they are often made too late, as with ACP. As a nation, providers are terrible at connecting patients to hospice and when the connection is made, it is often very late. Most of the time providers consult palliative care too late which in turn leads to late hospice referrals. It has been proven that effective communication enhances patients' understanding of medical treatments, clarifies their EOL wishes, enables cross-cultural support, and bridges the barriers between patients' wishes and documentation in the health record (Vearrier, 2016). Yet, healthcare providers are still hesitant and unwilling to initiate these discussions because they fear their patients will lose hope when facing their prognosis, as if they are bringing their illness and death full circle despite the evidence (Mullick, et al., 2013).

According to the United States Department of Health and Human Services, some problems that may arise from EOL decisions are communication issues between the healthcare provider and the patient, the patient and their family, or the healthcare provider and the family, mistrust between any of the above mentioned, denial of prognosis, and religious or cultural beliefs (USDHHS, 2008). Healthcare providers, as well as families try to avoid discussing, death, dying, and EOL decisions, hence the reason patients' EOL choices are misunderstood (USDHHS, 2008). Patients, providers, and family members have expressed difficulty when it comes to the topic of ACP, resulting in lack of discussions. In order for an ACP to be productive and beneficial certain things need to occur: comfort with the healthcare provider, a sense of compassion and respect, answer patient's and their family member's questions clearly and completely, determine who should be involved in the discussion, and the provider's undivided

attention (USDHHS, 2008). There are multiple barriers that impede ACP such as, ineffective application of AD in facilities, the limited education and experience healthcare providers have, and the US healthcare system (USDHHS, 2008).

Successful implementation of an ACP and ADs would result in a decrease of unwanted mechanical ventilation, feeding tubes, tracheostomies, hemodialysis, and unwarranted interventional procedures; on the other hand, palliative care, and hospice would increase to merely provide comfort in the setting the patient wished (Harlow, 2017). In addition, ADs and ACP have been proven in countless studies to decrease EOL costs by insurance companies, especially Medicare Advantage (Nicholas, Langa, Iwashyna, & Weir, 2011). Previous research has proved that ACP documentation is inconsistent in the patient's EHR (Tai-Seale et al., 2018). The benefit of an ACP is to educate patients about their treatment options and encourage them to voice and document their preferences for EOL care in order to ease their as well as their family's pain and suffering (Tai-Seale et al., 2018). The latest recommendations to initiate ACP discussions is when the individual's life expectancy is two years or less. A universal ACP tool should be incorporated into every individual's EHR, especially people with terminal illnesses and multiple chronic conditions (Tai-Seale et al., 2018). Healthcare providers should discuss their patient's values, treatment preferences, and goals and use the information from these discussions to educate their patients during every interaction to help them determine their decisions for EOL choices (Tai-Seale et al., 2018). Basically, ACP is based on discussions, but allows the patient to feel comfortable and more open because the topic is consistently being revisited and the patient is not being rushed or pressured to make any decisions. The current practice is ineffective when it comes to carrying out and honoring the patients' EOL wishes.

ACP allows the patient to understand all their options to help determine their wishes in order to specify them in an AD.

ACP, EOL discussions, and ADs have been proven in countless studies to benefit the patients, their families, healthcare providers, facilities, and insurance companies, yet there is hardly any research regarding the significance of proper preparation, education, and guidance of healthcare providers. All these aspects are crucial components that impact a patient's decision to complete an AD. It is essential to recognize the barriers healthcare providers face in order to create an effective plan which incorporates proper education, training, resources, and assistance. An evidence-based study is proposed to measure the amount of completed advance directives in medical/surgical units before and after educating healthcare providers.

### **Needs Assessment**

At City of Hope National Medical Center, the department of supportive care medicine created an ACP program which included disease specific workflows, multi-lingual workshops, and new policies to document ACP discussion in their electronic health records if the patient did not have an AD. They also created specific screening questions to be used by all providers, easy documentation of an ACP discussion and location of AD. The campaign they created was culturally sensitive and coined the phrase "plan today for tomorrow" (Zachariah et al., 2017). The rate of AD at this facility continued to increase from 12% in 2012 to 22% in 2016 and accounted for a decrease in cost and resource utilization. The patient's wishes were respected and carried out preventing unwanted medical treatment, hence a decrease in cost.

The College of Family Physicians of Canada in 2018 developed a guide for resident physicians by resident physicians about ACP discussions. It is a step by step guide pertaining to when and how to carry out ACP based on acuity and urgency and includes the actions that need

to take place for a successful ACP discussion and possibly ADs. The guide was brought about because about 76% of patients will be unable to participate in their EOL decisions and about 47% have never discussed their EOL wishes with their families or healthcare providers (Dhillon, Jerome, Teeluck, & Yu, 2018). The residents want to prevent and hopefully avoid unwanted medical treatments that may result in unnecessary suffering for both the patient and their family.

Only 30% of United States citizens have documented their EOL wishes, even with the multitude of evidence describing the benefits of ACP (Murphy, Martin-Plank, Shea, & Williams, 2018). The Conversation Project toolkit was used in North Carolina among African-American churches to educate and encourage AD and EOL options from 2017-2018, which resulted in a positive manner from 2,678 to 3,044 increase in ADs (Kebaso, Black, Stevens, & Tesh, 2018). The conversation project finds different methods to allow individuals to feel comfortable to discuss their EOL wishes and the toolkit is used to educate them. Exploration of a patient's perspective on illness, living well, EOL issues, and decision making formed the core part of most guides (Fahner et al, 2019). A study was conducted during 2011 through 2016 to determine the amount of living wills and/or durable power of attorneys completed in the United States, the results were eye-opening. A systematic review of 150 studies which included 795,909 individuals resulted in 36.7% had ADs and 29.3% had a living will (Yadav et al., 2017). Surprisingly, the results of ADs among healthy patients and patients suffering from chronic illnesses were almost similar at 32.7% to 38.2% (Yadav et al., 2017). Data analyzed from a 2013 HealthStyles survey resulted in 48.7% of Americans discussed EOL with their physicians and 48.6% did not (Rao, Anderson, Lin, & Laux, 2014). Out of 7,943 respondents 26.3% had completed an AD and 74.7 did not, the top 2 reasons for not completing an AD were "I don't know what advance directives are" and "My family knows my wishes" (Rao et al., 2014).

In 2008, studies have found that about 18% to 36% have completed an AD and they were mostly completed by individuals who were suffering from a terminal illness (USDHHS, 2008). Sadly, these specific individuals did not have the ADs located in their charts or medical records. In addition, about two-thirds of these patients' physicians were unaware that they had one (USDDHS, 2008). The United States began to focus their attention towards the ethnic minority groups because numerous studies have proved that the individuals included in this group have little to no knowledge about ADs or EOL options. Ethnic minorities consistently reported low health literacy regarding ACP, lacked proper knowledge what ACP was and how to complete such documents or completely misunderstood (Hong, Yi, Johnson, & Adamek, 2018). Another reason these individuals did not have an AD is because it might go against their beliefs and traditions. The United States recommends that individuals who may or currently suffer from dementia should have an ACP discussion with their physicians or families about their EOL choices because eventually they will lose their decision-making abilities with time (USDHHS, 2008). The guideline of the Alzheimer's Association urges all physicians to have ACP discussions resulting in ADs when their decision-making abilities are still intake, particularly with regard to future and current invasive medical procedures and life-sustaining measures (USDHHS, 2008).

The Dartmouth Atlas Project (DAP) uses Medicare data to analyze national, regional, and local information with regards to the distribution of medical resources (The Dartmouth Atlas Project, 2019). The results of their research allow policymakers and others to improve health systems. The State of New Jersey Department of Health (NJDH) utilizes this information to discuss the possible barriers or issues causing these results. According to the DAP Medicare beneficiaries at the end of life or near the end of their life exhaust more resources than any other

state (NJDH, 2018). The elderly have difficulty navigating the healthcare systems and palliative care services are mostly offered in hospitals. Not all hospitals offer outpatient palliative care services and therefore the elderly are vulnerable and have a difficult time understanding or even being aware of the resources available to them. The Centers for Medicare and Medicaid Services decided to reimburse physicians for voluntary ACP under the Medicare physician fee schedule effective January 1, 2016 (Dingfield, & Kayser, 2017). The physicians can file claims for ACP services with one or two billing codes based on the description. There is a once per year limit for this service as it is considered a preventative service according to CMS (Jacob, 2015). A 2016 poll determined that “3 out of 10” NJ adult residents who are 65 years old are aware of advance directives” (NJDH, 2018). Also 33% did not have any ACP discussions, 78% are aware of hospice care, yet 50% are unaware of NJ state laws regarding ADs (NJDH, 2018). The state of NJ is a concern for costly and invasive medical treatments administered within the last 6 months of a patients’ life, without regard to hospice or palliative care (NJDH, 2018). NJ joined several advocates across the nation, including the Conversation Project every year at the National Healthcare Decisions day. National Healthcare Decisions day is held every year in order to educate and empower healthcare providers as well as the public about the importance of ACP. Each year both the healthcare providers and the public are urged to take part in ACP.

The assessment of whether an AD is carried out primarily by the nurses upon admission on the medical/surgical unit at the institution. The primary nurses ask each patient if they have an AD and based on their answer and new window is populated with further questions and prompts in their electronic health record. If the patient states they have an AD, but it is not on their person, the patient is asked to have a family member bring in a copy. If the patient states that do not have an AD then a new section appears prompting the nurse to ask the patient if they would

like further information. If the patient would like further information, then an automatic referral is sent to the social workers. The social workers will provide the patient with a pamphlet describing an AD and when the patient feels that they are ready, he or she will let the primary nurse know that they want to complete an AD. The AD form will be signed by the patient and witnessed by two healthcare professionals to be deemed valid. According to the institutions' policy a new AD can be created if the patient is deemed competent until their original is brought in. New Jersey law and regulations require the hospital to provide community education programs about AD, yet most of the patients admitted in this institution's medical/surgical pulmonary stepdown unit are unaware of the existence of an AD. Most code statuses are created emergently as a medical DNR. The social workers rarely receive any referrals regarding ADs because they can easily be bypassed by the primary RN or providers. The institution used to rely on the patient advocate to handle all the ADs. The patient advocate was a Chaplin who educated and kept up to date on all policies and procedures with regards to ADs and is resource for both the patients and the providers. Unfortunately, the patient advocate position is vacant, and most resident physicians and nurse practitioners are unaware of the exact process needed to create an AD. When residents and nurse practitioners are asked about the location of the AD at random, they usually reply somewhere in the chart. Resident physicians and nurse practitioners need further education so that may be able to inform their patients about all their options because when providers are asked about ADs they usually refer them to social workers or patient advocates. A random search regarding the amount of completed AD in the medical/surgical pulmonary stepdown unit was 3 of 36 patients. Advance care planning is an underutilized resource across the healthcare spectrum (Booth, & Lehna, 2016)

### **Problem/Purpose Statement**

The PSDA established in 1990 allowed individuals to take control of their medical decisions, yet most people are not taking the opportunity to do so. With the improvements in healthcare and technology, the general population is living longer, and chronic medical conditions are growing more complex with each passing day. As a result, cost of healthcare may increase due to the aggressive life sustaining measures which coincides with a rise in Medicaid and/or Medicare enrollment to cover current and future healthcare costs. Despite efforts and regulations put into place by CMS and the Joint Commission for providers to be educated on the topics such as ACP, AD, and EOL choices; most of them don't understand them fully. When providers are asked to explain AD and EOL choices they provide a very brief overview but cannot explain the aspects in detail. As far as ACP most providers have never heard of it when asked at random at this institution. If the providers are not properly educated nor trained, how can they be a resource to their patients about said topics? Most Americans have not completed an AD for a variety of reasons, but mostly because they are under the impression that their families know their wishes and/or they never knew that an AD existed. Healthcare today revolves around patient-centered care in which patients are made aware of all their options and decide what is best for them due to the PSDA. If the patients are unaware of all their options and resources, then how can they make an educated decision? This project came about as a result of the author's awareness that current practice does not always correlate with a patient's wishes. Evidence based studies have determined that ACP discussions are low despite all the information provided explaining its importance as per the PSDA. Therefore, it is imperative for providers to receive adequate education, and resources to effectively communicate these topics to their patients. The purpose of this evidence-based project is to assess the impact of an educational intervention to

healthcare providers in the hospital setting with regards to completed ADs on the medical/surgical pulmonary stepdown unit (PSDU) at this institution.

### **Clinical Question**

In hospitalized patients on the medical-surgical pulmonary stepdown unit who are under the care of the residents physicians and nurse practitioners (P) does an educational plan for providers (I), in comparison to prior practice which does not include education for providers (C), result in a change in the implementation of advanced care planning (O)?

### **Objectives and Aims**

The aim of this project was to increase the number of advance directives on file in the medical/surgical pulmonary stepdown unit.

The project sought to achieve this through the following objectives:

- 1.** Educating healthcare providers in the PSDU on the process of Advance Care Planning
- 2.** Implementing the guide to advance care planning discussion created by the College of Family Physicians of Canada (refer to Appendix A, and Appendix B for permissions to implement)
- 3.** Reinforcing advance care planning using the College of Family Physicians of Canada's acuity chart at all workstations
- 4.** Appointing an ACP Champion

It was the hope of this project that by applying the stated objectives, healthcare providers will have the knowledge to conduct advance care planning discussions with their patients therefore leading to an increase in advance directives completion rates.

## **Review of Literature**

### **Search Strategy**

A comprehensive review of the literature was performed to identify the educational needs for healthcare providers regarding advance care planning, focusing on current practice guidelines on initiating the conversation and the recommendations described by expert organizations concerning end-of-life care. The databases utilized were CINAHL, Google Scholar, Medline (Ovid) and PubMed and the keyword “advance care planning” was initially entered and yielded 1,817,095 results. Literature published from 2015 to the present were included to ensure the literature is current, which narrowed the results down to 74,509. The search was further narrowed down using the additional key phrases, “advance directives,” “end-of-life,” “decision-making,” “barriers,” “tools,” “educational intervention,” and “usual care”.

The articles included in the study for an educational intervention to increase completion rates of ADS were based on the following inclusion criteria: published in English; patients with life-limiting or life-threatening conditions; communication gaps between clinicians and patients; education or tools to utilize in ACP for healthcare professionals; evidence-based research; credible sources: U.S. government and the Institute of Medicine. After applying the inclusion criteria there were 45 sources remaining. Articles were excluded if they didn't mention healthcare provider education regarding ACP, as this is the focus of this project. Articles were also excluded if the results were inconclusive or were rated as low quality per the John Hopkins evidence appraisal tools for research and non-research literature. After carefully surveying the literature in detail, eleven resources were chosen, comprised of nine research articles and two evidence-based guidelines (refer to Appendix C for the PRSIMA selection flowchart).

### **Content and Quality Assessment**

The selected literature met all of the inclusion criteria, comprising of eight systematic reviews, one non-experimental study and two non-research sources. Ten out of the eleven articles reviewed stress the importance of healthcare providers being properly educated about advance care planning and having access to the proper tools to adequately and effectively communicate with patients. The final study explains the significance of a patient's quality of life in regard to end of life care. According to the John Hopkins' appraisal tool, the review of literature for the research articles consisted of one high level of quality and ten good quality level. The research literature ranged from a level II for three of the articles and a level III for the remaining six. Both of the non-research literatures were considered a level IV (refer to appendix D for Table of Evidence).

### **History and Significance**

Despite the PSDA of 1990, CMS, evidence-based research encouraging and stressing the importance of ACP discussions, the implementation of AD continues to remain low (US Department of Health and Human Services, 2007). A systemic review conducted by the Perelman School of Medicine found that sixty-three percent of 795,000 Americans have not completed an AD, the factors contributing to this is providers, patients, and family members don't initiate end-of-life conversations until the patient's medical condition is life threatening. Therefore, the initiation of ACP discussions is the responsibility of the provider and is vital to understanding the patient's wishes without being placed in a stressful situation. The provider must discuss the patient's prognosis and each of their treatment options throughout their care in order for the patients to be equipped to determine their course of action; however, it has been reported that providers don't feel adequately prepared to discuss ACP and EOL care to improve

their quality of life (Yedidia, 2007). Most providers are reluctant to initiate ACP discussions because they lack the proper education and formal communication training to conduct such a complex discussion without feeling uncomfortable (DHHS, 2007).

### **Literature Review Discovery**

The main theme throughout all of the articles is the need for education and formal training on the providers' end regarding ACP initiation and equipping them with the appropriate clinical tools. There were three major themes identified throughout the articles: healthcare provider deficits regarding initiating ACP discussions, properly educating providers is crucial, and the impact of effective ACP regarding hospital admissions, re-admissions, cost, and hospital utilization.

### **Lacking in Knowledge and Education Needed**

According to the New Jersey Governor's Advisory Council on the End-of-Life Care in 2016 the biggest barrier is communication. Communication with regards to ACP, is defined as discussing prognosis, dealing with emotional and/or spiritual concerns, and finding the balance between hoping and preparing. Current medical and nursing curricula lack equipping their students with the necessary skills and education to effectively communicate EOL care as well as the hands-on training during their clinical rotations causing them to be ill prepared to conduct ACP discussions. (State of New Jersey Department of Health, 2018). Twenty-six recommendations were set forth and two of them (three and four) were put into place to address the lack of ACP communication by providers.

The New Jersey Governor's Advisory Council of 2018 third recommendation discusses the need for training programs to be developed for all healthcare professionals. The providers will learn how to utilize different educational tools to both properly educate and prepare their

patients about EOL decisions and to raise public awareness (SNJDH, 2018). As the medical world advances so do health systems and technology used in healthcare; therefore, EOL care needs to be addressed. Life-limiting and life-threatening conditions occur due to people living longer with chronic conditions which grow more complex or longer life expectancy and increased complexity of care as chronic conditions progress. Providers need to be competent in ACP, EOL care, hospice, and palliative care so their patients are capable of making educated decisions (SNJDH, 2018).

The New Jersey Governor's Advisory Council's fourth recommendation pertains to all healthcare professionals involved in patient care including chaplains, social workers, administration, and students in training (SNJDH, 2018). According to the New Jersey Governor's Advisory Council on the End-of-Life Care, current research reveals that when asked providers find it difficult to discuss EOL discussions, manage different cultural perspectives and identify goals of care (SNJDH, 2018). To improve EOL care for their patients, providers need to be knowledgeable about the topic and know when and how to initiate the conversation effectively.

The Institute of Medicine (IOM): *Dying in America: Improving quality and honoring individual preferences near the end of life* states that "the quality of communication between clinicians and patients who have advanced serious illness or are nearing death falls far short of ideal, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst" (IOM, 2015). The council's second recommendation emphasizes the importance of establishing standards regarding ACP that are implemented, measured, and more importantly evidence-based. The IOM explains that these standards should correlate with the public's healthcare needs as they

evolve and change. The aim of the recommendations is to encourage providers to initiate ACP conversations and to continue discussing it at every visit to ensure the patient's wishes correlate and to make changes accordingly.

When the ACP discussions are initiated when the patient is first diagnosed, it reduces stress and anxiety throughout the process; in addition, empowering the patient and giving them a sense of control over the situation (Hughes, O'Brien, Flynn, & Knighting, 2018). However, the provider must understand and have a sense of timing as to the right time to approach the patient about ACP and/or EOL care because if it is done at the wrong time it could lead to a loss of trust between the patient and the provider and can jeopardize their relationship (Zwakman et al., 2018). Timely communication is important, yet education and training are vital in order for the provider to be prepared to ensure the patients' wishes are respected and carried out (Myers et al., 2018). A structural ACP framework including a simplified decision-making tool to ensure health literacy throughout the entire process is imperative (Lund, Richardson, & May, 2015). Decision-making tools improve patients' knowledge about ACP, EOL care, as well as prepare them for such conversations when they are implemented (Austin, Mohottige, Sudore, Smith, & Hanson, 2015).

### **ACP and Healthcare Costs**

ACPs have been proven to decrease EOL healthcare costs. In a systematic review of four RCTs and four cohort studies, hospital admission, readmission, and length of stay rates were compared in a studies ranging from 12 weeks to 5 years, which resulted in a decrease in hospital admissions, readmissions, and hospital length of stays among the ACP group and an increase in hospice utilization during EOL care by 0.42 to 1.47 (Kernick et al., 2018). In addition, two other

studies discovered that patients preferred to die in their home, hospice, and nursing home, instead of in hospitals (Denvir et al., 2016 & Johnson, Nunn, & Hawkes, 2012).

### **Limitations within the Literature**

Limitations among these systemic reviews included research articles studying interventions to increase ACP participation throughout the review of literature articles. They entail that the patients were self-selected because they were ready to participate in the ACP process which could lead to a selection bias and create a positive outlook. The research also revealed that patients refused to participate which signifies resistance and lack of readiness in the ACP process. Another limitation is the various definitions of ACP across the regions included in the systematic review. The non-experimental qualitative studies included small convenience study population which limited the study.

### **Theoretical Framework**

Some healthcare providers utilize the nursing process of assessment, diagnosis, planning, implementation, and evaluation when caring for patients. King's theory of goal attainment (KTGA) includes all these stages because she believed this process is fundamental to goal setting and attainment (Caceres, 2015). The theory was derived from King's conceptual system and incorporates some of the components of personal: perception, self, growth and development, time, and personal space, and interpersonal: interaction, communication, transaction, role, and coping (Goodwin et al., 2002). The assessment phase includes perception, judgment, action, and reaction because the initial interaction between the patient and the provider formulates the motives, behaviors, and goals of the other (Caceres, 2015). The diagnosis phase consisted of the provider asking the patient about their environment, stressors, values, roles, and goals (Caceres, 2015). The planning phase is formulating mutual goal settings and exploring how to achieve

these goals (Caceres, 2015). The implementation phase is increasing the accountability of the patient and provider in trying to maintain the chosen plan (Caceres, 2015). The evaluation phase determines if the goals were attained by both the provider and the patient (Caceres, 2015).

KTGA is a continuous and open interaction between the provider and the patient, which allows them to re-visit the stages of the nursing process to achieve their goals (Caceres, 2015).

### **Theory Development**

Imogene King believed nursing is a science and scientific knowledge could be built based on the relationship of theory and research (Frey, Sieloff, & Norris, 2002). King's systems theory evolved into conceptual framework to conceptual system and finally TGA was created (Frey et al., 2002). The basis of King's worked is the Ludwig von Bertalanffy general systems model, which describes that everything is related to everything and the whole picture is created by the sum of its parts (McEwen, & Wills, 2018). King created the goal-oriented record to be used in the assessment to document the provider's perception of the patient during each interaction and developed the criterion referenced measure of goal attainment tool to be used during the diagnosis phase (Caceres, 2015). The tools allow the providers to document the patient's values, goals, stressors, roles, and environment which aid in the planning phase and are constantly being updated to reflect the patient's current values and perception (Caceres, 2015).

Some of the components of personal systems include: perception, self, learning, growth and development (Caceres, 2015). Perception is the transaction between the individual and the environment. Self includes memories and is subjective, it is what makes up who they are. Growth and development are constantly changing based on the individual evolving throughout their life. Learning is due to evolving as well but it is based on their sensory perceptions. Some of the components of interpersonal systems are interaction, communication, transaction, and role

(Caceres, 2015). Interactions consists of individuals communicating, formulating perceptions of each other which influences their future. Communication can be verbal or non-verbal which establish the relationship. Transaction is crucial according to King because it leads to goal attainment and meaningful interactions (Caceres, 2015). This is a major component of King's theory (refer to Appendix E for an illustration of the transaction process).

King described individuals as having three fundamental needs which are information about their health, care to prevent illness, and help when they can't care for themselves (Frey et al, 2002). An individual's health is correlated to both their internal and external environments; therefore, they need to adjust accordingly. The theory gives the provider a map, steering the conversation yet guiding the patient indirectly into determining their future goals. "King's focus on mutual decision-making is an underutilized resource that can provide great insight" into ACP (Caceres, 2015 p.151)

### **Theory Analysis**

KTGA can fit into three models of thematic analysis because it is so versatile. Thematic area 1: evidence-based practice, research utilization, and knowledge transformation process entails identifying a problem in healthcare, researching evidence, evaluating the evidence, and applying it to improve outcomes (Mitchell, Fisher, Hastings, Silverman, & Wallen, 2010). It is a systematic approach utilizing knowledge and research to improve quality of care in patients (Mitchell et al., 2010). KTGA identifies the problem during the assessment and diagnosis phases, researches the evidence during the planning phase, applies and evaluates the evidence during the implementation and evaluation phases. Thematic area 2: strategic and organizational change theory to promote uptake and adoption of new knowledge describes the method by which everyone disseminates new knowledge based on perspective

through interventions, evaluations, and feedback (Mitchell et al., 2010). In KTGA the providers educate the patients about their clinical diagnosis, quality of life, and take into consideration their goals and values to implement a plan. The plan is adjusted based on the patient's values at the time and their feedback regarding their goal attainment. Thematic area 3: knowledge exchange and synthesis for application and inquiry describes the regular interactions and supports the sharing of knowledge in a bidirectional manner to improve decision making (Mitchell et al., 2010). Both the providers and the patients need to meet more than once to discuss their prognosis, future, and ACP in order to make educated decisions about their future goals in KTGA.

### **Knowledge Translation Strategy**

Literature has proven that providers have three goals when it comes to interacting with their patients. The three goals are instrumental (providing information about their health, treatment, and resources), relationship (building a trusting relationship to enable compliance and decreasing anxiety), and self-presentation (demonstrating and providing compassion); which are all beneficial and extremely crucial in ACP and EOL care decisions (Leon-Demare, Macdonald, Gregory, Katz, & Halas, 2015). Interactions allow disturbances to be surfaced and lead to transaction which results in goal attainment. The perception in each of these steps permits whether trust is achieved causing decreased stress, tension, and allowing growth and development to occur (Leon-Demare et al., 2015). KTGA enhances communication which permits shared decision making to occur through provider and patient interactions (Caceres, 2015).

Over the last decade healthcare has shifted toward patient-centered care which encourages patients to be involved in all aspects of their care by working together with their

healthcare professionals and their families if they choose (Caceres, 2015). The collaboration between the patients and their healthcare providers engages them in open communication and allows them to come to a mutual goal that encompasses their values and goals (Caceres, 2015). Every patient will not have the same values and goals and the method of their communication will be different because one-size does not fit all (Caceres, 2015). Providers are educators and advocates at heart, therefore they are the best choice to initiate ACP discussions (Goodwin et al., 2002). King believed that all human beings have the right to knowledge about their health, the right to accept or reject healthcare, should participate in decision making that influences their quality of life and healthcare providers hav

e a responsibility to share information that will help them make informed decisions, and to gather relevant information about the perception of the patient so their goals are congruent (King, 2007).

An advance directive decision-making model (ADDMM) was adapted from King's theories to achieve mutual goal attainment, which facilitates patient's autonomy and compliance with the PSDA (Goodwin et al., 2002). The process of the ADDMM is to make the patients aware of their rights, to help them make their own decisions, and to advocate for their decisions (Goodwin et al., 2002). It consists of seven components from personal, interpersonal, and social systems which are perception, time, interaction, role, power, status, and decision making (Goodwin et al., 2002). Perception is the holistic overview wherein the provider must determine the appropriate time to educate and client decides when to make their decisions known and to who (Goodwin et al., 2002). Time is continuous and consistent, making decisions in the present is pertinent to the future; in addition, these discussions are appropriate at any age or health stage and not limited to the terminal and elderly (Goodwin et al., 2002). Interaction is communication

between the provider and the patient, it could be verbal or non-verbal; but it's not just communicating but also really listening in order to process the information (Goodwin et al., 2002). The provider must first assess the patient's level of understanding of ACP/AD in order to educate the patient and hopefully empower them to make educated decisions about their future (Goodwin et al., 2002). The role of the provider is merely to facilitate the discussion and not to enforce their personal goals or evaluate the patient's, also to be skilled and competent (Goodwin et al., 2002). The patient's role is to be a mutual partner who is active in deciding their EOL care goals. The patient has the power to control the interaction and the direct the information presented by the provider to formulate and verbalize their goals (Goodwin et al., 2002). The status of the provider is to be knowledgeable, supportive, and assisting the patient determine and achieve their goals, but most importantly recognizing that the patient has ability and the authority to make their own decisions (Goodwin et al., 2002). The provider's education needs to be adequate, effective and timely in order to facilitate the patient's decision making (Goodwin et al., 2002).

### **Methodology**

There is a vast knowledge deficit among healthcare providers with regards to ACP discussions being carried out appropriately with patients, according to the review of literature. Hence the need to properly educate healthcare providers on the topic of ACP and how it significantly impacts the cost of EOL care, especially in New Jersey. The goal of this project was to improve healthcare providers' knowledge on ACP, in addition to encouraging them to initiate ACP discussions with their patients.

**Study design**

This quality improvement project used a pre-test design to measure the healthcare provider's knowledge about ACP and a post-test to measure the knowledge gained post education about ACP the method of approaching the topic. The pre- and post-test are identical, and the questions were administered at the start and finish of the educational focus groups held (refer to Appendix F for test, and Appendix G for permission to use test). The pre- and post-tests remained deidentified. Additionally, the number of advance directives on file in the Medical/Surgical Pulmonary Stepdown Unit (PSDU) pre-implementation and post-implementation were evaluated.

**Setting**

The educational focus groups were held with all PGY-1 through PGY-3 internal medicine (IM) residents and nurse practitioners (NPs) that rotate through the medical/surgical PSDU at this institution (refer to Appendix H for Site Letter of Support). With the permission of the Chief of Pulmonology (██████████), educational focus groups were conducted with each group of IM residents starting with the new PGY-1 residents who started July 2019. Similar educational focus groups will be held with the PGY-2, PGY-3 residents and NPs separately. As per the Chief of Pulmonology, attendance at the educational focus groups were mandatory for the medical residents as a required component of their curriculum; it remained optional for the NPs at this time.

**Study population**

The eligibility criteria included healthcare providers employed by this institution with access to patient care within the medical/surgical PSDU. These focus groups were also open to all attendings that round on the unit, who wished to attend. Exclusion criteria included

employees providing care for patients admitted under the cardiac thoracic and general surgery departments, such as the cardiothoracic physician assistants, trauma physician assistants and the general surgery residents. The educational focus groups were held with the study population over a three-month span (September – December 2019). Residents who were away from the institution campus during the scheduled sessions were excused from the experience, making this a convenience sample.

### **Subject recruitment**

Subject recruitment began in June 2019 and carried over into July 2019 with an e-mail from the Chief of Pulmonology, Dr. Jyoti Matta to all the IM residents and NPs. She notified them of the educational focus groups on ACP. Both groups alike were encouraged to attend their pre-assigned educational focus groups. The principal investigator sent a reminder email to the assigned cluster of providers one week prior to the set date of the educational focus group meeting. For example, if the educational focus group for the PGY-1 IM residents met on July 8, 2019, a reminder email was sent to them on July 1, 2019. In addition, flyers were posted throughout the hospital in the doctors' lounge, cafeteria, staff bathrooms, and in the PSDU hallways, nurses' station, and restrooms; encouraging IM residents and NPs alike to attend these educational focus groups. It attracted healthcare providers to attend the educational focus groups as Current Procedural Terminology (CPT) Codes used to bill CMS for ACP services were discussed (refer to Appendix I for flyer, and Appendix J for codes).

### **Consent procedure**

Each participant completed a consent form at the beginning of the educational focus group (refer to Appendix K for Rutgers consent form).

**Risks, harms and ethics**

The risks to the study participants were minimal but included feelings of insecurity with the topic discussed, individual pre-test results, and the expectations of their attending physicians regarding ACP once they attended the educational focus groups. Pre- and post-test score results received by the principal investigator did not include any identifiable information attached to it. All data for analysis were de-identified, including the number of advance directives on file prior to and after project implementation. The benefits to participation included an increase in knowledge regarding ACP and therefore, improved adherence to PSDA of 1990 and CMS guidelines. Additional benefits included the potential for a long-term educational tool on ACP approach for this institution healthcare providers. The overall benefit was to ensure that patients' end-of-life medical care decisions were documented and honored.

**Subject costs and compensation**

There was no cost required of the study's subjects as they attended the educational focus groups while at the institution's campus for work. Healthcare providers that didn't attend were provided with the previously mentioned CPT codes in order to bill for ACP services regardless of location, whether it is a hospital or a private practice.

**Study interventions**

The study's intervention was an educational focus group on ACP that healthcare providers of the medical/surgical PSDU attended based on their cohort (PGY-1, PGY-2, PGY-3, and NPs). An identical pre- and post-test was administered at the beginning and end of the session.

The following education regarding ACP was discussed at the education focus groups:

- A brief overview of the problem:

- PSDA of 1990 requires health care institutions to provide education to all patients about advance directives (AD), verify if the patient has an advance directive, and if so, retrieve a copy and implement the wishes outlined in the advance directive (The New Jersey Advance Directives for Health Care Act, 1992).
- Implementation of advance directives is still low. According to a systematic review, among 795,000 Americans, sixty-three percent had not completed any advance directive (Perelman School of Medicine at the University of Pennsylvania, 2017).
- Dartmouth Atlas Project which uses Medicare data to analyze medical measures on different levels (national, regional, local, and individual facilities) which in turn helps improve healthcare provided in America. NJ was ranked first as the highest consumer in end-of-life care costs.
- Random survey revealed 3 out of 36 patients admitted to the medical/surgical PSDU had an AD on file.
- The New Jersey Health Care Quality Institute partnered with Rutgers-Eagleton on a poll that confirmed 6 in 10 believe it is imperative to plan end-of-life care, yet 6 in 10 people have also failed to take the initiative to document their wishes (Eagleton Institute of Politics, 2019).
- To enable and encourage the general population to discuss their healthcare wishes long before a serious illness or health crisis arises, the Conversation Project was launched in 2012 in collaboration with the Institute for Healthcare Improvement (IHI). Their goal is to “enable more people to sit down at the kitchen table with

family members and friends and talk about what will matter most at the end of their lives” (IHI: The Conversation Project, 2013).

- Many healthcare providers report feeling unprepared and deficient in providing discussions about ACP and treatment options to improve quality of life at the end-of-life (Yedidia, 2007).
- Before offering all medical interventions, providers must discuss goals of care with their patients. As practitioners we should “help patients get the care they need and no less, and the care they want and no more” (Goals of Care Coalition of New Jersey, 2018).
- Presented Championing Person-Centric Advance Care Planning PowerPoint presentation by Dr. Danielle J. Doberman, Medical Director of Palliative Medicine at Johns Hopkins Hospital (refer Appendix L for PowerPoint presentation, and Appendix M for permission).
- Defined and discussed ACP options
  - Advance directives = Living Will – written directions prepared by a patient in advance to say what kind of medical care they want in the event they are unable to make decisions for themselves. It addresses resuscitation, desired quality of life and end of life treatments including treatments not wanted by the patient.
  - Health-care proxy – the patient designates a person they trust to serve as their substitute, “standing in” for them in discussions with their physician and others responsible for their healthcare.
  - Combined directive – A single document in which the patient selects a health care representative and provides them with a statement of their medical treatment preferences.

- Practitioner orders for life-sustaining treatment (POLST) - Is an order set that must be completed by a physician or advance practice nurse that gives specific care instructions related to a patient's personal goals of care, artificial nutrition, resuscitation and re-hospitalization. Any incomplete section of POLST implies full treatment for that section. Discussion of how to complete a POLST in New Jersey will be discussed, it will be clarified that it remains valid in New York and Pennsylvania (refer to Appendix N).
- How to complete an AD at the institution (refer to Appendix O). The AD at this institution is considered a combined directive. Upon completion, the following steps are necessary:
  - Designation of health-care proxy
  - Instructive Directive (Living Will) – The patient decides between the following options:
    - If my condition becomes so serious that there is no reasonable chance of my recovery or having a meaningful quality of life, I want to be kept comfortable. I do not want any life prolonging measures that will not cure or reverse my condition. This may include (1) an incurable and irreversible condition that will result in death within a short period of time; or (2) being unconscious with no reasonable chance of regaining consciousness. I understand that life prolonging procedures or treatments could include:
      - Cardio-Pulmonary Resuscitation (CPR)
      - Breathing machine/ventilator

- Dialysis
- Artificial fluids and/or nutrition (feeding tube)
- Blood transfusions
- Surgery
- Radiation treatments
- Medicines to prolong life (including chemotherapy and medicines for my heart)
  - I direct that all measures and/or treatments be provided to prolong my life regardless of my condition.
- Organ/tissue donation if the patient desires
- Signature and witness; health care proxy cannot be a witness to patient's signature. It does not need to be signed by physician or advance practice nurse.
- Obtain copy and place in patient chart. Update EMR to indicate patient has an AD
- Patient keeps original AD and is to notify PCP and health-care proxy of AD
- Case-study reflection
- Obtained feedback from participants regarding potential solutions that may allow for better ACP
- Emphasized the importance of ongoing ACP discussions
  - Implement use of the Guide to Advance Care Planning Discussions Developed by Residents for Residents (refer to Appendix A). Each attendee will receive a laminated, pocket-size card of this guide for quick reference (refer to Appendix P).

- For the well patient – have a full ACP conversation during each periodic health exam and when triggered by important life events (i.e. marriage, pregnancy, new job); and emphasize choosing a health-care proxy
- For the patient with chronic disease – have a full ACP conversation during each periodic health exam and when triggered by medical events (i.e. new diagnosis, discharge from hospital); discuss the disease course and potential health outcomes as the disease progresses and at decision points that may arise in the future; revisit at regular intervals as appropriate
- For the patient with an acute deterioration in health – revisit the ACP conversation with the patient/health-care proxy, or initiate the discussion if this has not already been done; code status and/or goals of care must be discussed with the patient or health-care proxy at this point; healthcare provider may recommend best treatment based on patient’s goals, fears, values, and specific illness context; emphasize immediate or anticipated healthcare decisions.
  - Encourage ACP during interdisciplinary rounds on each patient in the medical/surgical PSDU.
- Appointed ACP Champion to facilitate completion of ADs in the medical/surgical PSDU.
- Provided alternate resources such as Goals of Care Coalition of New Jersey’s 4Step iCare Plan – HCP Conversation Assistant (refer to Appendix Q).

### **Outcomes measured**

Scores from the pre- and post- tests at each focus group along with the change in scores were used to measure the provided intervention. The change in scores before and after reflected

if the educational focus groups were in fact effective. The change of practice aimed for were evaluated by completing a chart review for the number of ADs three months before and three months after the educational focus groups were held. The number of ADs on file were extracted via Cerner, this institution's EMR. The data received did not have patient identifiers attached to it.

### **Project timeline**

Refer to Appendix R for Gantt chart of this project's timeline.

### **Project budget**

Other than the time dedicated to the project and financial responsibility of printing educational and advertisement materials, there were minimal costs to the investigator.

## **Evaluation Plan**

### **Data Analysis Plan**

A two sample t-test was used to measure the outcome of the pre/post-tests on the topic of ACP and a Pearson's square Chi test was used to measure the statistical significance of AD on file three months before and three months after the project implementation.

### **Data maintenance and security**

The data collected from the educational focus groups, including the completed pre- and post- tests were stored in the second drawer of a locked file cabinet on the first floor in the institution's Research Council department. The key remained with the Director of the research council. The principal investigator was given a report of the answers of the pre- and post- tests results by the director of the research council, independent of any personal identifiers and was stored on a password protected electronic device that is solely accessible by the principal investigator. The number of ADs on file pre- and post-intervention as well were extracted by the

principal investigator from the hospital's EMR program, Cerner without any patient identifiers. The report consisted of only the number of ADs on file for patients admitted to the medical/surgical PSDU, devoid of any patient identifiers, health condition, and length of stay. It was generated with the assistance of the IT department, providing the PI with the resources and methods to access and generate this report. In order to comply by Rutgers eIRB regulations regarding data retention and record keeping, all data will be retained by the institution's Research Council for at least three years after completion of project implementation, which is estimated to be until May 2023.

### **Results**

A paired *t* test was used to compare the pre- and post-test survey results to determine the association between reinforced education provided to residents as well as nurse practitioners and Advance Directive completion over a span of six months. There was a statistically significant difference between the pre-test and post-test results, as anticipated. An educational session was provided prior to the completion of the post-test, which proved to be a key element according to the statistics. Please refer to Appendix S for a detailed statistically result. The paired-samples *t*-test indicated that scores were significantly higher post-implementation ( $M = 39.5, SD = 7.5$ ) than pre-implementation ( $M = 30.5, SD = 5.8$ ),  $t(29) = -6.8, p < .05, d = 1.34$ .

The goals of this project were to increase the healthcare provider's knowledge and confidence about the ACP process and the regulations set by the JC and CMS on ACP, according to the results these goals were met. In addition to these goals being met, there was a statistically significant increase in the number of ADs on file for patients admitted on the PSDU. Refer to Appendix T, as the bar graph results portrayed that the number of ADs on file more than double over the three-month span post implementation at [REDACTED].

A Pearson chi-square test was used to determine the association between reinforced healthcare education and AD completion over a 6-month period. The results were skewed due to a limiting factor of only 24 cases (See Appendix U). This is due to the fact that while extracting data from the EMR, the PI was only able to obtain data on ADs on file and was not able to account for the number of ADs not on file. According to the Chi-square test, there was no association between reinforced education and AD completion rates (Chi-square = .029,  $p = .865$ ), which is a reflection of the limited number of cases used for data extraction.

### **Discussion**

The results of the pre-test revealed that there is a knowledge deficit as well as a lack of adherence to recommended guidelines existed regarding the ACP process. As predicted, the reinforcement of the ACP process increased knowledge based on the post-test results. The provided sessions have triggered a change in practice as evidenced by the number of ADs on file post-implementation compared to prior.

### **Facilitators**

From the beginning, the head of the Research Council supported this project and worked to assist in any way possible. They granted approval for this project to take place within the institution pending approval for the IM team. They continued to reach out throughout the process to ensure that there were no issues to deter the PI from implementing and holding the focus groups.

Both the Chief of Pulmonology and the chief residents worked to facilitate and coordinate their IM conference schedules to allocate time for these focus groups to take place. They supported this quality improvement project from the moment it was proposed and strongly encouraged the PI throughout the process. Moving forward, the chief residents shared

the information of these focus groups to the rest of the IM residents who were unable to attend due to their assignments.

In addition, the palliative care APN was appointed as the ACP Champion and will work toward assuring ACP is discussed during interdisciplinary rounds.

### **Barriers**

Implementation did not take place as scheduled due to a delay in Rutgers eIRB approval. Additionally, a delay in implementation within the institution was encountered due to improper navigation in setting up the focus groups with the IM residents and APNs. At first, the PI was directed to the palliative care APN to set up the focus groups who was away for some time. The APN then directed the PI to the chief residents to set up the dates for the focus sessions based on conference date availability. Dates were then selected later than anticipated.

### **Unintended consequences**

The focus groups were held in a building on the institution's campus other than the main hospital. Because of this, not all the IM residents were able to attend their pre-set sessions as they were mandated to be in the hospital, especially for those assigned as the medical officer of the day or those in the critical care units. In addition, not all the participants completed the post-test survey after the focus group was complete. Some of the participants completed both the pre- and post-test surveys prior to sitting through the presentation offered due to the fact that they were paged for admissions or to respond to patient care event.

In regard to the study design, the pre- and post-test is an unvalidated tool as it was a combination of two sets of questions from previous studies.

Lastly, data analysis was skewed by the data extraction process from the institution's EMR. In order to keep data de-identified, the PI was only able to collect the number of ADs on

file and not account for the number of ADs not on file. Thus, only 24 cases were evaluated resulting in an insignificant p value, yet the total number of ADs prior to and after implementation have increased as anticipated.

### **Implications and Recommendations**

#### **Clinical Practice**

The lack of knowledge regarding the ACP process is emulated by the number of ADs on file, as evident by the results. The offered intervention to increase AD on file in the PSDU is greatly recommended for ACP conversations to take place and be initiated by healthcare providers. Adherence to regulations regarding ACP allows patient's wishes to coincide with their medical care, therefore decreasing decision-making burden for both the family and healthcare providers (Portanova et al., 2017).

Such interventions to introduce, educate, and inform healthcare providers about the ACP process should be considered as part of clinical practice moving forward. Therefore, it is strongly recommended that all healthcare providers receive periodic updates and be aware of conversational guidance tools regarding the ACP process. If the interventional findings were to be applied to an overall hospital population, then it would likely result in an overall significant increase in completed ADs via a simple intervention. Hence, the objective of providing medical care that coincides with patient's wishes and improved outcomes at the end of life would become a reality.

Moreover, the implications of this intervention would similarly apply to an outpatient healthcare provider setting as in an inpatient setting. Certainly, further studies can be carried out to evaluate this type of intervention for ambulatory patients. If the results of such studies ended with similar outcomes, then this type of intervention should be considered on a larger and much broader scale. Both internal medicine residents and APNs are fittingly positioned to carry out

this change toward initiating ACP conversation in their healthcare facilities as part of their clinical practice.

### **Healthcare Policy**

As previously mentioned, the current institution policy which stems from the PSDA of 1990 does require a copy of an AD be obtained and respected, if the patient has one. However, it does not mandate the healthcare provider to initiate the ACP conversation in the case a patient does not have an AD, living will or POLST on file. Effective ACP was evident by the increase of ADs on file, according to the results of the intervention provided, with the limitation of a small sample size. This implies that there is room for policy reform regarding ACP as a standard of care for every admitted patient within the institution. Hence, if such an intervention were to become a permanent part of the internal medicine residency curriculum, it may greatly impact the care provided to patients at the end-of-life. In addition, this would place the institution in compliance with the regulations set by JC and CMS to provide education to healthcare providers and keep patients informed about ADs.

This implication goes hand in hand with the recommendations set forth by the New Jersey Advisory Council on End-of-Life Care in 2016 concerning the essential role of healthcare providers on initiating vital discussions with their patients regarding advance care planning and end-of-life care options. This committee emphasized the concept that many healthcare providers are reluctant about the topic due to a lack of preparation during their schooling and clinical rotations (SNJDH, 2018). Recommendation Three from the New Jersey Advisory Council on End-of-Life Care addresses the necessitate of developing training programs and the utilization of educational tools, such as the conversational guides incorporated in this intervention. Basically, with the advancements in medical technology patients are able to live longer, therefore the need for palliative care and quality end-of-life care becomes an integral part of a patient's life.

Therefore, healthcare providers of all disciplines who provide care to patients with life-limiting or life-threatening medical conditions should be competent to initiate “difficult conversations” (ACP); with respect to the patient’s conception of quality of life.

### **Quality & Safety**

As termed earlier, completion of an AD allows the patient to declare their wishes for end-of-life care if they become incapacitated. Furthermore, a healthcare proxy chosen by the patient will eliminate the struggle of identifying the patient’s legal next of kin, who will make medical decisions on their behalf in the case they are incapacitated. According to the literature, the lack of an AD prevents patient involvement in their end-of-life medical care which can result in unwanted physical and emotional suffering for both the patient and their loved ones as healthcare providers resort to full resuscitation techniques without regard to the patient’s overall quality of life.

The obligation to verify if a patient has an AD and implementation of the patient’s outlined wishes stems from the PSDA of 1990. It strongly impacts the quality of care and overall safety of the patient while hospitalized. Subsequently, the results of this implementation strongly recommend the need for healthcare providers to initiate the essential conversation in order to obtain such critical information found on the AD, especially at the end-of-life. Continuous reinforcement of the interventions offered would, in turn, allow patients to once again gain control of their own healthcare quality and safety, and ultimately, their own dying process.

### **Education**

The basis of this implementation is founded on offering education to healthcare providers regarding the ACP process through: defining and discussing ACP options, explaining the importance and necessity of ACP, how to complete and document an AD within the institution,

case reflections, reimbursement offered for ACP, and providing alternate sources such as the Goals of Care Coalition of New Jersey's 4Step iCare Plan – HCP Conversation Assistant and other conversation guides. The New Jersey Governor's Advisory Council on the End-of-Life Care of 2018 identified the lack of communication between clinicians and their patients with an advance illness and is the rationale as to why the offered education is strongly recommended. They have defined communication as discussing prognosis, dealing with emotional and/or spiritual concerns, and finding the balance between hoping for the best and preparing for the worst. They have attributed this lack of communication to the deficiency of current medical and nursing curricula with regards to the ACP process.

The results of the offered implementation conclude that a small informational session was able to significantly impact the current ACP process in the PSDU within the designated time frame of this quality improvement project. The hope is that similar informational sessions will be conducted periodically to keep healthcare providers informed on the ACP process in order to comply with the mandate set by the NJ Board of Medical Examiners to obtain 2 CME credits related to EOL care for biennial renewal of licensure. It would be encouraged that with the start of each new class of internal medicine residents that an educational session be held on the institution-specific ACP process.

### **Economic**

The literature discusses the overall decrease in end-of-life expenditures by Medicare though the utilization of advance directives. As Nicholas et al., 2011 emphasized in a large, nationally representative study reviewing Medicare claims have determined that treatment-limiting advance directives, in particular, are associated with lower Medicare expenditures especially in areas known to provide aggressive end-of-life care. They are also associated with

increased palliative or hospice care referrals and lower rates of in-hospital deaths in regions where it is common for patients to receive aggressive end-of-life management (Nicholas et al., 2011). According to Dartmouth Atlas Project, which utilizes Medicare data to analyze medical measures, has deemed that New Jersey patients received the most unwarranted aggressive care at the end-of-life than any other state. Thus, New Jersey ranked first in order of magnitude of resource consumption, during end-of-life care (The Dartmouth Institute for Health Policy and Clinical Practice, 2012). This information is particularly relevant to the aging population in New Jersey.

In a systematic review of four RCTs and four cohort studies, hospital admission, readmission, and length of stay rates were compared in a studies ranging from 12 weeks to 5 years, which resulted in a decrease in hospital admissions, readmissions, and hospital length of stays among the ACP group and an increase in hospice utilization during EOL care by 0.42 to 1.47 (Kernick, 2018). The long-standing goal of incorporating continued education as offered in this quality improvement project is to witness an eventual decrease in the economic burden of aggressive end-of-life care that does not suggest long-term benefit. The data of this limited study to date, may suggest a decrease in healthcare expenditures as a result of ADs on file which may limit life-sustaining measures that are not necessarily in line with the patient's goals of care.

### **Sustainability**

Similar to the goal of the Conversation Project, the goal of this project is to enable people to feel comfortable with discussing their end-of-life care wishes with both their loved ones and their healthcare providers. Continued efforts to encourage healthcare provider awareness of the ACP process and the need for provider-initiated conversations are imperative for sustainability of this project. The educational focus groups can be designed to address any facility's individual

needs regarding employee needs. As of now, the information is basic enough that it can be relevant to all medical practice settings within New Jersey.

Within the selected institution, the palliative care APN has been appointed as the ACP Champion to serve as a resource person to both the internal medicine residents and the other APNs within the facility. The palliative care APN will encourage and guide the primary care team to conduct early discussions regarding goals of care upon admission. It is anticipated that the constant reinforcement of the ACP process by an APN whose focus is palliative care will inspire provider-initiated ACP discussions upon admission without prompting. Overall, an interdisciplinary and ongoing approach to ACP is necessary for patients to open up and discuss their healthcare wishes.

#### **Professional Reporting & Plans for Future Scholarship**

The results of the project will be shared with the Chief of Pulmonology approving of this educational intervention, the palliative care APN – the ACP Champion, and the director of the Research Council at the selected institution.

The ACP presentation utilized to offer the educational sessions has been shared with the internal medicine resident chief as well as the palliative care APN to disseminate to the entire internal medicine team and APNs going forward. The decision to share this presentation was made on the expectation that ongoing distribution will encourage reporting of this topic to all interdisciplinary teams within the facility.

Furthermore, this project will be presented at the Rutgers University School of Nursing's DNP Poster Day in April of 2020 and the institution's Poster Day in May of 2020.

### **Conclusion**

This project achieved the objectives that were set forth. The goal of a significant increase in AD completion rates was met and healthcare providers were satisfied with the education that was offered. This process needs to be continued to truly have an impact on clinical practice. Healthcare providers need to be more conscientious of initiating conversations that would trigger patients to complete and advance directive. It is important for healthcare providers to stay informed about ongoing changes with regard to the ACP process and what resources they can utilize to initiate the very much needed conversations with their patients. Thus, it is imperative that education on ACP process for the healthcare provider be offered regularly, whether it be monthly, quarterly or annually.

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Appendix A

The Guide to Advance Care Planning Discussions Developed by Residents for Residents



**What is advance care planning?**

Advance care planning (ACP) is a process in which a person reflects on and communicates their values, beliefs, goals, and preferences to best prepare for their future medical care. The designation of a substitute decision maker (SDM) is a key element of ACP.<sup>1</sup>

**Why is ACP important?**

Up to 76 per cent of patients will be unable to participate in some or all of the decisions affecting their own health care at the end of life,<sup>2</sup> and 47 per cent of Canadians have not had a discussion with a family member or friend about what they would want or not want if they were ill and unable to communicate.<sup>3</sup> Without the direction provided by ACP, families often feel burdened by directing medical care in crisis situations, and may feel ill-prepared to make decisions due to a lack of understanding of the patient’s values and preferences. When no prior direction has been documented, physicians often resort to using full resuscitative and medical care. This can mean aggressive treatments that the patient might not have wanted, and may result in unnecessary suffering for both the patient and their family.

**Previous research has highlighted numerous benefits of ACP, including:**

- Improved quality of end-of-life care<sup>4</sup>
- Improved patient and family satisfaction with end-of-life care<sup>5</sup>
- Reduced stress and anxiety for families<sup>5</sup>
- Reduced hospital admissions and length of stay<sup>6</sup>
- Increased use of hospice care<sup>6</sup>
- Shorter intensive care unit stays<sup>7</sup>

**How to perform ACP:**

1. Triage the discussion according to the patient’s health status (Table 1)
2. Check for and review previous ACP conversations
3. Plan for a serious discussion in an appropriate setting (for well patients, this discussion may take only a minute or two; for patients with more serious conditions, this conversation will take some time)
4. Encourage the patient’s SDM to be present for ACP discussions
5. Have an ACP discussion using the Introduce, Discuss, Decide, Document (ID3) Framework (Table 2)
6. Revisit the ACP discussion over multiple visits/discussions as appropriate given the patient’s health status

Health Status	Acuity	Actions
Well patient	Non-urgent	<ul style="list-style-type: none"> <li>» Have a full ACP conversation during each periodic health exam and when triggered by important life events (e.g., marriage, pregnancy, new job)</li> <li>» Emphasize choosing an SDM</li> </ul>
Patient with chronic disease	Semi-urgent	<ul style="list-style-type: none"> <li>» Have a full ACP conversation during each periodic health exam and when triggered by medical events (e.g., new diagnosis, discharge from hospital)</li> <li>» In the patient with chronic disease, discuss the disease course and potential health outcomes as the disease progresses and at decision points that may arise in the future</li> <li>» Revisit at regular intervals as appropriate</li> </ul>
Patient with acute deterioration in health	Urgent; decision needed now	<ul style="list-style-type: none"> <li>» Revisit the ACP conversation with the patient/SDM, or initiate the discussion if this has not already been done</li> <li>» Code status and/or goals of care must be discussed with the patient or SDM at this stage</li> <li>» Physician may recommend best treatment based on the patient’s goals, fears, values, and their specific illness context</li> <li>» Emphasize immediate or anticipated health care decisions</li> </ul>

**ID3 Framework for ACP discussions**

The ID3 Framework (Table 2) provides an approach for clinicians to conduct ACP discussions. It may not be possible or appropriate to complete the full ID3 process during a single discussion. In between appointments, encourage the patient to review patient resources from Speak Up (available at [www.advancecareplanning.ca](http://www.advancecareplanning.ca)), and to discuss their values with their family and SDM.

Table 2: ID3 for ACP discussions – Introduce, Discuss, Decide, Document				
 <p><b>Introduce</b></p>	<ul style="list-style-type: none"> <li>» Introduce: “Can we talk about where things are with your health, and where things might be going?”*</li> <li>» Seek permission: “Is this okay?”*</li> <li>» Inform: What is ACP and why is it important? Describe the process. Explain that the patient’s decisions can be revised as their health/life situation changes.</li> <li>» After introducing the idea of ACP, it may be appropriate for the patient to return for a dedicated appointment to continue the rest of the process.</li> </ul>			
 <p><b>Discuss</b></p>	<p><b>Understanding</b></p>	<p><b>Goals</b></p>	<p><b>Fears</b></p>	<p><b>Trade-offs</b></p>
	<p>“How much do you (and/or your family) know about your illness?”</p> <p>“What information would you like from me?”*</p>	<p>“What are the most important things you want to do in life?”</p> <p>“What are some abilities in life you can’t do without?”*</p>	<p>“What are your biggest fears and worries about your health? About life in general?”*</p>	<p>“If you get sicker, what kinds of health care services are you willing to endure to gain more time?”*</p>
 <p><b>Decide</b></p>	<ul style="list-style-type: none"> <li>» Decide on an SDM: “If you are unable to speak for yourself about medical decisions, who do you want to speak for you?”*</li> <li>» Decide on patient-centred principles of care that are based on, and comply with, the values that the patient has identified as being most important in their life.</li> <li>» This component of the ACP discussion may require multiple discussions, if there is no medical indication for an urgent decision.</li> </ul>			
 <p><b>Document</b></p>	<ul style="list-style-type: none"> <li>» Document the designation of the SDM. The patient should ensure that their SDM is aware of their role and informed of the patient’s priorities and wishes.</li> <li>» Document any principles of care decisions that have been made.</li> <li>» Ensure that documentation complies with relevant provincial/territorial/regional regulations regarding the documentation of designated SDMs and decisions specifying principles of care.</li> </ul>			
<p>*Indicates text that has been adapted from the <i>Serious Illness Conversation Guide</i>,<sup>8</sup> licensed under the Creative Commons Attribution Non-Commercial-ShareAlike 4.0 International License, <a href="http://creativecommons.org/licenses/by-nc-sa/4.0/">http://creativecommons.org/licenses/by-nc-sa/4.0/</a>.</p>				

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7. Khandelwal N, Kross EK, Engelberg RA, Coe NB, Long AC, Curtis JR. Estimating the effect of palliative care interventions and advance care planning on ICU utilization: a systematic review. *Crit Care Med.* 2015;43(5):1102-11.
8. Ariadne Labs. *Serious Illness Conversation Guide*. Boston, MA: Ariadne Labs; 2015. Available from: <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&Tools>. (Accessed May 18, 2017)

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 Suggested citation: College of Family Physicians of Canada. *Guide to Advance Care Planning Discussions*. Mississauga, ON: College of Family Physicians of Canada; 2018.



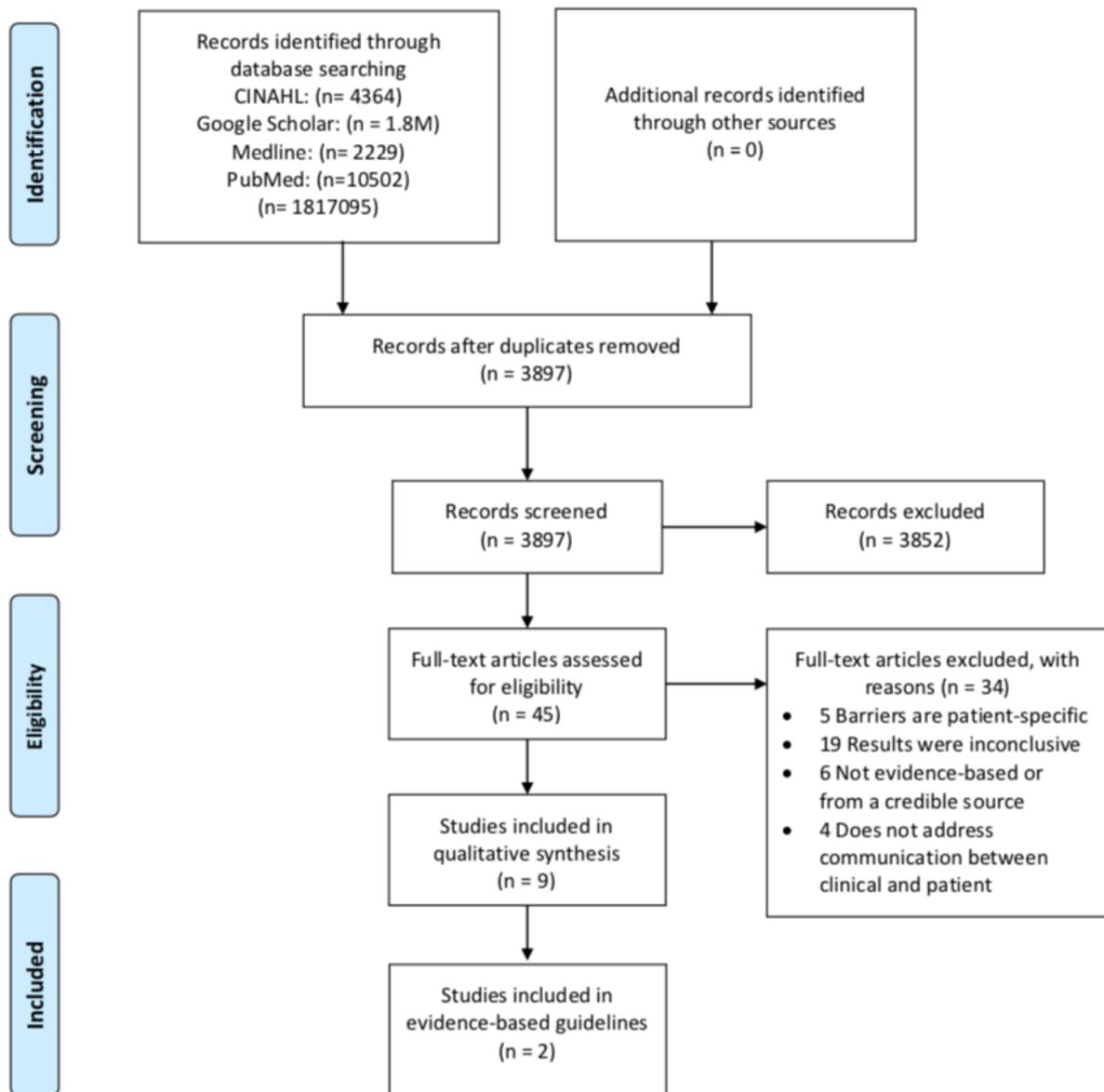






Appendix C

Prisma Flowchart



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

## Appendix D

Table of Evidence

In hospitalized patients on the medical-surgical pulmonary stepdown unit who are under the care of the residents physicians and nurse practitioners (P) does an educational plan for providers (I), in comparison to usual care which does not include education for providers (C), result in a change in the implementation of advanced care planning (O)?

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer the EBP question	Limitations	Evidence Level and Quality
1	Austin, C., Mohottige, D., Sudore, R., Smith, A., & Hanson, L. (2015).	Systematic review (17 randomized clinical trials and 21 non-randomized clinical trials: small pilot trials or pre-intervention - post-intervention study design) Reviewed clinical trials from 1/1/95 to 10/31/14	Adults living with advanced-stage or potentially life limiting diseases, including critical illness, metastatic cancer, advanced stages of renal or liver disease, COPD, cystic fibrosis, systolic congestive heart failure, HIV, AIDS, and advanced neurodegenerative diseases. 39 studies	A review of clinical tools to improve communication and decision making for patients facing serious illness. Seventeen RCTs, nearly all of moderate or high quality, form the primary body of evidence of these tools. Study results show that decision tools clearly improve patient knowledge and preparation for treatment choices, including ACP, palliative care and goals of care communication, feeding options in dementia, lung transplant in cystic fibrosis, and truth-telling in terminal cancer. Clinicians can access and use evidence-based tools to engage seriously ill patients in shared decision making.	Many of the study populations were small, causing the results to be inadequately powered for meaningful results. More than half of the studies used convenience samples. The review is limited to published research.	Level III - High Quality

<p>2</p>	<p>Booth, A., &amp; Lehna, C. (2016).</p>	<p>Needs assessment survey (11 items were assessed) Pre and post-tests</p>	<p>Urban Trauma ICU in Louisville, Kentucky  n=15</p>	<p>Advance care planning is an underutilized resource across the healthcare spectrum. Total post-test scores revealed a 2% improvement in correct responses. These findings point to the need for education of healthcare providers in the ICU to increase early AD and ACP discussions with patients and their families. The tests were to measure the providers' perceived knowledge, capability to communicate, and the awareness of the patient's level of illness. The majority of those surveyed did not have an AD (n = 19, 83%) and they were only moderately comfortable communicating with patients and their families about AD and ACP. Twenty-three HPs' cited time constraints. 23 HPs' revealed access to information as barriers to discussion. Most were uncomfortable discussing AD/</p>	<p>Only one facility involved in this study. Lack of time available for the HPs to focus in a quiet space and engage in a thorough formal educational session. Ironically, in the needs assessment a barrier HPs identified to AD completion and ACP discussions were time, which was a limitation of this study. HPs had limited time to complete all intervention tasks completely: fill out the pre- and post-tests; engage in meaningful discussion; view a PowerPoint; and discuss the contents of the informational packet.</p>	<p>Level III - Good Quality</p>
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				<p>ACP. This discomfort was further highlighted by the fact that 87% of respondents incorrectly indicated the patient’s level of illness influenced discussions about AD. HPs’ perceived comfort averaged 3.1 out of 5 suggesting factors such as chronicity, increased morbidity, and overall health status affect how HPs approach end-of-life discussions</p>		
3	<p>Fahner, J. C., Beunders, A. J. M., Van der Heide, A., Rietjens, J. A. C., Vanderschuren, M. M., Van Delden, J. J. M., &amp; Kars, M. C (2019)</p>	<p>Systematic Review and Meta-Analysis (21 randomized controlled trials, 3 non-randomized control trials, 13 observational studies, 11 quantitative part of a mixed method study, 13</p>	<p>Worldwide 82 studies (Articles were searched from 1/1/98 to 2/23/18)</p>	<p>Exploration of patient's perspectives on illness, living well, end-of-life (EOL) issues, and decision making formed the core part of the guides. 34 unique interventions were identified. ACP conversations conducted by healthcare professionals were supported by conversation guides. A thematic analysis of identified conversation guides revealed 4 subsequent phases of ACP conversations: preparation, initiation exploration, and action</p>	<p>Essential component of conversation guides for healthcare providers were limited. Most of the interventions lacked a comprehensive theoretical underpinning.</p>	<p>Level III Good Quality</p>

		qualitative studies)				
4	Hong, M., Yi, E.-H., Johnson, K. J., & Adamek, M. E. (2018).	Systematic Review (6 experimental studies, 12 cross-sectional surveys, 8 qualitative studies)	Nationwide  26 studies	<p>A range of engagement in ACP from 0 up to 29% among ethnic minority populations. Ethnic minorities consistently reported low health literacy regarding ACP, lacked proper knowledge what ACP was and how to complete such documents. Ethnic minorities misunderstood ACP. They believed AD was related to insurance and financing of healthcare and their last will. Ethnic minorities did not know where and how to engage in ACP. Educational interventions that delivered information about ACP were found to be effective in improving attitude toward ACP and completion of ADs.</p>	<p>Convenience sampling, so caution should be used in generalized findings. Quantitative studies employed cross-sectional surveys, and causality cannot be between some of identified facilitators or barriers and engagement in ACP. Distinctions between ethnicities was not always clear or possible and some results were combined.</p>	Level III Good Quality
5	Hughes, B., O'Brien, M. R., Flynn, A., & Knighting, K. (2018).	Systematic Review (3 qualitative studies, 19 mixed method studies)	United States, United Kingdom, France, Germany and Japan Children hospitals, clinics,	<p>4 themes arose from the studies: how ACP works in practice, communication, training and education, and relationships. Providers need to have a structured ACP intervention to create positive relationships and effective</p>	<p>Varied nature of studies can make it difficult to synthesize the information. There can be a bias for over-representing one or more studies or themes. Various terms and definition among the articles. Small</p>	Level III Good Quality

		<p>Articles searched between 1/1/90 – 10/31/17</p>	<p>and medical centers  22 studies</p>	<p>communication which will facilitate participation and reduce both stress and anxiety.                  Providers should start the conversation when the patient is diagnosed in order to make them feel empowered and facilitate their participation.                  - Poor and incorrect timing of ACP communication can cause unnecessary tension and create barriers to engage in ACP process.                  High quality communication can help people understand the care they need and develop skills to convey their wishes.                  Providers should respect patients by being honest and having meaningful discussions about dying by having open communication. When providers are reluctant or uncomfortable about discussing EOL choices it causes a barrier in the patient's decision-making process.                  Training can enhance the quality of both communication and</p>	<p>amount of literature found on the topic. Qualitative framework can present a potential bias. Studies varied in quality, sampling methods.</p>	
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				<p>relationships of those in ACP process.</p> <ul style="list-style-type: none"> <li>- Poor communication skills and unwillingness to discuss ACP have been identified as potential training needs for providers.</li> </ul> <p>A structured ACP process may help reduce tension by providing framework in which to discuss wishes openly and intimately because it gives everyone a clear role.</p> <ul style="list-style-type: none"> <li>- Building a trusting relationship is vital for the ACP process.</li> </ul> <p>-Evidence stresses that quality relationships are based on mutual understanding, trust, and respect can help recognize the wishes of each person as valuable within ACP. Successful relationships depend on developing effective communication and accessing relevant training.</p> <p>Evidence recognized that ACP is a complex process and the availability of training for providers is crucial to both</p>		
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				<p>help understand these complexities and overcome potential barriers.</p> <p>Training to enhance provider's knowledge and understanding of relevant policies and legislation.</p> <p>Communication training would facilitate introduction and engagement of patients in ACP process.</p> <p>Training can raise ACP awareness</p>		
6	Institute of Medicine (2015)	Non-research	N/A	<p>Clinicians need to recognize the multiple barriers to effective communication on these issues, initiate the conversation themselves, and take time and make the effort to ensure that patient and family decisions are made with adequate information and understanding. The quality of communication between clinicians and patients who have advanced serious illness or are nearing death falls far short of the ideal, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding</p>	N/A	Level IV - Good Quality

				<p>the right balance between hoping for the best and preparing for the worst.</p> <p>Recommendation 2. Professional societies and other organizations that establish quality standards should develop standards for clinician- patient communication and advance care planning that are measurable, actionable, and evidence-based.</p> <p>These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies.</p> <p>Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality.</p> <p>Payers should tie such standards to reimbursement, and professional societies should adopt policies that facilitate tying the standards</p>		
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				to reimbursement, licensing, and credentialing to encourage		
7	Kernick, L. A., Hogg, K. J., Millerick, Y., Murtagh, F. E. M., Djahit, A., & Johnson, M. (2018).	Systematic Review (3 RCTs studies, 1 observational study) articles searched 1990 through 3/23/17)	United States, United Kingdom, Canada, Sweden, and Hong King: community and inpatient settings  14,537 participants	The time period of the study ranged from 12 weeks through 5 years and 4 of the studies showed a reduction in hospital admission and readmission. The ACP group at 6 months was 0.42 compared to 1.47 in the control group for readmission. 2 studies reported place of death in preferred location and an increase in out of hospital deaths with ACP. - Johnson et al. showed preferred place of death achieved in 61% and hospital deaths just over 40% compared with national figures of 82%. Butler and McAlister showed the patients with evidence of ACP had increased hospice compared to without. McAlister study of hospice with ACP showed 22.3 vs 6.4 without ACP.	The exact elements of advance planning were included or how it was conducted were not provided. Blinding of participant and clinicians wasn't completely possible and can cause a bias. The risk of contamination at multi-sites was not documented. Many confounders in the observational.	Level II Good Quality

				<p>Butler study of hospice with ACP showed 5 vs 1 without ACP.</p> <p>ACP changes patterns of health service utilization. ACP increases ADs, hospice use, reduces hospital use, and supports patients in their preferred place of care and death.</p> <p>ACP as an additional component improves symptoms and quality of life.</p> <p>ACP as part of routine care would help early identification of those who would benefit, and careful prep is needed with serious illness.</p> <p>Most health costs in advanced heart failure are driven by hospital admission and the use of invasive but futile interventions in the last weeks of life administered in hospitals.</p> <p>ACP as a component of generic intervention of care is associated with reduced healthcare costs at end of life.</p>		
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8	Lund, S., Richardson, A., & May, C. (2015).	Explanatory systematic review of qualitative implementation studies	<p>Across continents (United States, United Kingdom, California, Australia)</p> <p>13 studies (qualitative methods were used)</p>	<p>The findings of this review suggest that the interventions the most likely to facilitate ACPs are those that will equip front line professionals to manage both the interactional processes and procedural activities involved, and will provide them with a structured framework for action. The workability of ACPs is likely to be increased if the conversations that underpin them can be focused on a simplified decision-making tool. Providing clinicians with simple tools that do not require high levels of specialist preparation is likely to increase the likelihood of their adoption and normalization in practice, and is likely to increase patients' willingness to engage with them.</p>	<p>Much useful information about the process of implementing and delivering ACP is missing. The literature used is likely to be bias towards the presentation of positive results, and inadequate reporting of intervention design and methods of evaluation. The studies were interpreted using theoretical framework, which is not according to the original authors.</p>	Level III - Good Quality
9	Myers, J., Cosby, R., Gzik, D., Harle, I.,	Systematic Review	Outpatient and inpatient pediatric and adult settings	<p>Most used ACP provided tool was Respecting Choices. The key feature of respecting choices program is to train</p>	<p>Inconsistency in definitions and desired outcomes need to be addressed to ensure better understanding of</p>	Level III Good Quality

	<p>Harrold, D., Incardona, N., &amp; Walton, T. (2018).</p>		<p>38 studies (11 randomized controlled trails, 27 non-randomized control trails)</p>	<p>providers about the ACP process.                  Respecting choices is a type of intervention that can result in an increase of ADs and more involvement in end of life decisions, increased ACP knowledge, fewer symptoms of anxiety and depression.                  Respecting choices training demonstrates an increase in motivation, confidence, preparedness, and skill at facilitating ACP discussions.                  A comprehensive approach to ACP includes community engagement, professional education, development of standard practices through quality improvement initiatives, supporting polices and practices, and a technology infrastructure.                  Respecting choices model demonstrates how the training of providers who are interested and willing is a critical strategy for impacting patient outcomes.                  The most important patient related outcome of any future</p>	<p>effective healthcare provider tools.                  Regional variations of ACP.</p>	
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				or current care decision-making process is that the patient receives the care that they wished for or desired		
10	State of New Jersey Department of Health. (2018).	Non-research	N/A	<p>Barrier #2 - Lack of Communication and Conversations:</p> <p>Although practitioners have access to numerous resources on how to facilitate difficult discussions, actual training to develop effective communication skills is still lacking in most medical and nursing curricula. Consequently, many practitioners struggle with advance care planning and end-of-life care discussions, and shy away from delivering bad news or having honest conversations with patients near the end-of-life.</p> <p>Recommendations 3 &amp; 4: Development of training programs for professionals as well as specific educational tools to best inform patients and the public on issues that must be discussed in</p>	N/A	Level IV - Good Quality

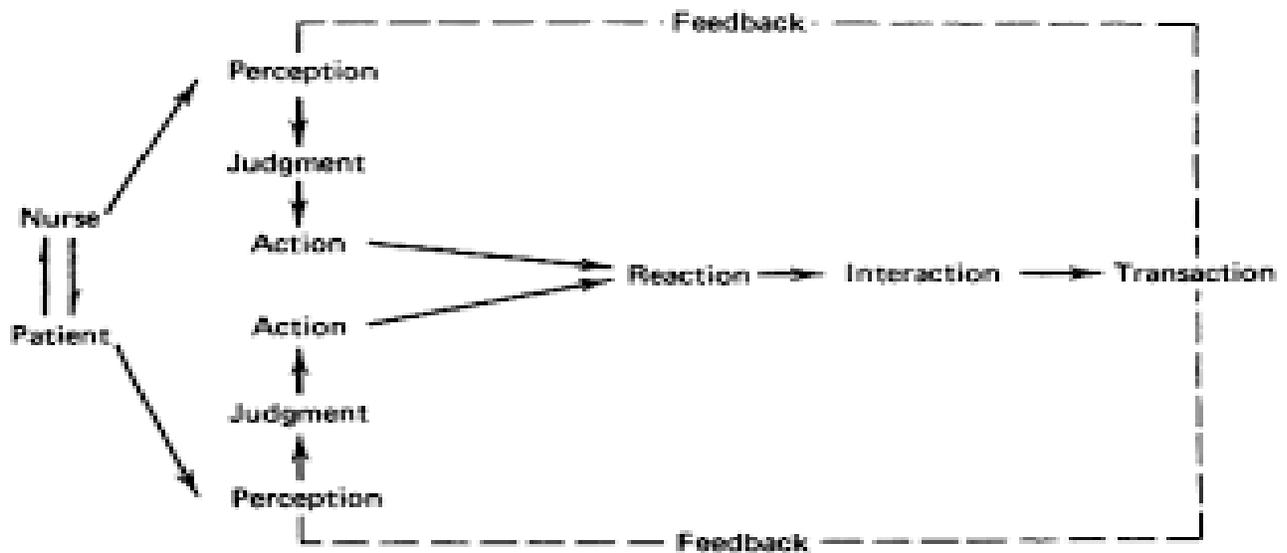
				<p>preparation for end-of-life decisions.</p> <p>Develop and require education on EOL care options and planning for all licensed health professionals &amp; students in training, counselors, chaplains, administrative staff of all healthcare facilities to increase their knowledge of the applicability of palliative care for patients with advanced serious illnesses.</p>		
11	Zwakman, M., Jabbarian, L. J., van Delden, J. J. M., van der Heide, A., Korfage, I. J., Pollock, K., ... Kars, M. C. (2018).	Systematic Review of the literature and a thematic synthesis was conducted.	<p>Western countries, mostly Canada</p> <p>20 studies (19 articles were qualitative studies and 1 mixed-methods design)</p>	<p>The information patients received during ACP conversation and the way it is provided determines the patient's aspect about the topic in general.</p> <p>The patient's needs to feel empowered, respected, and heard in order to be involved.</p> <p>ACP at the wrong moment could both harm the patient's well-being and the relationship between the patient and the healthcare provider.</p> <p>Patients need to know as much information in order to make decisions.</p>	The articles included were research studies and ACP intervention were done in a research context. The patients were self-selected because they were ready to discuss ACP, causing a bias. Articles were limited to the ones published in English.	Level III Good Quality

				<p>Patients who completed a document indicated it was helpful way to organize their thoughts and experienced it as a means of protecting their autonomy.</p> <p>Providers need to talk and treat patients on an individual basis.</p> <p>When healthcare providers have an open-dialogue it enables the patient to ask questions related to ACP and plan for both current and future medical care.</p> <p>Patients believed ACP conversation was about refusing treatment and conflicts with doctor's work.</p> <p>Providers need to show a degree of informality toward patients, be supportive and sensitive in order to allow them to feel comfortable, respected; so they can express their wishes and thoughts.</p> <p>If patients remain unaware of ACP, they are denied the opportunity to benefit.</p>		
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				<p>Providers need to be sensitive and willing to openly discuss the difficulties involved.</p> <p>It is vital for providers to be adequately educated and guided about all aspects of ACP.</p> <p>Providers need different tools or ACP interventions to use in the care of patients during EOL trajectory</p>		
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Appendix E

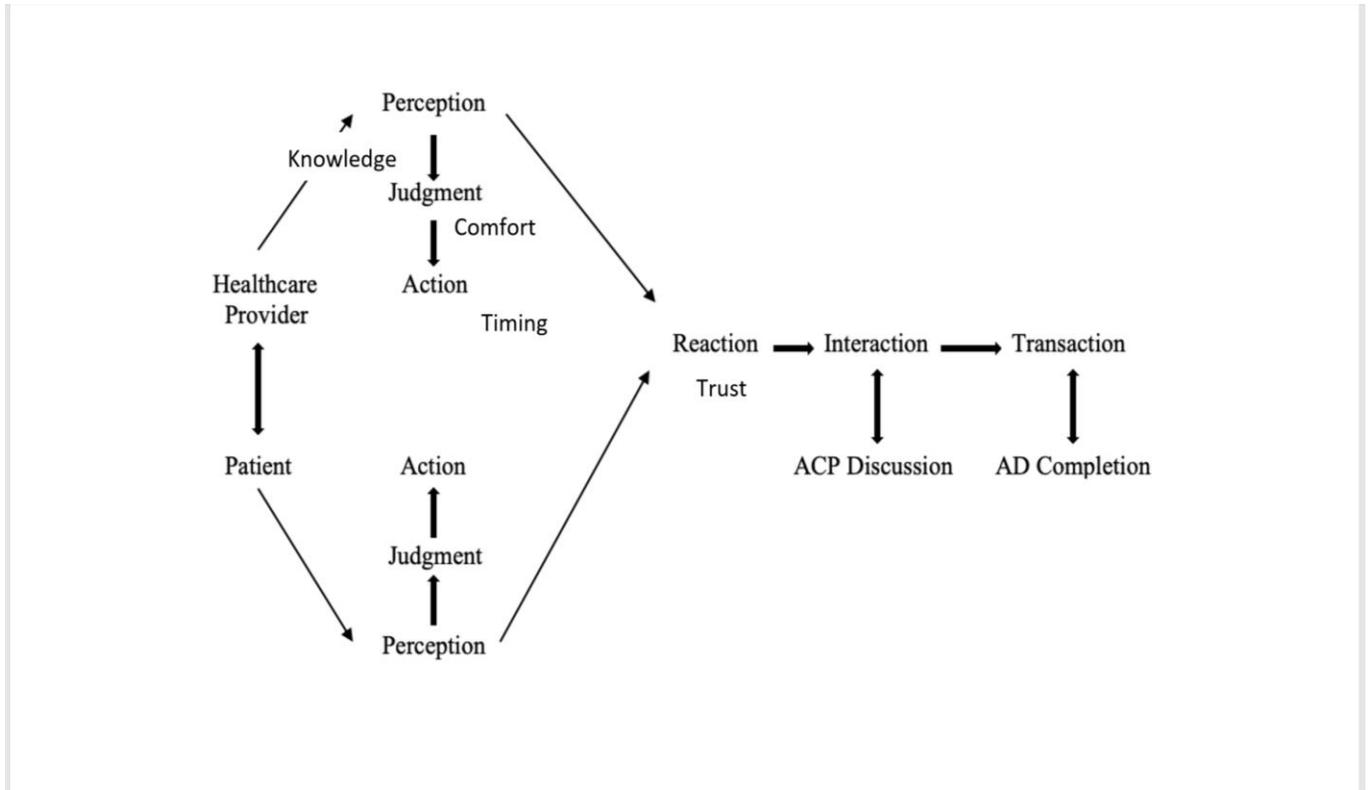
Theoretical Framework



From: King, M., I. (1981). *A Theory for Nursing: Systems, Concepts, Process* (p. 145)

King IM. (2007). King's conceptual system, theory of goal attainment, and transaction process in the 21st century. *Nursing Science Quarterly*, 20(2), 109–111. Retrieved from

<https://login.proxy.libraries.rutgers.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=106136773&site=ehost-live>



Adapted from: King, I. M. (1981). *A theory for nursing: Systems, concepts, process*. New York, NY: John Wiley & Sons, Inc.

Appendix F  
Pre- and Post-Test

1. How often do you review a patient's advance directive in the EMR when completing a hospital admission?  
Never      Rarely      Sometimes      Most of the time      Always
2. How often do you discuss advance care planning (ACP) with your older patients?  
Never      Rarely      Sometimes      Most of the time      Always
3. When do you discuss advance care planning (ACP) with your hospitalized patient?
  - a. When prompted by patient or family
  - b. Upon admission
  - c. Upon discharge
  - d. After new diagnosis or change in health status
  - e. At age 65
  - f. Other
4. What provider-level barriers prevent you from discussing advance care planning (ACP) with your patients? Select all the apply.
  - a. I do not remember to discuss ACP
  - b. I do not feel is important
  - c. I worry that the patient will be offended
  - d. I worry that the patient will not understand the issue
  - e. I am uncomfortable initiating the ACP discussion
  - f. ACP is not the resident's responsibility
5. What system-level barriers prevent you from discussing advance care planning with your patients? Select all the apply.
  - a. Not enough time to discuss ACP
  - b. My patients are not prepared to discuss ACP
  - c. Lack of continuity with patients encountered
  - d. Not enough time to complete
  - e. Process is too complicated
  - f. Written materials are too difficult to understand
6. What patient-level barriers prevent you from discussing advance care planning with your patients? Select all that apply.
  - a. PCP did not recommend
  - b. Patients do not want to think about this topic

7. Patients do not see a need because they are healthy
- Religious/cultural preferences
  - Patients feel loved ones “know what I would want”
  - Patient feels that the topic is too depressing/anxiety provoking
8. I am confident of my ability to lead a goals-of-care discussion with a patient and their family.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree
9. I know which patients to prioritize discussing advance directives and goals-of-care with.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree
10. I understand the legalities and the differences between advance directives, health care proxy and living will.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree
11. I feel confident that I could teach someone else about advance directives and advance care planning with a patient.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree
12. XXXXXXXXXXXXXXXXXXXX IM residency program provides sufficient training for residents in discussing advance care planning with patients.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree
13. I know where to document and find advance directives for a patient within Cerner.
- Strongly Disagree      Disagree      Neutral      Agree      Strongly Agree





We will be slightly adapting the questions as found below.

Thank you for your time!

Sincerely,

Jennifer Samaan & Nancy Awad

<https://journals.sagepub.com/doi/abs/10.1177/1049909113485636?journalCode=ajhb>



## Improved Resident Physician Confidence With Advance Care Planning After an Ambulatory Clinic Intervention

Many primary care providers feel uncomfortable discussing end-of-life care. The aim of this intervention was to assess internal medicine residents' advance care...

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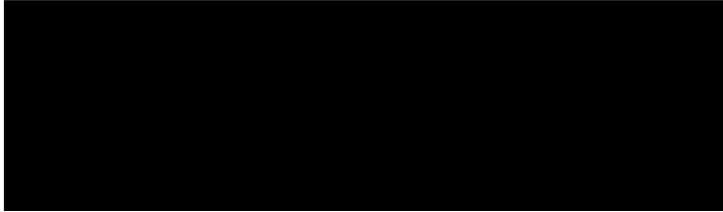
1. How often do you review a patient's advance directive in the EMR when completing a hospital admission?
 

Never      Rarely      Sometimes      Most of the time      Always
2. How often do you discuss advance care planning (ACP) with your older patients?
 

Never      Rarely      Sometimes      Most of the time      Always
3. When do you discuss advance care planning (ACP) with your hospitalized patient?
  - When prompted by patient or family
  - Upon admission
  - Upon discharge
  - After new diagnosis or change in health status
  - At age 65
  - Other
4. What provider-level barriers prevent you from discussing advance care planning (ACP) with your patients? Select all the apply.
  - I do not remember to discuss ACP
  - I do not feel is important
  - I worry that the patient will be offended
  - I worry that the patient will not understand the issue
  - I am uncomfortable initiating the ACP discussion
  - ACP is not the resident's responsibility

5. What system-level barriers prevent you from discussing advance care planning with your patients? Select all the apply.
- Not enough time to discuss ACP
  - My patients are not prepared to discuss ACP
  - Lack of continuity with patients encountered
  - Not enough time to complete
  - Process is too complicated
  - Written materials are too difficult to understand
6. What patient-level barriers prevent you from discussing advance care planning with your patients? Select all that apply.
- PCP did not recommend
  - Patients do not want to think about this topic
  - Patients do not see a need because they are healthy
  - Religious/cultural preferences
  - Patients feel loved ones “know what I would want”
  - Patient feels that the topic is too depressing/anxiety provoking

Appendix H  
Site Approval Letter



Date: February 12, 2019

**Re: Letter of Cooperation for** [REDACTED]

Dear Jennifer Samaan,

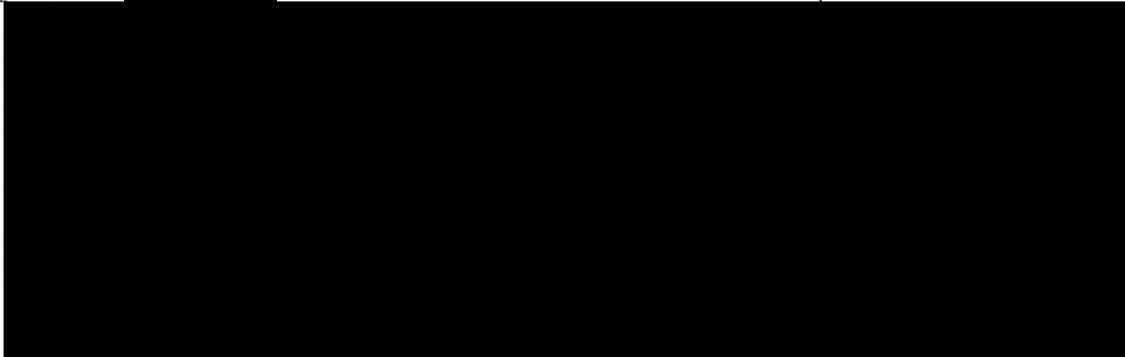
This letter confirms that that I, as an authorized representative of [REDACTED] allow the Principal Investigator access to conduct study related activities at the listed site(s), as discussed with the Principal Investigator and briefly outlined below, and which may commence when the Principal Investigator provides evidence of IRB approval for the proposed project.

- **Research Site(s):** [REDACTED]
- **Study Purpose:** To educate healthcare staff on advance care planning and, ultimately, to increase patient involvement in their end-of-life medical care decisions through the completion of advance directives.
- **Study Activities:** Education to healthcare providers along with distribution of surveys. Access to database to ascertain number of advance directives on file.
- **Subject Enrollment:** Healthcare providers that rotate through the medical/surgical units.
- **Site(s) Support:** Provide space to conduct study activities, authorize principal investigator to communicate with and educate healthcare providers that rotate through the medical/surgical units, and retrieval of data pertaining to advance directives on file for patients admitted to the medical/surgical units.
- **Data Management:** The data retrieved will be de-identified. It will only specify the total number of advance directives on file within a specified time frame in the medical/surgical units. It will not be associated to the patient by any of the following identifiers: name, age, date of birth, gender, medical record number, account number or medical diagnosis.
- **Anticipated End Date:** May 2020

We understand that this site's participation will only take place during the study's active IRB approval period. All study related activities must cease if IRB approval expires or is suspended. I understand that any activities involving Personal Private Information or Protected Health Information may require compliance with HIPAA Laws and Rutgers Policy.

Our organization agrees to the terms and conditions stated above. If we have any concerns related to this project, we will contact the Principal Investigator. For concerns regarding IRB policy or human subject welfare, we may also contact the Rutgers IRB (see [orra.rutgers.edu/hspp](http://orra.rutgers.edu/hspp)).

Regards,



Appendix I  
Flyer

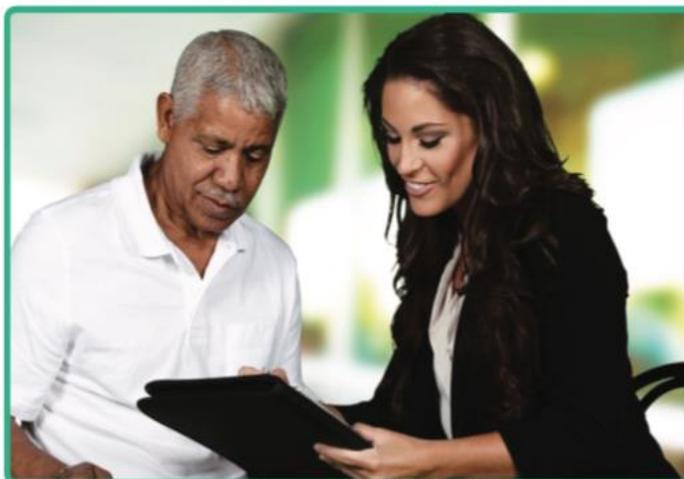


Appendix J  
CMS CPT Codes

**PROVIDER AND LOCATION ELIGIBILITY**

**Physicians and non-physician practitioners (NPPs) may bill ACP services** if their scope of practice and Medicare benefit category include the services described by the Current Procedural Terminology (CPT) codes in Table 1. Hospitals may also bill them.

There are no place-of-service limitations on ACP services. You can appropriately furnish ACP services in **facility and non-facility settings**. ACP services are not limited to a particular physician specialty.



**DIAGNOSIS**

CMS requires no specific diagnosis to bill the ACP codes. Report the condition for which you are counseling the patient using an International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) code to reflect an administrative examination, or a well exam diagnosis when furnished as part of the Medicare AWV.

**CODING**

Hospitals, physicians, and NPPs should use the CPT codes in Table 1 to file claims for ACP services.

**Table 1. CPT Codes and Descriptors**

CPT Codes	Billing Code Descriptors
99497	Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate
99498	Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes (List separately in addition to code for primary procedure)

From: American Medical Association. (2018). *Advance care planning MLN fact sheet*. Retrieved from: <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>

Appendix K  
Consent for Participation



**RUTGERS**

School of Nursing

*Paper Questionnaire Research with Adults*

**CONSENT TO TAKE PART IN A RESEARCH STUDY**

**TITLE OF STUDY:** An Education Intervention to Increase Advance Directive Completion in the Medical/Surgical Pulmonary Stepdown Unit

**Principal Investigator:** Jennifer Samaan, RN, BSN, DNP candidate

This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. After all of your questions have been answered and you wish to take part in the research study, you will be asked to sign this consent form. You will be given a copy of the signed form to keep. Your alternative to taking part in the research is not to take part in it.

**Who is conducting this research study and what is it about?**

You are being asked to take part in research being conducted by Jennifer Samaan, RN, BSN who is a Rutgers DNP-FNP graduate student in the Dept. of Nursing. The purpose of this study is to improve the healthcare providers' knowledge on ACP according to the guidelines and recommendations of CMS, in addition to encouraging them to initiate ACP discussions with their patients at [REDACTED] in the medical/surgical pulmonary stepdown unit.

**What will I be asked to do if I take part?**

The questionnaire will take about 10 minutes to complete it. We anticipate 20 subjects will take part in the study.

**What are the risks and/or discomforts I might experience if I take part in the study?**

The risks to study participants are minimal but may include feelings of insecurity with the topic discussed, individual pre-test results, and the expectations of their attending physicians regarding ACP once attending the educational focus groups. Breach of confidentiality is a risk of harm but a data security plan is in place to minimize such a risk. Also, some questions may make you feel uncomfortable. If that happens, you can skip those questions or withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire your answers will NOT be recorded.

**Are there any benefits to me if I choose to take part in this study?**

There no direct benefits to you for taking part in this research. You will be contributing to knowledge about The benefits to participation include an increase in knowledge regarding ACP and therefore, improved adherence to PSDA of 1990 and CMS guidelines. Additional benefits include the potential for a long-term educational tool on ACP approach for [REDACTED] healthcare providers. The overall benefit would be to ensure that patients' end-of-life medical care decisions are documented and honored.

**Will I be paid to take part in this study?**

You will not be paid to take part in this study. There will be no cost required of the study's subjects as they will attend the educational focus groups while at the [REDACTED] campus for work. Healthcare providers that do attend will be compensated with previously mentioned CPT codes in order to bill for ACP services regardless of location, whether it is a hospital or a private practice.

**How will information about me be kept private or confidential?**

All efforts will be made to keep your responses confidential, but total confidentiality cannot be guaranteed.

- We will not collect any information that can identify you or other subjects. Completed forms will be stored in a locked cabinet controlled by the investigator. Responses may be converted to digital format and stored on a password-protected computer that can only be accessed by the study team. Paper copies will then be destroyed. We plan to delete the data at the completion of the project: May 2020

No information that can identify you will appear in any professional presentation or publication.

**What will happen to information I provide in the research after the study is over?**

- The information collected about you for this research will not be used by or distributed to investigators for other research.

**What will happen if I do not want to take part or decide later not to stay in the study?**

Your participation is voluntary. If you choose to take part now, you may change your mind and withdraw later. You may leave without turning in a completed form or by turning in a blank or incomplete form. However, once you turn in the form, you can no longer withdraw your responses as we will not know which ones are yours.

**Who can I call if I have questions?**

If you have questions about taking part in this study, you can contact the Principal Investigator: Jennifer Samaan, RN, BSN Rutgers DNP-FNP graduate School of Nursing,  
[REDACTED]

If you have questions about your rights as a research subject, you can call the IRB Director at: Newark Health Sciences (973)-972-3608;

Please keep this consent form if you would like a copy of it for your files.

By beginning this research, you acknowledge that you have read the information and agree to take part in the research, with the knowledge that you are free to withdraw your participation without penalty.

**AGREEMENT TO PARTICIPATE****1. Subject consent:**

I have read this entire consent form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form and this study have been answered. I agree to take part in this study.

Subject Name (printed): \_\_\_\_\_

Subject Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**2. Signature of Investigator/Individual Obtaining Consent:**

To the best of my ability, I have explained and discussed all the important details about the study including all of the information contained in this consent form.

Investigator/Person Obtaining Consent (printed): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Appendix L  
 Championing Person-Centric Advance Care Planning PowerPoint Presentation



## Championing Person-Centric Advance Care Planning

Danielle J. Doberman, MD, MPH, HMDC  
 Medical Director, Palliative Medicine  
 Johns Hopkins Hospital

No Relevant Financial Relationships with Commercial Interests

No Conflicts of Interest

Danielle J. Doberman, MD, MPH, HMDC  
 May 30, 2018

**Objectives:**

- Obtain a broad understanding of available tools and models to ensure patients' wishes are respected throughout the care continuum
- Learn about community-wide partnerships promoting patient-centric advance care planning practices
- Understand user needs and state activities to progress access to advance care planning tools
- Identify common challenges, opportunities, and focus areas for statewide efforts

**Objectives:**

- Compare and contrast Goals of Care conversations, Advance Directives & MOLST/POLSTs
- How are these related?




- 64 y/o man with DM2, HTN, CHF, CAD, ESRD on HD with an AICD.
- He has arthritic pain in his knees and hips, neuropathy in his feet.
- He is in your office for f/u of HTN & CHF and pre-op evaluation for knee replacement



**George 64 y/o M, multimorbid**



- What questions might you ask?
- What anticipatory guidance will you provide?
- Is he Terminally Ill?
- Surprise question?

**Healthcare Today: Technology**



### Advance Care Planning: Communication Pointers



### What is Advance Care Planning (ACP)?

- Process of planning for future medical care where:
  - \_ Patients values and goals are explored
  - \_ Proxy decision maker identified
  - \_ Conversation documented
    - A communication process, not a legal process
- Process of creating "Advance Directives"
- Not a one time event



### Benefits of ACP:

- Promotes patient autonomy & control
- Creates trust between clinician & patient
- Avoids future confusion and conflict
- Increases patient peace of mind



### Joan Rivers' Living Will:



Melissa explained: "**She had written in specifically that she was to be able to go onstage. For an hour. And be funny.**"

"It was an amazing gift to give me, knowing exactly how she wanted her life to be. Not that it's ever an easy decision, but I knew I was making the right one."

*"Joan Rivers' daughter knew she was right to switch off her mother's ventilator because the 81-year-old star had a living will which explained the quality of life she wanted."*  
 — People Magazine

### When should ACP be addressed?

Can we hard-wire assessment into standard work-flows?

- \_ On all intake forms?

Introduce the topic at routine times?:

- \_ New patient evaluations
- \_ Complete physicals/annual exams
- \_ Pre-op physicals
- \_ New or worsening significant diagnoses or test results

Create a culture of normality and ownership by all?

### What should be addressed?

**Routine, healthy patients?**

- Healthcare Proxy
- General goals and values discussion
- Evaluate presence of living will, etc.

**Serious or chronic illness? Evolving disease?**

- Confirm Proxy
- Refinement in goals of care discussion
- Document discussion & Encourage living will

**Terminal disease**

- Confirm Proxy
- Re-evaluate goals of care & their priorities
- Review living will and/or prior documentation

### What are "Goals of Care?"

**Goals of Care = Patient Values**

- Cure disease • Avoid disability
- Avoid early death • Avoid dependence
- Maintain or • Maintain alertness improve function • Improve life quality
- Prolong life • Stay in control
- Avoid pain • Support family

©Danielle J. Doberman, MD, MPH



Maryland Medical Orders for Life-Sustaining Treatment (MOLST)

**CERTIFICATION FOR THE BASIS OF THESE ORDERS:** Mark any and all that apply

Having verified that these orders are entered as a result of a discussion with and the informed consent of the patient:

- The patient's health care agent as named in the patient's advance directive, or
- The patient's qualified personal representative as designated in the patient's will, or
- The patient's surrogate as set forth in the patient's Health Care Decisions Act, or
- If the patient is a minor, the patient's legal guardian or another legally authorized adult.

Do I hereby certify that these orders are based on:

- My own personal knowledge of the patient's condition, or
- Information provided to me by the patient's health care provider. All supporting documentation must be contained in the patient's medical records.

Mark the following if the patient's advance directive meets criteria to describe it as portable, make a duplicate, and have it available:

- The patient's or authorized decision maker's participation in the preparation of the MOLST is voluntary.
- The patient or authorized decision maker has not been coerced, unduly influenced, or otherwise provided by law, CPST, or by attempted and other treatments will be given.

**CPST (SOCIOECONOMIC STATUS):** This information must follow the International Classification of Diseases (ICD) procedure. **Altering CPST:** Certain medical interventions are not covered, although cardiopulmonary resuscitation (CPR) and efforts to restore and/or stabilize cardiopulmonary function.

If the patient or authorized decision maker does not so indicate, no restrictions regarding CPST status will be entered. **Exception:** If valid advance directives declare CPST, it is automatically enforceable, even if there is some other legal barrier to overriding CPST, such as one of the CPST options below.

**1. No CPST, Option A, Comprehensive Efforts to Prevent Arrest:** This is to arrest, administer all resuscitation needed to restore and/or stabilize cardiopulmonary function, and all other resuscitation (the CPST) that does not result in death.

**Option A.1, Resuscitate:** Comprehensive efforts may include intubation and artificial ventilation.

**Option A.2, Do Not Resuscitate (DNR):** Comprehensive efforts may include limited ventilation supported by CPST, CPST, but not intubation.

**No CPST, Option B, Palliative and Supportive Care:** Prior to arrest, provide palliative support for comfort and control any external bleeding. Prior to arrest, provide medications for pain relief as needed, and no other medications. Do not intubate or give CPST or DNR. Consider quality palliative care support. Do not attempt resuscitation (the CPST). Do not attempt to restore and/or stabilize cardiopulmonary function.

**Signature of Physician, Nurse Practitioner, or Physician Assistant (Signature and date are required to validate orders)**

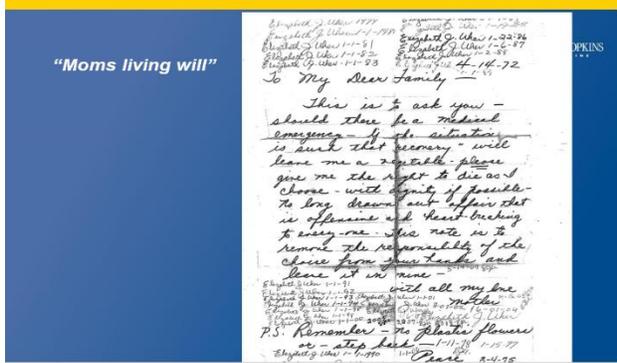
Physician Name: \_\_\_\_\_ Date: \_\_\_\_\_

Physician Number: \_\_\_\_\_

“Orders” but do not allow for description or caveat.

Do not define “Quality of Life”

NOT Advance Care Planning!



### Advance Directives vs. MOLST

**Differences between POLST and advance directives**

CHARACTERISTICS	POLST	ADVANCE DIRECTIVES
Population	For the seriously ill	All adults
Time frame	Current care	Future care
Who completes the form	Health care professionals	Patients
Resulting form	Medical orders (POLST)	Advance directive
Health care agent or surrogate role	Can engage in discussion if patient lacks capacity	Cannot complete
Portability	Provider responsibility	Patient/family responsibility
Periodic review	Provider responsibility	Patient/family responsibility

POLST = Physician Orders for Life-Sustaining Treatment

<http://polst.org/wp-content/uploads/2015/01/2013.09.26Final-POLST-Article.pdf>

- ### Goals of the ACP:
- NOTE: Goal is NOT to get the DNR!
- Goal is to understand the patient, their values, and hopes
    - “Goals of care” for health is much broader than resuscitation status!
    - Use patient’s values to guide your medical recommendations
  - Establish decision maker

- ### Evolution in Advance Care Planning
- Movement away from fixed statements about future medical treatments
    - E.g.: “No intubation if I am in a “terminal state”
      - Definitions are challenging
    - Living wills never cover every situation

- ### Evolution in ACP
- Movement towards discussion of Goals:
    - Acceptable functional outcomes
      - “Life is worth living as long as I can still sing in the choir.”
      - “I want to talk and make sense.” “Sail my boat”
    - Milestone events
      - “I want to live long enough to see my daughter’s graduation”
  - Once elicited, medical treatments can be tailored to reach patient’s goals

- ### ACP in the Clinics/Admission:
- Be straightforward, calm & positive
  - Incorporate in your Routine
- Social History:**
- “Do you smoke or drink alcohol?”
- “What do you do for a living?”
- “Do you have a living will, advance directive or other healthcare wishes I should respect when caring for you?”
- Proxy:**
- “If sickness ever makes it such that you cannot speak to me, who should I call who knows you best, and can speak on your behalf?”
- Values & Goals Assessment**

*"I want to help you achieve what you want out of your health care, & I have some questions to ask."*

- "What are your most important hopes? What are your biggest fears about your health?"
- "What makes life worth living? What if you could no longer do these things?"
- "Would there be any circumstances under which you would find life not worth living?"
- "Has anyone close to you ever died? *What are your feelings about that experience?*"
- "What brings you joy? What makes you smile?"

Quill, JAMA 2009

**George 64 y/o M, multimorbid**



- Healthcare Proxy is son
- Goals:
  - Reduce pain
  - Increase ambulation
  - Increase exercise
  - Improve health by exercising more
  - Maintain independence
  - Avoid being a burden

**Phrases to Avoid:**

- "Do you want us to do everything?"
- "Do you want us to start your heart if it stops?"
- "If we do CPR we will break your ribs and you will need to be on a breathing machine – you don't want us to do that – do you?"
- "Will you agree to discontinuing care?"
- "There is nothing more we can do..."



**Phrases to Avoid:**

- "If your heart stops, do you want us to use electrical shocks and chest compressions to try to get it beating again? Or if you stop breathing, do you want us to put a tube down your throat into your lungs and attach you to a breathing machine to help you breathe?"
  - Does not address treatment outcome or alternatives
  - Burden of decision making is on pt/family, without MD guidance
  - Does not assess patient goals of care – Fails to convey patient's prognosis – Devoid of empathy – Time limited trial?

**Can We Do Better?**



*"For someone in your condition, CPR is rarely successful. Most patients die in spite of our best efforts, or may live for a few more hours or days before dying, but they are comatose. I would suggest we make all efforts at preventing your death with antibiotics and transfusions, but if you are on a different path, to focus aggressively on your comfort."*



**Summary**

- Advance care planning can increase patient control and strengthen the clinician-patient relationship.
- ACP should be anchored in the patient's values and goals for healthcare.
- Once goals have been illuminated, healthcare efforts can be patient centered, and directed towards goal attainment.

©Danielle J. Doberman, MD, MPH

**Thank you for listening!**



**Questions?**

Danielle J. Doberman, MD, MPH, HMDC  
doberman@jhmi.edu

<https://theconversationproject.org/>



**Your Conversation Starter Kit**  
When it comes to end-of-life care, talking matters.

<https://theconversationproject.org/> JOHNS HOPKINS

### How To Talk To Your Doctor

Discussing end-of-life care with your doctor, nurse, or other health care provider.

the conversation project

### Your Conversation Starter Kit

For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia

the conversation project

<https://www.prepareforyourcare.org> JOHNS HOPKINS

**PREPARE** for your care

### PREPARE Advance Directive

Advance directives are legal forms that let you have a say about how you want to be cared for if you get very sick. Share the advance directives with your family, friends, and medical providers.

**Get Your State's Advance Directive**

Select your state below to download and fill out your state's advance directive.

Maryland

**PREPARE for your care** JOHNS HOPKINS

**TODAY, IN YOUR CURRENT HEALTH**

Put an X along this line to show how you feel today, in your current health.

My main goal is to live as long as possible, no matter what.      Equally Important      My main goal is to focus on quality of life and being comfortable.

---

**AT THE END OF LIFE**

Put an X along this line to show how you would feel if you were so sick that you may die soon.

My main goal is to live as long as possible, no matter what.      Equally Important      My main goal is to focus on quality of life and being comfortable.

If you want to write down why you feel this way, go to Page 10.

**PREPARE for your care** JOHNS HOPKINS

**Part 2: Make your own health care choices** Maryland Advance Health Care Directive

**What Matters Most in Life: Quality of life differs for each person. What is important to you?**

**AT THE END OF LIFE,** some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

At the end of life, which of these things would be very hard on your quality of life?

Check the things below that would make you want to focus on comfort rather than trying to live as long as possible.

- Being in a coma and not able to wake up or talk to my family and friends
- Not being able to live without being hooked up to machines
- Not being able to think for myself, such as dementia
- Not being able to feed, bathe, or take care of myself
- Not being able to live on my own
- Having constant, severe pain or discomfort
- Something else \_\_\_\_\_

OR, I am willing to live through all of these things for a chance of living longer.



Appendix N  
NJ POLST

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

**NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)**

Follow these orders, then contact physician/APN. This Medical Order Sheet is based on the current medical condition of the person referenced below and their wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

PERSON NAME (LAST, FIRST, MIDDLE)	DATE OF BIRTH			
<b>A</b>	<p><b>GOALS OF CARE</b> <i>(See reverse for instructions. This section does not constitute a medical order.)</i></p>			
<b>B</b>	<p><b>MEDICAL INTERVENTIONS:</b> <i>Person is breathing and/or has a pulse</i></p> <p><input type="checkbox"/> <b>Full Treatment.</b> Use all appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section D for resuscitation status.</p> <p><input type="checkbox"/> <b>Limited Treatment.</b> Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use noninvasive positive airway pressure. Generally avoid intensive care.</p> <p style="margin-left: 20px;"><input type="checkbox"/> Transfer to hospital for medical interventions.</p> <p style="margin-left: 20px;"><input type="checkbox"/> Transfer to hospital only if comfort needs cannot be met in current location.</p> <p><input type="checkbox"/> <b>Symptom Treatment Only.</b> Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures. Use oxygen, suctioning and manual treatment of airway obstruction as needed for comfort. Use Antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current location.</p> <p>Additional Orders: _____</p>			
<b>C</b>	<p><b>ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION:</b> <i>Always offer food/fluids by mouth if feasible and desired.</i></p> <p><input type="checkbox"/> No artificial nutrition.</p> <p style="margin-left: 300px;"><input type="checkbox"/> Defined trial period of artificial nutrition.</p> <p style="margin-left: 300px;"><input type="checkbox"/> Long-term artificial nutrition.</p>			
<b>D</b>	<table style="width:100%; border: none;"> <tr> <td style="width: 50%; border: none; vertical-align: top;"> <p><b>CARDIOPULMONARY RESUSCITATION (CPR)</b> <i>Person has no pulse and/or is not breathing</i></p> <p><input type="checkbox"/> Attempt resuscitation/CPR</p> <p><input type="checkbox"/> Do not attempt resuscitation/DNAR</p> <p><input type="checkbox"/> Allow Natural Death</p> </td> <td style="width: 10%; text-align: center; vertical-align: middle; border: none;">  </td> <td style="width: 40%; border: none; vertical-align: top;"> <p><b>AIRWAY MANAGEMENT</b> <i>Person is in respiratory distress with a pulse</i></p> <p><input type="checkbox"/> Intubate/use artificial ventilation as needed</p> <p><input type="checkbox"/> Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort.</p> <p><input type="checkbox"/> Additional Order (for example defined trial period of mechanical ventilation) _____</p> </td> </tr> </table>	<p><b>CARDIOPULMONARY RESUSCITATION (CPR)</b> <i>Person has no pulse and/or is not breathing</i></p> <p><input type="checkbox"/> Attempt resuscitation/CPR</p> <p><input type="checkbox"/> Do not attempt resuscitation/DNAR</p> <p><input type="checkbox"/> Allow Natural Death</p>		<p><b>AIRWAY MANAGEMENT</b> <i>Person is in respiratory distress with a pulse</i></p> <p><input type="checkbox"/> Intubate/use artificial ventilation as needed</p> <p><input type="checkbox"/> Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort.</p> <p><input type="checkbox"/> Additional Order (for example defined trial period of mechanical ventilation) _____</p>
<p><b>CARDIOPULMONARY RESUSCITATION (CPR)</b> <i>Person has no pulse and/or is not breathing</i></p> <p><input type="checkbox"/> Attempt resuscitation/CPR</p> <p><input type="checkbox"/> Do not attempt resuscitation/DNAR</p> <p><input type="checkbox"/> Allow Natural Death</p>		<p><b>AIRWAY MANAGEMENT</b> <i>Person is in respiratory distress with a pulse</i></p> <p><input type="checkbox"/> Intubate/use artificial ventilation as needed</p> <p><input type="checkbox"/> Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort.</p> <p><input type="checkbox"/> Additional Order (for example defined trial period of mechanical ventilation) _____</p>		
<b>E</b>	<p>If I lose my decision-making capacity, I authorize my surrogate decision maker, listed below, to modify or revoke the NJ POLST orders in consultation with my treating physician/APN in keeping with my goals: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><input type="checkbox"/> Health care representative identified in an advance directive <span style="margin-left: 150px;"><input type="checkbox"/> Other surrogate decision maker</span></p> <p>_____ Print Name of Surrogate (address on reverse) <span style="float: right;">Phone Number</span></p>			
<b>F</b>	<table style="width:100%; border: none;"> <tr> <td style="width: 50%; border: none; vertical-align: top;"> <p><b>SIGNATURES:</b> <i>I have discussed this information with my physician/APN.</i></p> <p>Print Name _____</p> <p>Signature _____</p> <p><input type="checkbox"/> Person Named Above</p> <p><input type="checkbox"/> Health Care Representative/Legal Guardian</p> <p><input type="checkbox"/> Spouse/Civil Union Partner</p> <p><input type="checkbox"/> Parent of Minor</p> <p><input type="checkbox"/> Other Surrogate</p> </td> <td style="width: 50%; border: none; vertical-align: top;"> <p>Has the person named above made an anatomical gift: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p><i>These orders are consistent with the person's medical condition, known preferences and best known information.</i></p> <p>_____ PRINT - Physician/APN Name <span style="float: right;">Phone Number</span></p> <p>_____ Physician/APN Signature (Mandatory) <span style="float: right;">Date/Time</span></p> <p>_____ Professional License Number</p> </td> </tr> </table>	<p><b>SIGNATURES:</b> <i>I have discussed this information with my physician/APN.</i></p> <p>Print Name _____</p> <p>Signature _____</p> <p><input type="checkbox"/> Person Named Above</p> <p><input type="checkbox"/> Health Care Representative/Legal Guardian</p> <p><input type="checkbox"/> Spouse/Civil Union Partner</p> <p><input type="checkbox"/> Parent of Minor</p> <p><input type="checkbox"/> Other Surrogate</p>	<p>Has the person named above made an anatomical gift: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p><i>These orders are consistent with the person's medical condition, known preferences and best known information.</i></p> <p>_____ PRINT - Physician/APN Name <span style="float: right;">Phone Number</span></p> <p>_____ Physician/APN Signature (Mandatory) <span style="float: right;">Date/Time</span></p> <p>_____ Professional License Number</p>	
<p><b>SIGNATURES:</b> <i>I have discussed this information with my physician/APN.</i></p> <p>Print Name _____</p> <p>Signature _____</p> <p><input type="checkbox"/> Person Named Above</p> <p><input type="checkbox"/> Health Care Representative/Legal Guardian</p> <p><input type="checkbox"/> Spouse/Civil Union Partner</p> <p><input type="checkbox"/> Parent of Minor</p> <p><input type="checkbox"/> Other Surrogate</p>	<p>Has the person named above made an anatomical gift: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p><i>These orders are consistent with the person's medical condition, known preferences and best known information.</i></p> <p>_____ PRINT - Physician/APN Name <span style="float: right;">Phone Number</span></p> <p>_____ Physician/APN Signature (Mandatory) <span style="float: right;">Date/Time</span></p> <p>_____ Professional License Number</p>			

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

---

PRINT PERSON'S NAME (LAST, FIRST, MIDDLE) DATE OF BIRTH

---

PRINT PERSON'S ADDRESS

---

CONTACT INFORMATION

---

PRINT SURROGATE HEALTH CARE DECISION MAKER ADDRESS PHONE NUMBER

**DIRECTIONS FOR HEALTH CARE PROFESSIONAL**

**COMPLETING POLST**

- Must be completed by a physician or advance practice nurse.
- Use of original form is strongly encouraged. Photocopies and faxes of signed POLST forms may be used.
- Any incomplete section of POLST implies full treatment for that section.

**REVIEWING POLST**

POLST orders are actual orders that transfer with the person and are valid in all settings in New Jersey. It is recommended that POLST be reviewed periodically, especially when:

- The person is transferred from one care setting or care level to another, or
- There is a substantial change in the person's health status, or
- The person's treatment preferences change.

**MODIFYING AND VOIDING POLST** - *An individual with decision making capacity can always modify/void a POLST at any time.*

- A surrogate, if designated in Section E on the front of this form, may, at any time, void the POLST form, change his/her mind about the treatment preferences or execute a new POLST document based upon the person's known wishes or other documentation such as an advance directive.
- A surrogate decision maker may request to modify the orders based on the known desires of the person or, if unknown, the person's best interest.
- To void POLST, draw a line through all sections and write "VOID" in large letters. Sign and date this line.

**SECTION A**

What are the specific goals that we are trying to achieve by this treatment plan of care? This can be determined by asking the simple question: "What are your hopes for the future?" Examples include but not restricted to:

- Longevity, cure, remission
- Better quality of life
- Live long enough to attend a family event (wedding, birthday, graduation)
- Live without pain, nausea, shortness of breath
- Eating, driving, gardening, enjoying grandchildren

*Medical providers are encouraged to share information regarding prognosis in order for the person to set realistic goals.*

**SECTION B**

- When "limited treatment" is selected, also indicate if the person prefers or does not prefer to be transferred to a hospital for additional care.
- IV medication to enhance comfort may be appropriate for a person who has chosen "symptom treatment only."
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), or bi-level positive airway pressure (BiPAP).
- Comfort measures will always be provided.

**SECTION C**

Oral fluids and nutrition should always be offered if medically feasible and if they meet the goals of care determined by the person or surrogate. The administration of nutrition and hydration whether orally or by invasive means shall be within the context of the person's wishes, religion and cultural beliefs.

**SECTION D**

Make a selection for the person's preferences regarding CPR and a separate selection regarding airway management. A defined trial period of mechanical ventilation may be considered, for example, when additional time is needed to assess the current clinical situation or when the expected need would be short term and may provide some palliative benefit.

**SECTION E**

This section is applicable in situations where the person has decision making capacity when the POLST form is completed. A surrogate may only void or modify an existing POLST form, or execute a new one, if named in this section by the person.

**SECTION F**

POLST must be signed by a practitioner, meaning a physician or APN, to be valid. Verbal orders are acceptable with follow-up signature by physician/APN in accordance with facility/community policy. POLST orders should be signed by the person/surrogate. Indicate on the signature line if the person/surrogate is unable to sign, declined to sign, or a verbal consent is given. Remind the person/surrogate that once completed and signed, this POLST will void any prior POLST documents.

**SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED**

Appendix O  
Advance Directive at [REDACTED]

## ADVANCE DIRECTIVES

### INTRODUCTION

*The decision to fill out an advance directive is your choice. Your medical care does not depend on whether or not you complete an advance directive. Please consider your advance directive choices carefully. It is important that you fully understand its meaning and what treatment you will receive as a result of it. Please note that this form goes into effect only if you are unable to make your own healthcare decisions.*

*This four (4) page form has four (4) parts.*

- 1. A part where you choose a medical decision maker who can make health care decisions for you if you are too sick to make them yourself. These persons are known as Health Care Representatives or Proxies.*
- 2. A part where you make your own choices about the kind of health care you want, so that those that care for you do not have to guess what you want if you are too sick to tell them yourself. These written choices are called Instructive Directives or Living Wills.*
- 3. A part where you can choose to donate your organs or tissues from your body after your death.*
- 4. A place to sign the form, and to have it witnessed or notarized.*

*You may complete **either** or **both** the first and second parts; you **MUST** complete the signature portion of this document. If you chose not to complete a section please draw an "X" through that part.*

### PART 1

#### HEALTH CARE REPRESENTATIVE (Durable Medical Power of Attorney / Health Care Proxy)

*As a competent adult you have the right to make decisions about your health care. There may come a time when you are unable, due to physical or mental disability (incapacity), to make your own health care decisions. If this happens, those caring for you will need direction and they will turn to someone who you trust and who knows your values and health care wishes. By writing this document, you appoint a health care representative (proxy) with the legal authority to make health care decisions on your behalf after speaking with your physician.*

This document allows my Health Care Representative (also known as a medical power of attorney or proxy) to make any and all healthcare decisions for me, including the decision to accept or refuse any treatment, service, or procedure used to diagnose or treat my physical or mental condition; and the decision to withhold or withdraw life-sustaining medical treatment, to include a "Do Not Resuscitate" or "Allow Natural Death" medical order. I direct that my Health Care Representative make decisions on my behalf consistent with my wishes as stated in this document, or if it is not stated in this document then as otherwise known to him/her. In the event that my wishes are not clear, my Health Care Representative is authorized to make decisions that he/she feels are in my best interest based upon the medical information that is provided by the health care team. I direct that this document become part of my permanent medical record.



This durable power of attorney for healthcare shall take effect in the event that I become unable to make my own health care decisions as determined by the physician who has primary responsibility for my care.

I hereby designate \_\_\_\_\_ (proxy's name)  
as my Health Care Representative.

Relationship: \_\_\_\_\_ Telephone number(s): \_\_\_\_\_

Address: \_\_\_\_\_

Other contact information (email, text number, etc.): \_\_\_\_\_

If the person named above is unable to act as my Health Care Representative, I designate the following person(s), in the order listed below, to do so:

1. \_\_\_\_\_ (alternate proxy's name)

Relationship: \_\_\_\_\_ Telephone number(s): \_\_\_\_\_

Address: \_\_\_\_\_

Other contact information (email, text number, etc.): \_\_\_\_\_

2. \_\_\_\_\_ (alternate proxy's name)

Relationship: \_\_\_\_\_ Telephone number(s): \_\_\_\_\_

Address: \_\_\_\_\_

Other contact information (email, text number, etc.): \_\_\_\_\_

3. \_\_\_\_\_ (alternate proxy's name)

Relationship: \_\_\_\_\_ Telephone number(s): \_\_\_\_\_

Address: \_\_\_\_\_

Other contact information (email, text number, etc.): \_\_\_\_\_

**PART 2**

**INSTRUCTIVE DIRECTIVE (Living Will)**

I, \_\_\_\_\_ (name), \_\_\_\_\_ (date of birth),  
being of sound mind make this statement as a directive to be followed if for any reason I become unable to participate in the decision-making regarding my health care.

I have initialed the statement(s) below with which I agree (select A or B).

A. \_\_\_\_ If my condition becomes so serious that there is no reasonable chance of my recovery or having a meaningful quality of life, I want to be kept comfortable. I do not want any life prolonging measures that will not cure or reverse my condition. This may include (1) an incurable and irreversible condition that will result in death within a short period of time; or (2) being unconscious with no reasonable chance of regaining consciousness.

I understand that life prolonging procedures or treatments could include:

- a. **Cardio-Pulmonary Resuscitation (CPR)** that may involve pressing extremely hard on my chest to keep blood pumping, electrical shocks to jump start my heart, and emergency medicines in my veins.
- b. **Breathing machine / ventilator** that pumps air into my lungs and breathes for me. I will not be able to talk when on this machine.
- c. **Dialysis** – a machine that cleans my blood if my kidneys stop working.
- d. **Artificial fluids and/or nutrition (feeding tube)**, which may include a tube placed down my throat into my stomach, or placed surgically into my digestive tract, to give me nutrition when I can no longer swallow.
- e. **Blood transfusions** that would put blood / blood products in my veins.
- f. **Surgery.**
- g. **Radiation treatments.**
- h. **Medicines** to prolong life (including chemotherapy drugs and medicines for my heart).

I do not want life prolonging measures to be started or if they have been started, they should be stopped. I prefer a natural death, with care that focusses on my dignity and comfort.

B.  I direct that all measures and/or treatments be provided to prolong my life regardless of my condition.

Additional comments or instructions: \_\_\_\_\_

**PART 3**

**ORGAN / TISSUE DONATION**

Donating my organs and/or tissues after I die can help improve and even save the lives of others. If I choose to be a donor I initial below.

Upon my death I am willing to donate any part(s) of my body that may benet others.

**PART 4**

**SIGNATURE**

By writing this durable power of attorney for health care and/or instructive directive, I am informing those caring for me of my wishes regarding my health care. I have discussed these wishes with my Health Care Representative(s) and trust their judgement on my behalf. My Health Care Representative(s) is willing to accept this responsibility and carry out my wishes. I understand the purpose and effect of this document and sign it knowingly, voluntarily, and after careful consideration.

Signed On This: \_\_\_\_\_ Day of: \_\_\_\_\_ 20 \_\_\_\_ Time: \_\_\_\_\_

Signature: \_\_\_\_\_ Print Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

*You must have either two witnesses, OR a notary or an attorney-at-law in the State of New Jersey, sign below in order to validate this document.*

WITNESSES: I declare that the person who signed this document did so in my presence; he/she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as this person's Health Care Representative.

WITNESS:  
Signature: \_\_\_\_\_

WITNESS:  
Signature: \_\_\_\_\_

Print Name: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_

## ADDITIONAL INFORMATION

### Who should I choose as my Health Care Representative?

Your Health Care Representative should be someone who knows you very well, and who you trust to make serious medical decisions for you. A family member or good friend may be the best choice, but sometimes intense emotions can make it hard a loved-one to make difficult decisions. Choose the person who knows your values, will respect your wishes, and will be able to make sure your wishes are followed.

Remember, the person you choose as your Health Care Representative (or as alternate(s)) cannot be one of the witnesses signing this document.

### What if I change my mind?

If you change your mind about anything in this document, including your Health Care Representative or your Instruction Directive (Living Will) choices, you can do any or all of the following:

- Tell your doctor or nurse and let them write down your current wishes
- Destroy all copies of this document
- Complete a new Advance Directive document

### Does this document direct my care in a medical emergency?

This Advance Directive document will **not** be helpful in a medical emergency. In an emergency, first responders and care providers in the Emergency Department **MUST** provide life-sustaining treatment (like CPR) **UNLESS** they are given separate instructions, like a **NJ Practitioner Orders for Life-Sustaining Treatment (POLST)** form. A POLST form, completed by you and your physician/Advance Practice Nurse, can direct the type of care you wish to receive in a medical emergency. Please contact your physician/ APN for more information.

### What do I do now with this Advance Directive document?

Give a copy of this document to your doctor, Health Care Representative, and any other persons involved in your care. Your health care team will include this Advance Directive in your medical chart. Keep the original in a secure but easily accessible place – so that loved-ones or your Health Care Representative can find it in an emergency.

Appendix P

Pocket Guide to Advance Care Planning Conversations

<b>Advance Care Planning (ACP) Guide to ACP Conversations</b>	<b>The ID3 Framework for ACP Conversations: Introduce, Discuss, Decide, Document</b>										
<p><b>ACP conversations:</b></p> <ul style="list-style-type: none"> <li>• Prepare patients for future health care decisions by exploring their values, beliefs, goals, and preferences</li> <li>• Help patients decide on a surrogate decision maker (SDM) and engage the SDM in the ACP process</li> <li>• Are for everyone, not just the seriously ill</li> <li>• Do <b>not</b> require decisions be made after just one discussion</li> <li>• Are <b>not</b> just about resuscitation orders</li> </ul>	<p><b>1. Introduce:</b></p> <ul style="list-style-type: none"> <li>• Seek permission: “Can we talk about where things are with your health and where things might be going?”*</li> <li>• Explain ACP’s rationale and that the patient’s decisions can be revised as their health/life situation changes.</li> </ul>										
<p style="text-align: center;"><b>Triage ACP conversations according to life situation:</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 20%; text-align: center;"><b>Well patient</b></td> <td>Full, focused ACP discussion triggered by life events (e.g., marriage, pregnancy, new job); emphasize choosing an SDM</td> </tr> <tr> <td style="text-align: center;"><b>Patient with chronic disease</b></td> <td>Full ACP discussion at regular intervals and following medical events (e.g., new diagnosis, discharge from hospital)</td> </tr> <tr> <td style="text-align: center;"><b>Patient with acute ↓ in health</b></td> <td>Revisit the ACP discussion with the patient or SDM emphasizing immediate or anticipated health care decisions</td> </tr> </table>	<b>Well patient</b>	Full, focused ACP discussion triggered by life events (e.g., marriage, pregnancy, new job); emphasize choosing an SDM	<b>Patient with chronic disease</b>	Full ACP discussion at regular intervals and following medical events (e.g., new diagnosis, discharge from hospital)	<b>Patient with acute ↓ in health</b>	Revisit the ACP discussion with the patient or SDM emphasizing immediate or anticipated health care decisions	<p><b>2. Discuss:</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; padding: 5px;"> <p><b>Understanding:</b> “How much do you (and/or your family) know about your illness? What information would you like from me?”*</p> </td> <td style="width: 50%; padding: 5px;"> <p><b>Goals:</b> “What are the most important things you want to do in life?” “What are some abilities in life you can’t do without?”*</p> </td> </tr> <tr> <td style="padding: 5px;"> <p><b>Fears:</b> “What are your biggest fears and worries about your health? About life in general?”*</p> </td> <td style="padding: 5px;"> <p><b>Trade-offs:</b> “If you get sicker, what health care services are you willing to endure to gain more time?”*</p> </td> </tr> </table>	<p><b>Understanding:</b> “How much do you (and/or your family) know about your illness? What information would you like from me?”*</p>	<p><b>Goals:</b> “What are the most important things you want to do in life?” “What are some abilities in life you can’t do without?”*</p>	<p><b>Fears:</b> “What are your biggest fears and worries about your health? About life in general?”*</p>	<p><b>Trade-offs:</b> “If you get sicker, what health care services are you willing to endure to gain more time?”*</p>
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<b>Patient with chronic disease</b>	Full ACP discussion at regular intervals and following medical events (e.g., new diagnosis, discharge from hospital)										
<b>Patient with acute ↓ in health</b>	Revisit the ACP discussion with the patient or SDM emphasizing immediate or anticipated health care decisions										
<p><b>Understanding:</b> “How much do you (and/or your family) know about your illness? What information would you like from me?”*</p>	<p><b>Goals:</b> “What are the most important things you want to do in life?” “What are some abilities in life you can’t do without?”*</p>										
<p><b>Fears:</b> “What are your biggest fears and worries about your health? About life in general?”*</p>	<p><b>Trade-offs:</b> “If you get sicker, what health care services are you willing to endure to gain more time?”*</p>										
<p><b>Remember:</b></p> <ul style="list-style-type: none"> <li>• <b>Check</b> for and review previous ACP conversations</li> <li>• <b>Follow up</b> over time to better understand patient’s context and monitor changes in patient’s health status and decisions</li> </ul>	<p><b>3. Decide:</b> Decide on an SDM and on patient-centred principles of care. Reaching a decision may require multiple visits, depending on urgency.</p>										
<p>Compiled and prepared by the CFPC Section of Residents (2017) Key references and resources: <a href="http://www.cfpc.ca/sectionofresidents_training_guides/">http://www.cfpc.ca/sectionofresidents_training_guides/</a> © 2018 The College of Family Physicians of Canada</p>	<p><b>4. Document:</b> Document the discussion and encourage your patient to record their wishes (i.e., SDM, values) in a formal document. Complete province-specific ACP documents.</p> <p><small>*Adapted from the <i>Serious Illness Conversation Guide</i>, licensed under the Creative Commons Attribution NonCommercial-ShareAlike 4.0 International License, <a href="http://creativecommons.org/licenses/by-nc-sa/4.0/">http://creativecommons.org/licenses/by-nc-sa/4.0/</a>.</small></p>										

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<http://creativecommons.org/licenses/by-nc-sa/4.0/>

From: The College of Family Physicians of Canada. (2018). *Guide to advance care planning discussions*. Mississauga, ON: College of Family Physicians of Canada.

Appendix Q

Goals of Care Coalition of New Jersey’s 4Step iCare Plan – HCP Conversation Assistant



The 4Step iCare Plan is an individualized, simple, 4-step approach to help patients make difficult medical decisions. Patients and families often need help with decision-making when facing life-threatening illness. This is particularly true for minority populations who may experience various language and cultural barriers to end-of-life care. In NJ, there is a very diverse population of patients and healthcare providers, which can increase the risk for cultural misunderstandings that can affect the quality of communication.

It can help to practice “cultural humility” and to approach each patient as an individual with unique life experiences and values that may influence their perspective on end-of-life care. A patient’s ethnicity, race, religion, and other social factors may influence their views on end-of-life care. Of course, patients and their families may have their own biases, depending on their background and past experiences with the healthcare system. It may be helpful to point out that everyone involved has the shared aim of providing treatment that reflects the patient’s wishes and goals of care.

**The 4Step iCare Plan will guide you and your patients through a conversation about Advance Care Planning. The goal is to ensure that your patients understand their diagnosis (Step 1), understand their prognosis (Step 2), and express their goals (Step 3), so that you can recommend a course of treatment that aligns with their wishes (Step 4).**



**Step 1**

**Share the patient’s diagnosis**

- › Be aware of communication styles and family dynamics. Is the patient comfortable talking to you? Ask if there’s a friend or family member whom you should talk to as well.
- › When sharing a difficult diagnosis, provide some warning (e.g., “Unfortunately, I have bad news...”).
- › Don’t use medical jargon.
- › Ask open ended questions and avoid “yes or no” questions to gauge a patient’s understanding.



**Step 1: Understand Diagnosis**

**Ask your healthcare provider:**

- › What is my diagnosis? (What is my illness or condition?)
- › Are there other medical problems I need to consider?
- › Do you have additional information on my condition?

NOTES: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Step 2**

**Share the patient’s prognosis**

- › Ask questions to determine how well the patient/family understands the prognosis.
- › Remember, nonverbal communication is very important and varies across cultures.
- › You may want to ask, “How much detail will be helpful as we discuss this condition and the treatment options?” “What is your understanding of the situation and how long you might live with this condition?”



**Step 2: Discuss the Prognosis**

**Ask your healthcare provider:**

- › What is my prognosis, how will my condition affect my future?
- › How much time will I have?
- › Will I be able to do my favorite activities and live independently?
- › Will I have pain or trouble sleeping?
- › How will the time I have or the quality of that time change with or without aggressive medical treatment?

NOTES: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Step 3

### Identify the patient's goals of care

- › Recognize that a patient's religion, ethnicity, and family dynamics can significantly influence their values and goals.
- › Realize that with some patients or their families there may be a degree of mistrust based on previous experiences with the healthcare system.
- › You may want to ask, "Given the prognosis, what is most important to you during this time?" "Are there specific goals you'd like to accomplish or events to attend?" "At what point might you consider shifting your focus to comfort and quality of life?"

#### KEY FACTS:

NJ has the most ethnically diverse healthcare provider population and the 3rd most diverse patient population in the US. It is important for all engaged in end-of-life conversations to be mindful that ethnic or cultural differences can lead to misunderstanding or seeming insensitivity based on lack of awareness.

### 3

#### Step 3: Identify Goals of Care

##### Tell your healthcare provider:

- › What matters most to you at this time?
- › How important is it for you to remain at home?
- › How much quality of life are you willing to sacrifice to live longer?
- › How important is it for you to remain comfortable and avoid unpleasant treatments?
- › At what point would you want to avoid aggressive treatment and focus on the best quality of life?

NOTES: \_\_\_\_\_

**Step 4**

**Align treatment with the patient's goals**

- > You may want to say “Based on what’s important to you, this is what I recommend...”
- > Ask clarifying questions as necessary to ensure understanding by the patient and family.
- > Remember to use short clear sentences avoiding medical jargon.
- > If the time is appropriate, you may want to discuss a POLST (Practitioner Order for Life-Sustaining Treatment) form with the patient and the family. A form can be downloaded at [goalsofcare.org](http://goalsofcare.org).

**4**

**Step 4: Align Treatment**

**Ask your healthcare provider:**

- > What are the treatment options given my prognosis and goals of care?
- > What are the benefits and risks of these options?
- > What other treatments are there or which doctors I should consult?
- > What treatments or medications are no longer necessary?
- > Under what circumstances would returning to the hospital be necessary?
- > To what extent would beginning or continuing artificial nutrition (feeding tube) and hydration (IV fluids) align with my goals?
- > What are my chances of surviving cardiopulmonary resuscitation (CPR) and how would emergency procedures like that help me achieve my goals of care?
- > Is a NJ POLST\* form appropriate for me at this time?

NOTES: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**KEY FACTS:**

Being mindful of a patient's communication preferences and fostering a culturally-sensitive conversation about end-of-life care will lead to more accurate planning and documentation of medical preferences.

To further help patients, Goals of Care Coalition of NJ created a series of videos guiding them through each step:

 [goalsofcare.org/patients-family/4step-icare-plan](http://goalsofcare.org/patients-family/4step-icare-plan)

Patients and HCPs can also download the 4Step iCare Plan and the HCP Conversation Assistant online at:

 [goalsofcare.org/patients-family/4step-icare-plan](http://goalsofcare.org/patients-family/4step-icare-plan)

Appendix R

Gantt chart of Project Timeline

Key Steps	January – May 2019	June 2019	July 15th 2019	August 2019	September 2019	October 2019	December 2019
ACP Data Collection through research and educational requirements							
Recruitment Flyers							
ACP Educational Workshops							
Data collection pre-educational intervention							
Data collection pre- and post-test							
Data collection post educational intervention							

Appendix S

Paired Sample *t*-test Results

**Paired Samples Statistics**

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	pretest	30.5333	30	5.81753	1.06213
	posttest	39.4667	30	7.47748	1.36519

**Paired Samples Correlations**

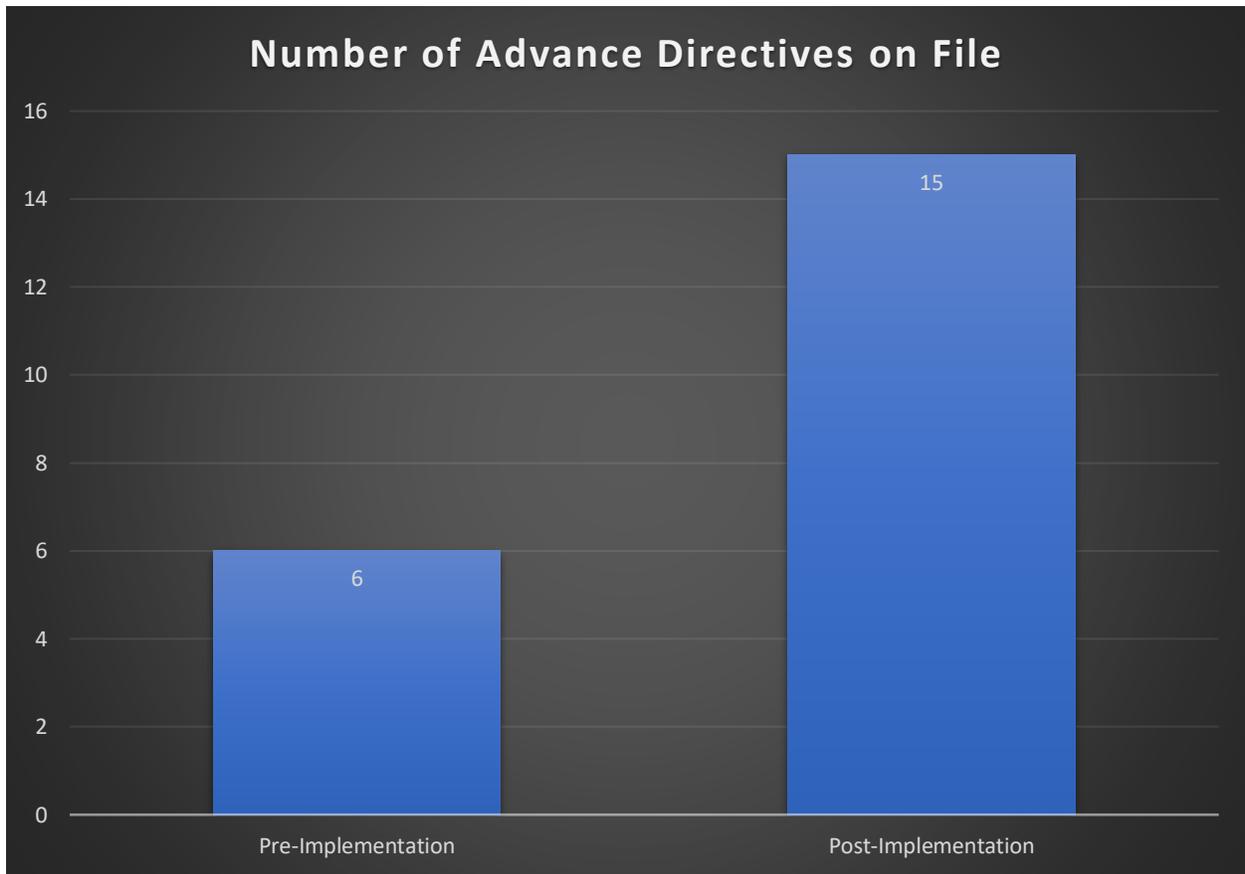
		N	Correlation	Sig.
Pair 1	pretest & posttest	30	.433	.017

**Paired Samples Test**

		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		t	df	Sig. (2-tailed)
Paired Differences					Lower	Upper			
Pair 1	pretest - posttest	-8.93333	7.21556	1.31738	-11.62767	-6.23900	-6.781	29	.000

Appendix T

Number of Advance Directive Pre and Post Implementation



Appendix U

Pearson Chi-Square Test Results

**Case Processing Summary**

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Implementation * Outcome	24	100.0%	0	0.0%	24	100.0%

**Implementation \* Outcome Crosstabulation**

Count

		Outcome		Total
		AD on file	No AD on file	
Implementation	Pre-implementation	6	1	7
	Post-implementation	15	2	17
Total		21	3	24

**Chi-Square Tests**

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.029 <sup>a</sup>	1	.865		
Continuity Correction <sup>b</sup>	.000	1	1.000		
Likelihood Ratio	.028	1	.867		
Fisher's Exact Test				1.000	.664
Linear-by-Linear Association	.028	1	.868		
N of Valid Cases	24				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is .88.

b. Computed only for a 2x2 table