Spring 5-12-2023

IMPROVING ADVANCE DIRECTIVE DOCUMENTATION IN A PRIMARY CARE CLINIC IN THE MIDWEST

Teresa Hagedorn
Pittsburg State University, thagedorn@gus.pittstate.edu

Recommended Citation

Hagedorn, Teresa, "IMPROVING ADVANCE DIRECTIVE DOCUMENTATION IN A PRIMARY CARE CLINIC IN THE MIDWEST" (2023). *Doctor of Nursing Practice Scholarly Project*. 88.
https://digitalcommons.pittstate.edu/dnp/88

IMPROVING ADVANCE DIRECTIVE DOCUMENTATION IN A PRIMARY CARE CLINIC IN THE MIDWEST

A Scholarly Project Submitted to the Graduate School in Partial Fulfillment of the
Requirements for the Degree of Doctor of Nursing Practice

Teresa Gayle Hagedorn

Pittsburg State University

Pittsburg, Kansas

May 2023

Acknowledgments

I want to express my greatest gratitude to Dr. Greg Belcher, Dr. Gena Coomes, and Dr. Janis Schiefelbein for their time, expertise, and commitment to this Quality Improvement project. I would also like to thank Cox Health Care for allowing me to complete my project within their facility, with a special mention to Autumn Freiburger (Clinic Manager), Melissa Hitchcock (FNP-C), and Shane Reichert (Informatics Manager). Lastly, I would like to thank my husband and the rest of my family for their support and understanding throughout this three-year journey.

IMPROVING ADVANCE DIRECTIVE DOCUMENTATION IN A PRIMARY CARE CLINIC IN THE MIDWEST

An Abstract of the Scholarly Project by
Teresa Gayle Hagedorn

Advance care planning (ACP) is a continuous communication process linking patients, family members, caregivers, and healthcare providers. Personal values, life goals, and preferences regarding future medical care are significant to every person as we will inevitably reach the end of life. Advance directives (ADs) promote patient autonomy and provide legal documentation of a patient's wishes for future care. According to the National Institute of Health (2018), only 1 in 3 adults in the United States have a documented AD in their electronic medical records (EMR). This quality improvement project aimed to determine if ACP discussions initiated in a primary care clinic in the Midwest would increase the percentage of documented ADs in the EMR. The patients of one provider in a rural clinic were randomly chosen to receive an intervention discussing ADs, and patients were given time to ask questions. The intervention period was over six months. The data from 200 random charts were examined to determine if the intervention increased the percentage of patients' charts with ADs. The intervention results did not show a significant increase in the rate of charted ADs. However, the opportunity for the provider to initiate the topic and provide evidence-based AD education cannot be discounted entirely.

TABLE OF CONTENTS

Contents

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Advanced care planning (ACP), as defined by a multidisciplinary Delphi Panel, is a process that supports adults at any age or stage of health in understanding and sharing their values, life goals, and preferences regarding future medical care (Sudore et al., 2017). This chapter has two focuses. The first focus is introducing ACP and the purpose of the project. The second focuses on the theoretical framework and logic model used to guide the project.

The evolution of ACP started with the first AD proposed by Luis Kutner in 1967. Mr. Kutner's "living will" document allowed a person to specify under what conditions life-support systems should be discontinued (Knight, 2021). Barry Keene introduced living will legislation in 1976, and California became the first state to sanction living wills legally. By 1992, all 50 states had passed legislation to legalize some form of AD (Hecht & Shiel, 2004). In 1990 the United States Supreme Court was involved in the infamous Cruzan vs. Director, Missouri Department of Health hearing. Nancy Cruzan was a 25-year-old southwest Missouri woman thrown from her car in 1983. She lay in a vegetative state until her parents petitioned to be allowed to order the termination of her artificially administered hydration and nutrition. The court ruled that individuals had the right to refuse medical treatments that could prolong their lives, including feeding tubes.

The last significant piece of legislation involving ACP was in 1991 with the introduction of the Patient Self- Determination Act (PSDA). The PSDA specifies that all hospitals receiving Medicaid or Medicare reimbursement must ascertain whether patients have or wish to have advanced directives (Patient Self Determination Act, 1990).

Unfortunately, the court's decision came too late for some individuals, or the victims' families still had to suffer long battles in court fighting for what their loved ones wanted. Karen Ann Quinlan was 21 years old in 1975 when she passed out and stopped breathing for an extended time after partying with some friends. It was later determined that she was vegetative and would never regain normal function. Quinlan's father wished to remove her from the ventilator because Karen had verbalized that she did not want to live in a state where she had to have assistive devices. However, her physician and the facility both refused his request. Mr. Quinlan hired an attorney and filed suit. The case was lost, and Karen remained ventilated until March of 1976 when the Supreme Court of New Jersey held that he could authorize the cessation of the ventilator and the hospital must comply. Quinlan continued to breathe until 1985 when she contracted pneumonia. This case is credited with creating formal hospital ethics committees (CDC, 2023).

In 1990, Terri Schiavo collapsed after suffering a cardiac arrest. She was later diagnosed as being in a persistent vegetative state. In 1998, her husband petitioned the courts in Florida to remove her feeding tube, stating that she had verbalized not wanting extra lifesaving measures if she was in a vegetative state. Mrs. Schiavo's parents fought her husband in court not to remove her feeding tube, hoping she would someday regain consciousness. The court agreed with Terri's husband and ordered the feeding tube removed. Sadly, the case did not end there. Multiple groups and prominent individuals pushed back against the court's decision, and the feeding tube was reinserted four days later. Ultimately the original court's decision was upheld, and in March 2005, Mrs. Schiavo died. This case was unfortunate, having the PSDA signed into law in 1991.

Since the PSDA and the court enactment, more needs to be accomplished in healthcare to support patients with the end-of-life (EOL) care they desire. End-of-life care and ACP resurfaced in 2008. The Office of the Assistant Secretary for the U. S. Department of Health and Human Services released the *Advance Directives and Advance Care Planning: Report to Congress.* The report listed three key findings:

- Effective ACP is an ongoing process best accomplished through continuing communication among individuals, clinicians, and family members.
- Interventions for ACP can be carried out successfully and promise improvement.
- ACP must shift from an emphasis on formal written ADs to a developing discussion process.

Today the state of Missouri, where the project was completed, has a defined "Right to Life" policy on durable powers of attorney (DPOA) for healthcare decisions, ADs, and wills to live. The DPOA for healthcare decisions is defined in Missouri as someone who will advocate for a patient with the healthcare system when they can no longer express themselves (Mo.Rev.Stat 404.800-.872). Missouri law on ADs specifies that a person may be deprived of medical care and treatment that would keep the person alive when unconscious only if there is clear and convincing evidence that the person stated his or her wishes to be deprived in advance. Missouri's living will document is the "Health Care Choices Directive." This living will becomes effective only when the declarant's condition is terminal and the declarant does not have the capacity to make healthcare decisions (Mo.Rev.Stat 459.025). For an AD to be recognized in Missouri, your signature must be notarized, and two witnesses must sign. These witnesses cannot be related to you or financially connected to your estate. A do not resuscitate (DNR) only applies when the patient's heart or breathing has stopped. This form m, must be completed in Missouri with a doctor who will counter-sign the documents. This document is maintained in the chart and is only applicable inside the hospital. If the patient wants the DNR to continue, an out of hospital do not resuscitate (OOH-DNR) is needed. This form also needs to be signed by a physician.

Significance

Quality improvement is a necessary constant in healthcare. Building on the existing knowledge surrounding advance directives has implications for everyone involved in EOL care. The responsibility for improvement lies with patients, their families, healthcare providers, and communities.

Patient and Family Significance

Advanced care planning enables patients and families to make informed healthcare decisions and improves the quality of care and patient outcomes. According to ACP Decisions Organization (2023), many evidence-based benefits exist for patients and families with a plan in place.

- Promotes patient-centered care by focusing on patients' preferences about their treatments.

- Helps ensure that patients receive care that is consistent with their preferences.
- Raises the likelihood that families understand and comply with personal preferences.
- Increases the probability that patients with life-limiting illnesses can die in their preferred place.
- Allows caregivers to proactively arrange for patients to remain home rather than go to a hospital.
- Reduces the burdens of decisions for families.
- Improves the bereavement experience of families by reducing stress, anxiety, and depression after loved ones’ death.
- Enhances families’ satisfaction with EOL care and understanding what to expect during the dying process.
- Prevents unwanted hospitalizations and increases the use of palliative and hospice services.
- Diminishes the use of aggressive treatments at the EOL. Reduces the cost of EOL care without increasing mortality.
- Promotes higher completion rates of ADs.
- Improves EOL care for those with dementia by allowing them to express their preferences before cognitive decline.
- Improves population health because of increased goal-oriented care.

The benefits of ACP cannot be overstated; however, many patients are not allowed to express their EOL choices when they feel well enough to process the information. According to the Institute of Medicine [IOM] (2014), ACP discussions rarely occur because providers, patients, and their families expect the other person to introduce them. The age group most affected by the challenges of the current system in place for ACP is the elderly.

Significance to Society

Planning and implementation of EOL care can prevent unnecessary financial hardships in communities by alleviating unnecessary costs associated with unwanted medical treatments and increased use of palliative services. The elderly population is increasing significantly in the United States (US). The Federal Interagency Forum on Aging-related Statistics (2020) states that by 2030, more than 20% of US residents are projected to be 65 or older, and 2.6% are expected to be 85 or older. Compare that with statistics in 1970, only 9.9% of the population was 65 or older, and only 0.7% was 85 or older. According to the National Association of Chronic Diseases (2012), approximately 5% of Medicare beneficiaries will die in any given year, accounting for about 25% of the total Medicare spending. To bring this amount into perspective, in 2018, Medicare part A and part B combined had a total of $404.7 billion in gross fee-for-service spending (Centers for Medicare and Medicaid [CMS], 2018). According to *Daily Caring* (2021), for chronically ill elderly patients, there is less than a 5% chance of survival after a resuscitation attempt in the hospital.

Nursing Significance

The American Nursing Association [ANA] (2010) Code of Ethics Provision 1.4 describes the significance of ACP:

> Patients have the moral and legal right to determine what will be done with and to their person; to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; and to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment.

Despite healthcare's best efforts, many patients at risk for a medical crisis are not identified promptly (Hadley, 2020). Advanced practice nurses (APRNs) are increasingly used in various healthcare settings, including primary care. In 2015, to help mitigate the rising costs in the last few years of life, CMS instituted a reimbursement plan for clinicians that provide ACP consultations with their patients (Carr & Luth, 2017). Advocates of the new legislation say that this rule will encourage clinicians to make time for these lengthy discussions and assist patients when considering EOL choices (The Hospitalist, 2015). With bedside nursing skills and advanced education, APRNs are in a prime position to drive ACP discussions (Goswami et al., 2020).

Description of the Clinical Problem

Too often, patients cannot advocate for themselves due to illness upon hospital admission. This leaves family members making difficult EOL decisions if an AD is not in place or cannot be located (Pirinea et al., 2016). A low percentage of individuals have discussed their wishes with family or close friends (The Conversation Project, 2022). A meta-analysis of sixteen studies examining the accuracy of next-of-kin knowing patients' EOL wishes was found to be 68% (Shalowitz, Garett-Mayer, & Wendler, 2006). Family members can become overwhelmed emotionally and financially.

Various barriers have been noted throughout the literature as to why healthcare is not seeing an increase in the percentage of patients completing documented ADs. Barriers include thinking an AD is unnecessary, not wanting to think about death or burdening people, not knowing enough about ADs and associated forms, and lack of time with the doctor. Primary care providers can and should address all of the listed barriers regularly. Primary care offices provide an atmosphere of trust between providers and the patient population that has developed over months to years. Primary care providers should capitalize on multiple appointments to discuss EOL care in tandem with other healthy lifestyle habits that are routinely repeated to solidify the significance of holistic care.

Purpose

The Doctor of Nursing Practice (DNP) scholarly project aimed to provide patients at a rural Missouri clinic with information regarding ACP. Questions or preconceived ideas they may have had were also addressed. The goal is to see an increase in the percentage of patients with a documented AD in their EMR after five months.

Theoretical Framework

Jean Watson's Philosophy and Science of Caring Theory supplied the framework for the project (Figure 1 below). Watson's theory expresses that humans are individuals and must be viewed and treated holistically with the fundamental human caring attribute at the treatment center. By implementing this project, the provider/patient relationship created through caring promoted an environment to achieve the individual's best outcome related to EOL care. The most significant level of wellness is first reached individually and then carries over into the family and community.

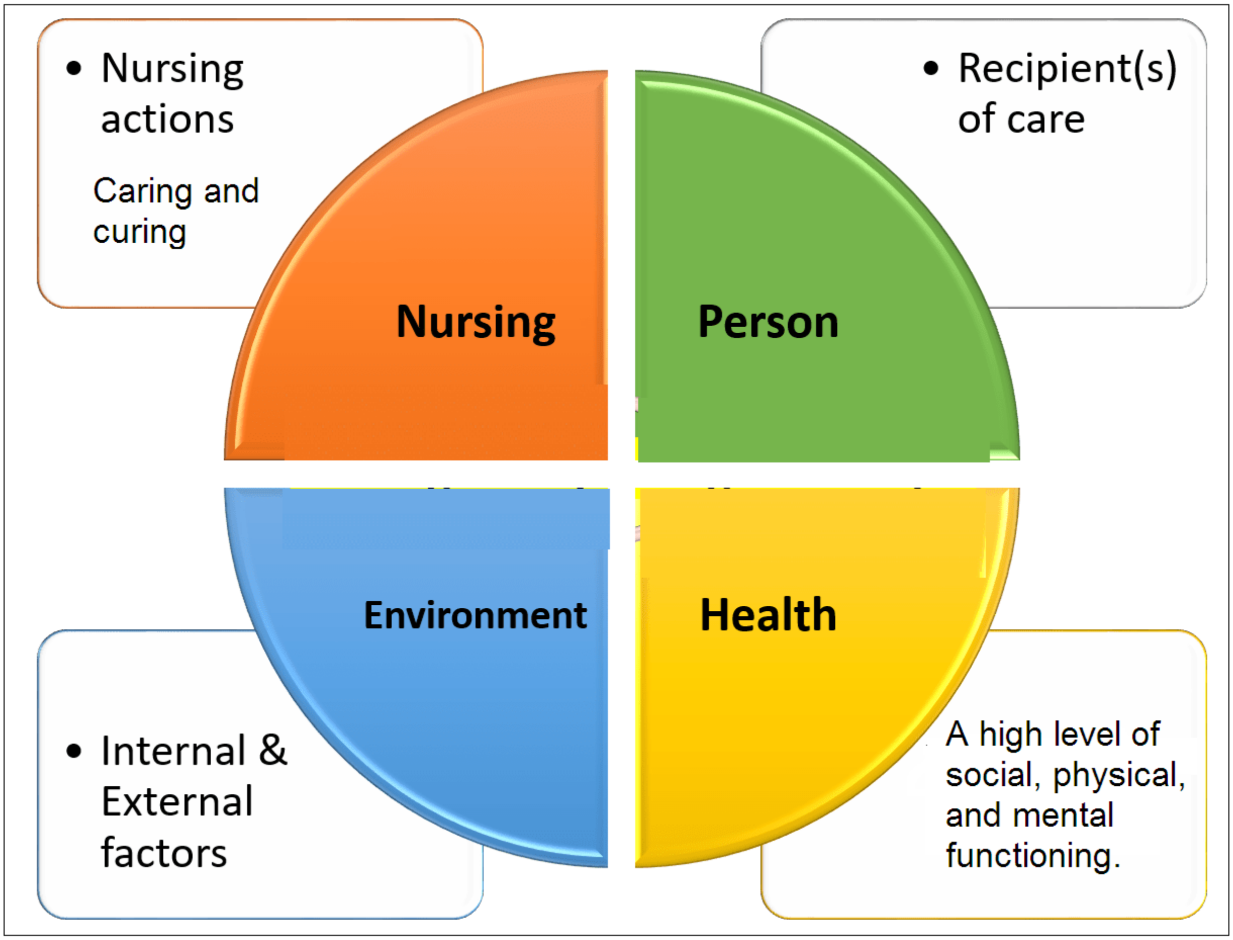
There are seven significant assumptions of the framework. Watson's theory states that caring can be effectively demonstrated and practiced only interpersonally (Nursing Theory, 2020); caring consists of "carative" factors that result in the satisfaction of particular human needs; effective caring promotes health and individual or family growth; caring responses accept the patient as they are now, as well as what they may become; a caring environment offers the development of potential while allowing the patient to choose the best action for him or herself at a given point in time; the science of caring is complementary to the science of curing; and the practice of caring is central to nursing.

The model has four concepts: human beings, health, environment/society, and nursing. Each of the four concepts is applied to the project. The first concept, the human being, is the focus of nursing practice and the project's direction. The second concept, health, encompasses the holistic approach to nursing that includes physical, mental, and social aspects of well-being

throughout the lifespan (including death). The third concept, environment/society, is relevant because when clinicians care for individual needs, the whole community enjoys a better quality of life. The last concept, nursing, can be related to the ability of the project administrator to identify a problem in EOL care in nursing and intervene to improve the process.

Figure 1

The interaction model of Watson's Philosophy and Science of Caring Theory



Note: Reprinted from "Ivy Panda Essays"

IvyPanda. (2020, December 16). *Watson's Caring Theory for Nurse Practitioners.*

Project Questions

The project aims to improve documentation of ADs in the primary care provider's office, where the environment is calm, controlled, and free of momentary crises. Significant questions the project anticipated answering are as follows:

- What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett have documented ADs available in their medical records before an educational intervention concerning ADs?
- What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett have documented ADs available in their medical records after an educational intervention concerning ADs?

Definition of Key Variables

For the project, clarification of terms includes advance directives, cardiopulmonary resuscitation, do-not-resuscitate, do-not-intubate, durable power of attorney, end-of-life care, healthcare provider, intubation, invasive procedure, living will, physician's order for life-sustaining treatment, and primary care provider. Each variable has a pivotal role in the project.

Advance Directive: a document that lets your healthcare team and loved ones know what kind of healthcare you want or whom you want to make decisions for you when you cannot. An advance directive can help you think ahead of time about what kind of care you want (American Cancer Society, 2019).

Cardiopulmonary Resuscitation (CPR): a procedure designed to restore normal breathing after a cardiac arrest that includes the clearance of air passages to the lungs, mouth-to-mouth method of artificial respiration, and heart massage by the exertion of pressure on the chest (Merriam-Webster, 2021).

Do Not Intubate (DNI): a legal order that tells a healthcare team that a patient does not want to be intubated in the event of a life-threatening situation. Chest compressions and cardiac drugs may be used during a patient’s care, but no breathing tube will be placed within the patient (Harbor Light Hospice, 2021).

Do Not Resuscitate (DNR): a medical order written by a doctor. It instructs healthcare providers not to do cardiopulmonary resuscitation (CPR) if a patient stops breathing or their heart stops beating (U.S. National Library of Medicine, 2020).

Durable Power of Attorney (DPOA)/Healthcare Proxy: a legal document that enables the grantor to designate another person called the agent or attorney-in-fact to act on behalf of the principal, even in the event the individual becomes disabled or incapacitated (US Legal, n.d.).

End-of-Life (EOL): a final period in a person’s life in which it is medially apparent that death is imminent or a terminal state cannot be prevented (The Free Medical Dictionary, 2021).

Intubation: the introduction of a tube into a hollow organ (such as the trachea) (Merriam-Webster, 2021).

Invasive Procedure: entry into the living body (by incision or by inserting an instrument) (Merriam-Webster, 2021).

Living Will: a document in which the signer requests to be allowed to die rather than be kept alive by artificial means if disabled beyond a reasonable expectation of recovery (Merriam-Webster, 2021).

Physician’s Order for Life-sustaining Treatment (POLST): a portable medical order that transfers from one setting to another with the patient and is intended to give healthcare providers immediate information about what interventions should or should not be undertaken (Patients’ Rights Council, 2015).

Primary Care Provider (PCP): the nurse practitioner, physician's assistant, or physician to whom a patient first goes to address a problem with their health (The Free Medical Dictionary, 2021).

Logic Model

The DNP scholarly project aimed to increase the percentage of patients with documented ADs in a primary care clinic in rural Missouri. The documentation of the ADs in the EMR can be made available electronically in various locations, including the emergency department, should a crisis occur. The logic model below (Figure 2) visually illustrates the relationship between the project's resources, activities, and intended effects. The short-term outcomes of the project are to raise patient awareness regarding EOL care and increase the percentage of patients with documented AD in the EMR of a primary care clinic. Long-term effects include the expectation that other providers in the clinic will recognize the need for improving documentation of patient EOL wishes through ACP and take the initiative to incorporate the change within their practices.

Assumptions affecting the outcome of this project include the following:

1. The staff is underprepared for ACP planning.
2. The staff is not comfortable discussing ACP.
3. The community will benefit from conversations directed toward ACP.
4. The clinic's existing policies can be improved.

External factors had a role in the outcomes of the project, including the following:

1. Approval of the project by Cox Health Care
2. Timely responses from the administration of Cox Health Care
3. Availability and willingness of provider cooperation

4. Personal beliefs, experiences, and attitudes toward EOL and ACP.

Barriers to the project include, but are not limited to, the following:

1. Change is difficult in any setting.
2. There is a lack of time in all healthcare settings.
3. The subject of death is difficult to approach.
4. Culture and language barriers exist.

Facilitators of the project include the following:

1. Reimbursement from CMS.
2. Patient satisfaction.
3. Family satisfaction.
4. Providing a higher quality of patient care.
5. Providing care that lasts throughout the lifespan continuum.

Figure 2

Logic Model

NAME OF PROGRAM/PROJECT:
Improving Advance Directive Documentation in a Primary Care Clinic in the Midwest

SITUATION:
Many individuals either do not have an AD or their loved ones do not know how to access their AD when it is needed. This project aims to improve communication and documentation of ADs in EMRs.

PRIORITIES:
Educating provider and the community regarding EOL decisions and ACP

INPUTS (What we invest)	**OUTPUTS**		**OUTCOMES**		
	Activities (What we do)	**Participants (Who we reach)**	**Short-term**	**Medium-term**	**Long-term**
• Trained and experienced provider • Strong relationship with stakeholders • Educational materials • Practice materials • Doctor of Nursing practice student • Investment in peers' quality	• Assess readiness of clinic to change • Get stakeholders to invest • Develop and establish roles • Provide evidence-based information • Identify appropriate patients	• Any patients over the age of 18 that are not cognitively impaired • Family members • Staff	• Improve communication between patients/families/ healthcare members. • Increase patient and provider understanding • Increase awareness of EOL decisions and ACP significance. • Increase percentage of documented ACP	Continued communication improvements throughout the clinic.	Continued communication and improvements in the ACP process throughout the health system.

ASSUMPTIONS	**EXTERNAL FACTORS**
1.Communication between family/patients/providers is poor at best during a medical crisis. 2. Patients' individual choices for EOL care are not always known or carried out due to lack of documentation. 3. It is assumed that if documentation is carried out and made available electronically in a primary controlled setting, it will likely be available in the event of a health crisis.	Barriers: 1. Change is never easy 2. Lack of time in primary care setting 3. The topic of death is challenging 4. Culture/language Facilitators: 1. Reimbursement 2. Patient/family satisfaction 3. Higher quality of care 4. Total lifespan care

EVALUATION PLAN:
Charts will be checked before and after intervention assessing for percentage increase in documented ADs.

Summary

Advance directives have been acknowledged in the medical community since the late 1960s. Since its inception, healthcare has made little effort to initiate safe practice guidelines allowing patient requests to be carried out appropriately. Many patients and family members nearing the end of life may no longer be physically or mentally able to make care decisions. Therefore, ACP is critical while patients are healthy to ensure that goals and needs are met. The primary care provider offers a setting of comfort and trust where patients can begin the process of setting up an ACP.

CHAPTER II

REVIEW OF LITERATURE

Successful healthcare outcomes are significant at every stage of the human lifecycle beginning at conception and ending with death. Prioritizing healthy outcomes starts for most individuals before they are even conceived. The pregnant mother emphasizes nutrition and healthy habits to prepare her body for conception and birth. She then takes great care to eat well, seeks early and routine prenatal care, and takes vitamin supplements to provide a “good birth.” This healthy behavior is followed throughout infancy, adolescence, and early adulthood. Individuals then attempt to live a “good life” by adopting positive health choices. What happens when individuals facing EOL are not given the information and the opportunity to plan a “good death?” The current system of ACP does not offer a growing number of patients the chance to decide on their EOL choices. The literature provides multiple suggestions as to why EOL planning remains poor after being acknowledged many years ago. There is one common theme cited throughout the review process, and that is a lack of education.

A comprehensive literature review was completed utilizing the following databases: Cochrane, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medscape, PubMed, and ProQuest. The search criteria included the following: DNR, advance directives, EOL, compliance rates, nursing knowledge, barriers to EOL care, and electronic accessibility to ADs. Select governmental sources were accessed for necessary data.

Lack of education regarding ADs can be broken down further into the following categories:

- Nursing Education
- Provider Education
- Patient Education

Nursing Knowledge of Advance Care Planning

The ANA requires nurses to educate patients about ACP and to discuss the different forms outlined in *The Code of Ethics with Interpretive Statements* (ANA, 2015). Thus far, nursing education rarely provides content highlighting the responsibility of assisting patients in understanding their options (McKenzie et al., 2017). Coffey et al. (2016) completed a cross-sectional study involving five countries that revealed a clear link between nursing education levels and confidence in providing ACP information to their patients. The study also noted that decision-making in the U.S. is often poorly applied, and patients need to receive care consistent with their EOL preferences. From the data, 77% of nurses employed in med/surg, rehab, oncology, ICU, and recovery units scored low in general AD knowledge, PSDA knowledge, and state law regarding ACP (Coffey et al., 2016). Kunte et al. (2017) applied an educational program created by The End-of-Life Nursing Education Consortium (ELNEC) to a group of nurses and certified nursing assistants (CNAs) at two select long-term care facilities. Participants rated their knowledge of ACP with a before and after survey. The surveys showed a 67% improvement in the CNAs’ expertise and a 36% improvement in the nurses’ knowledge.

Howard et al. (2018) surveyed healthcare professionals and found that nursing identified their lack of knowledge and difficulty accessing physicians as barriers to improving ACP.

Provider Knowledge of Advance Care Planning

Family practice is where relationship-centered care is provided throughout the life cycle for a significant percentage of Americans. Barriers exist to provider interactions with patients regarding EOL and ACP that could be improved by interventions focusing on communication. Between November 2014 and June 2015, questionnaires were sent to physicians asking about perceived barriers to advanced care planning with their patients in primary care (Howard et al., 2018). Physicians rated insufficient time, inability to transfer documentation across settings electronically, and decreased interaction with patients near EOL (Howard et al., 2018). To overcome the barriers, physicians must communicate honestly with their patients. Plenty of time should be set apart so the patient does not feel rushed. In 2010, the U. S. Department of Health and Human Services (USDHHS) stressed multiple problems with the current ACP process and made suggestions for improvement. Most improvements centered on enhanced communication between physicians, patients, and their family members. The USDHHS further suggests that primary care providers approach the subject on routine patient visits when the patient is 50 years old, has a diagnosis of progressive chronic disease, or is increasingly frail or dependent. Dartmouth Institute for Health Policy & Clinical Practice (2017) concluded in *The Report of the Dartmouth Atlas Project* that physicians seldom talk with patients about their EOL preferences, and less than half of those providers knew when patients desired to avoid CPR. A Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) from the Robert Wood Johnson Foundation (1995) suggests the same shortcomings. In the randomized study of over 4000 patients, nearly a third reported not wanting CPR, but fewer than half of their physicians knew of this preference.

Patients’ and Families’ Knowledge of Advance Care Planning

Advance care planning is intended to improve the quality of death for individuals and their loved ones; however, only one-third to one-half of adults in the United States have a completed AD (Carr & Luth, 2017). Many dying older adults cannot communicate their EOL preferences because they are debilitated when the decision is required. The IOM (2014) estimates that 45-70% of older adults facing EOL decisions are incapable of making decisions themselves. An educational approach that targets AD completion, patient knowledge, and caregiver training is needed to enhance quality care for individuals faced with EOL decisions. In one quasi-experimental trial by Wissow et al. (2004), it was found that an interventional approach consisting of provider education and information delivered from the provider to the patients led to an AD completion rate of 7.8%. However, another study by Rando-Matos et al. (2019) using the same interventional approach showed no effect on AD completion rates but increased interest among participants.

Disagreements that cause family tension are another cause individuals give for not wanting to discuss ADs (Hemsley et al., 2018). Sizoo et al. (2012) considered this and many other barriers to ACP when suggesting specific guidelines for healthcare providers on when introducing ACP would be helpful. An ongoing conversation regarding ACP at every routine visit would help cement the normalization of ACP to patients and family members.

How Often “Do Not” is Done

Perry & Lawand (2017) studied data from 200,000 long-term care residents in four different providences in Canada to better understand how often DNR and Do Not Hospitalize (DNH) orders were followed. One patient in 2,500 received CPR against their wishes, and almost 6,000 patients with a documented DNH were transferred to the hospital during the three years studied. It is suggested that the orders were not respected due to family intervention in several cases. The study raised awareness, and hospitalizations among long-term care residents dropped by 50% over the three years it was carried out. Researchers at the University of California surveyed more than 800 elderly patients that stated they had completed and given ADs to a healthcare provider. The ADs were unavailable in more than half of the individuals’ charts (Yung et al., 2010). In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT, 1995), a sample of 479 patients was asked about a preference for dying at home or in another healthcare facility (391 stated they wished to die at home). A total of 216 of those 391 died in a hospital setting anyway. Johnson et al. (2015) say that the most significant potential for adopting ACP across services and jurisdictions is the EMR.

Transfer of DNR Orders to the ED

Transitioning care from a nursing home to a hospital is a vulnerable time. Many states have statutes concerning the transfer of ADs when patients are moved from extended care facilities to a higher level of care. In the State of Missouri, where the project was carried out, section 190.603 of the Missouri Revisor of Statues states that

> “An outside the hospital DNR order shall be transferred with the patient when the patient is transferred from one health care facility to another health care facility. Suppose the patient is transferred outside of a hospital. In that case, the outside-the-hospital DNR form shall be provided to any other facility, person, or agency responsible for the patient’s medical care or the patient’s representative.”- (Missouri Revisor of Statutes, 2021).

A study in Ohio attempted to examine how often a DNR order follows patients into the emergency department (ED) upon transfer. Out of fifty patients transported, only 28% had their DNR orders transferred with them. The study further discovered that ED providers were less likely to write for a DNR order at the hospital without proper paperwork from the transferring facility (McQuown et al., 2017). The current system for documenting ADs in the ED could be better, despite some states making the process mandatory.

Introduction of the POLST and Electronic Medical Records

In 1991, the State of Oregon introduced the Physician Orders for Life-Sustaining Treatment (POLST) form. In 2014, the IOM wrote a report promoting all states to create a POLST program. The POLST documentation now exists in some form in 50 states (National POLST, 2021). The POLST is filled out during the clinical encounter with the primary provider and therefore remains in the EMR and travels with the patient. The form is meant for individuals that are expected to die within one year. Because the POLST form is completed when death is expected sooner than later, they include specific treatment at EOL (CPR, feeding tubes, comfort measures only) (Carr & Luth, 2017). If a patient is at home when 911 is called, the POLST form is an actual physician order that paramedics must carry out when treating the patient.

Electronic medical records were introduced to the medical community for safety and continuity of care. Little has changed since the inception to improve ADs and patients' code status. Sehgal & Wachter (2007) highlighted the unsafe practices involving the widely varying methods of documenting DNR orders. Paper, EMR, and color-coated wristbands were three different distinctions to specify DNR status. More than 70% of the respondents in the survey recalled situations when confusion around a DNR order led to problems in patient care. Skrocki (2013) expressed the same concerns, stating that until healthcare achieves standardization with technologies, the goals of the EMR will not be realized. Neubauer et al. (2015) found that code status documentation is generally unavailable in the patient's health record. The ongoing challenges with ACP have been documented, confirming that a distinct process is needed to apply ACP principles in ways that prompt communication between provider and patient. The obstacles involved may be addressed by community initiatives and educational programs designed so that the patient and caregivers can confidently communicate that personal choices will be made.

Getting Involved

Cohen-Mansfield et al. (2016) found that 75% of nurses surveyed were familiar with the family's EOL wishes, and only 46% of the interviewed physicians had the same knowledge. The ANA position statement on nursing care for DNR and Allow Natural Death (Nursing World, 2020) decision is evident in the nurse's involvement.

1. Educate patients and their families about using biotechnologies at the EOL, termination of treatment decisions, and ADs.

2. Encourage patients to consider EOL preferences in illness or health crises.
3. Support patients, their families, and their surrogates to have EOL discussions with their providers.
4. Ensure ADs are implemented.
5. Communicate information relevant to EOL decisions to appropriate healthcare personnel.
6. Advocate for a patient's EOL preferences regardless of surrogate decision makers' or physician's desire to not honor them if they reflect restorative care.

With special attention to number one above, the nurses' focus on educating patients and families using biotechnologies was the project's aim.

Educational Opportunities

Three different educational opportunities found throughout the literature that are evidence-based and in line with the project are the following:

- *The Conversation Project*
- *The End-of-Life Nursing Education Consortium (ELNEC)*
- *Five Wishes*

The Conversation Project

The Conversation Project is an Institute for Healthcare Improvement (IHI) initiative to help individuals discuss their EOL wishes. The project promotes starting the conversation at the dinner table with loved ones before a crisis arises. The project was started in 2010 by various individuals in various careers, from Pulitzer Prize winners to clergy and medical professionals. The project has a website full of free information and available starter guide materials to download and print at no charge. Videos are available to watch on a multitude of subjects, including but not limited to:

- Normalizing EOL conversations
- Dementia and Alzheimer's Disease
- Letter writing to loved ones about difficult choices
- Who will speak for you?

The project offers free resources to assist anyone who wishes to get involved, including healthcare, faith-based, or in a community setting. Anyone can sign up for a free newsletter for updates and significant announcements.

The End-of-Life Nursing Education Consortium

The End-of-Life Nursing Education Consortium is an educational resource, from The American Association of Critical-Care Nurses, for all nurses and nursing specialties that provide training in EOL and palliative care. Many nursing schools are now utilizing the online curricula provided by ELNEC. The trainers from ELNEC are reaching out to practicing nurses in underserved communities. Some of the online learning modules include the following topics:

- Introduction to palliative care
- Communication in palliative care
- Pain management in palliative care
- Symptom management in palliative care
- Final hours of life
- Advance practice nursing leadership in serious illness

The program charges $29.00 for a full year of course access. The program also offers regional, national, and international studies.

Five Wishes

Five Wishes is a program offered by the Aging with Dignity group. It is another not-for-profit organization that assists healthcare and communities in approaching the discussion and documentation of EOL choices, including ADs. *Five-wishes.org* supplies videos and information on community presentations free of charge and a visual map of existing community programs. The healthcare portion of the program offers training, consultations, guides, documents, outreach presentations, and toolkits if a clinician would like to make the project part of their facility or community. Five Wishes was developed with support from the Robert Wood Johnson Foundation in 1998 and distributed by over 40,000 organizations.

Summary

The PSDA was placed into law in 1991. Over the past 30 years, multiple flaws have been identified, including ethical and legal issues. However, healthcare providers are responsible for educating, implementing, and ensuring compliance. The significance of ACP to nursing and patient education has been embedded throughout the literature. A multipronged method targeting ACP and documentation with caregiver/patient knowledge is needed to enhance the quality of EOL care for individuals desiring a “good death.”

CHAPTER III

METHODOLOGY

Enhancing quality improvement in healthcare can be challenging, and improving ACP documentation is difficult. Barriers include time constraints, sustaining interventions without funding, insufficiently trained staff, and incompatible information technology systems (Nagarajan et al., 2022). This DNP scholarly project aimed to improve the documentation of advanced directives in a primary care clinic in the Midwest. This chapter will describe the methodology behind data collection and sampling related to the DNP scholarly project.

Project Design

The DNP scholarly project is an interventional study design utilizing a pre-post study format. The pre-post study design focuses on percentages of patients with documented ADs in the EMR before and after the educational intervention. This specific study design was chosen because it is specifically tailored to evaluate the direct impact of therapy (Thiese, 2014). Interventional or experimental studies are those where the researcher intercedes as part of the design.

The project was carried out in a rural community clinic in Monett, Missouri. The project's initial phase involved the Monett clinic manager and the informatics manager at Cox Health Care conducting a retrospective chart review. Two hundred random charts meeting the criteria were manually audited for a baseline percentage of the NP’s primary care patients with a documented AD in the EMR. The author of the project was not privy to any patient identifiers.

The project’s second phase involved the author providing the primary care provider with additional education regarding advanced care planning. The instruction was presented in PowerPoint format, and evidence-based information was obtained from The Conversation Project. The provider and author of the study selected patients on a daily schedule meeting the criteria. They provided participants with information emphasizing the significance of documenting those choices in the EMR. The process’s initial goal was to reach 144 patients with the intervention. Patient receptiveness to the intervention was so successful that 207 patients received the intervention.

The third and final stage of the project involved a post-audit of 200 random charts of patients meeting the criteria to understand if the intervention was statistically significant. The informatics manager of Cox Health System again conducted the post-audit, not allowing any patient identifiers to be seen by the author.

Target Population

The project's target population included patients from a Midwest Missouri rural health clinic over 50 years of age and seen by a specific primary care provider. Choosing individuals in this age group was based on the suggestion from the U. S. Department of Health and Human Services (2010). The chosen primary care provider is an APRN who sees 3,600 patients yearly. Using a confidence level of 95%, a confidence interval (margin of error) of 8, and an expected proportion of 0.5, the intended sample size initially was 144 patients over five months. That number was increased to 207 patients due to the positive response from patients and families.

Target Population Recruitment

The project utilized convenience sampling. This type of sampling is a non-probability sampling technique that increases the likelihood of obtaining samples not representative of the target population (Gray & Groves, 2021). However, convenience samples are inexpensive, accessible, and require less time than other sampling methods. Participants were asked if they had an AD and if it was on file in the EMR. Patients who met the criteria were given information from the primary care provider or the project's author.

Inclusion Criteria

The main inclusion criteria for the participants were: established patients in the clinic, patients of the selected primary care provider, participants needed to be 50 years of age or older, cognitively capable of understanding the information provided, and needed to understand the English language. Exclusion criteria for the participants included any patients in distress; new patients establishing care; anyone under 50; any cognitive diagnosis that could interfere with the patient's ability to understand the information provided; and inability to understand English.

Protection of Human Subjects

Before data collection, approval was obtained from the Irene Ransom Bradley School of Nursing Institutional Review Board, Pittsburg State University Institutional Review Board [IRB] (Appendix A), and Cox Health Care review board (Appendix B). All regulations were strictly followed and adhered to. The project author did not visualize any identifying patient information. The project examined percentages of AD documentation in the EMR without viewing patient data that could put them at risk of being identified.

There were risks and benefits associated with the DNP project. The hazards included potential psychological consequences, such as eliciting emotional responses of anxiety or guilt from previous experiences. However, Rolnick et al. (2019) found that patient interest in AD completion increased when presented with open and honest information.

The benefits of the DNP scholarly project included the development of an improved method of communicating and storing personal EOL decision-making preferences.

Instruments

A PowerPoint presentation was created and presented to the APRN (Appendix C). The presentation contained pertinent information within this report and an in-depth explanation of reimbursement. The APRN created a login and completed educational modules embedded in The Conversation Project website to supply her with current and most up-to-date evidence-based materials to engage with her patients.

Measurement using existing databases or secondary healthcare data analysis was used to obtain the pre-and post-intervention percentage of AD documentation in the EMR. The project committee included a statistician to monitor the data collection.

Procedure

After project approval was obtained from Pittsburg State University and Cox Health Care, the IT department was responsible for securing chart percentages before the educational intervention. The primary care provider was given her educational materials, and any questions were addressed. The participants were randomly chosen daily until 207 participants were provided with the information. After five months, the IT director randomly chose 200 patient charts for audit. The principal investigator did not have access to any patient charts.

Outcomes

The educational project outcomes were three-fold. The first intended outcome was to bring attention to the significance of ACP planning and implementation. The second intended outcome was that the percentage of people documenting ADs improved after the educational intervention. Lastly, awareness was brought to the entire clinic, making ADs a more routine patient discussion, and improving documentation.

Evaluation Plan

This DNP scholarly project hypothesized that the percentage of AD documentation would increase after the educational intervention. The project focused on enhancing EOL care, as evidenced by an increase in AD completion, and hopes to raise awareness of the significance of ADs. The evaluation measures included pre- and post-AD completion percentages in the EMR of a primary clinic in the Midwest.

Plan for Sustainability

Moran et al. (2020) state that there are four factors specific to the sustainability of a project:

1. Input and buy-in from the organization and critical stakeholders. Cox Health is seeking to improve the organizational process of readily accessing ADs.

2. Short-term and long-term policy strategies need to be in place. This project has been a short-term trial for Cox Health to build upon until the long-term goal of improving the organizational process is complete.
3. Acquiring the needed resources. There was no financial investment in this project for Cox Health. The facility allowed the use of the clinic setting and to follow the APRN employed through the company.
4. Defining the steps for ongoing documentation and structure of the project with continuous evaluation.

The project's author was constantly present in the project clinic setting and participated in communication with the chosen provider and patients. Allowing the key stakeholders to participate in the project significantly improved the buy-in and sustainability of the project.

Short-term policy strategies of the project were successful implementation. With the project focusing on primary care providers' patients as participants, the hope that other clinic providers noticed was also met. Two APRNs working within the same office space showed interest in ACP and asked the author several questions during the project implementation.

Long-term policy strategies of the project are to inject the project outcomes throughout the Cox Health Systems organization.

Summary

An interventional study design was utilized for the project, coupled with a convenience sampling technique allowing for an inexpensive, accessible, and time-friendly project. The project focused on improving the documentation of ADs in a primary care clinic in the Midwest. An analysis of percentages was conducted through the informatics manager, not containing any patient identifiers, to assess project outcomes.

CHAPTER IV

EVALUATION RESULTS

This project aimed to improve the documentation of ADs in the primary care provider's office. The purpose of utilizing primary care was that the environment was calm and controlled. The primary care provider also had a large clientele, with many patients developing close, trusting relationships with her. This DNP scholarly project attempted to answer the project questions:

Demographics

Once approval from Pittsburg State University and Cox Health Systems was obtained, the project went live in the clinic on July 1, 2022, and data collection was completed on December 31, 2022. To participate in the project, patients had to be 50 years or older, established patients, cognitively capable of understanding the information, and fluent in the English language. Exclusion criteria included patients in acute distress, new patients, anyone under 50 years of age, a cognitive diagnosis that could interfere with the patient's ability to understand the information provided, and anyone unable to understand English. The total number of participants was 207 patients from a rural clinic.

Demographic information collected was patient age for chart auditing purposes and patient sex. One hundred and seventeen of the participants who received the intervention were female, and 90 were male. The range of issues the patients were being seen with at the clinic ranged from very minor to complex chronic diseases. However, no one in acute distress was given the intervention. All the patients seen were already established patients of the APRN.

Table 1. 1 Demographics of Participants (N=207)

Gender	N	%
Female	117	57
Male	90	43
Age Range		
50-59	73	35
60-69	71	34
70-79	39	19
80-89	13	6
90-99	11	5

Analysis of Project Questions

1. What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records before an educational intervention concerning ADs?
2. What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records after an educational intervention concerning ADs?

Project Question One

What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records before an educational intervention concerning ADs?

Based on the pre-interventional audit conducted by the Cox Informatics manager, the control group with ADs was 15%. This was based on manually auditing 200 charts of patients over the age of 50. This is well below the U.S. average of adults with documented ADs. One of the largest systematically reviewed studies, including 795,909 people in 150 studies, found that 36.7% had completed an AD. The findings did not change significantly between patients with chronic illnesses (38.2%) and healthy adults (32.7%) (Yadav et al., 2017).

Project Question Two

What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records after an educational intervention concerning ADs?

After the educational intervention, the experimental group with ADs was 16.5%. To evaluate the effectiveness of the educational intervention, a Chi-Square test was performed using the software SPSS. This test is used to determine whether there is a significant change between two categorical variables (Statology, 2023).

Table 2 1 Advance Directive Crosstabulation

		Advanced Directive		
		Yes	No	Total
Group in	Control	30	170	200
	Experimental	33	167	200
Total		63	337	400

Chi-Square = .170, p = .681

Although there was an increase in the number of advanced directives, the results from the Chi-Square test comparing the control and experimental group and the number of ADs did not show a significant increase in ADs from the control to the experimental group.

Summary

This study aimed to answer two research questions using a random pre-intervention chart audit and then a random post-intervention chart audit. A Chi-Square test was utilized to measure the intervention's significance and effectiveness. The values of the Chi-Square test did not identify a statistically significant improvement in AD completion after the intervention.

CHAPTER V

DISCUSSION

This project aimed to improve the documentation of ADs in the primary care provider's office. Primary care was used to present pertinent information in a calm and controlled environment. The primary care provider also had a large clientele, with many patients developing close, trusting relationships with her. This project resulted in a slight increase in the percentage of patients with a documented AD in their EMR after receiving an educational intervention explaining the significance of EOL care. However, the increase was not significant, as evidenced by the Chi-square test results.

Relationship of Outcomes to Research

This project aimed to answer two questions:

- What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records before an educational intervention concerning ADs?

The first audit completed provided data that 15% of the patient population had an advance directive on file in the EMR. The percentage is far below the national average of 37.7% (healthaffairs.org, 2017). In a systemic review of 150 studies led in the U.S. from 2011 to 2016, 37% had completed an AD (UpToDate, 2023). The clinic site operates in a rural underserved area. The disparities between rural and suburban settings must be considered for this low percentage. A study by Buchanan et al. (2004) found that residents from suburban areas were significantly more likely to have executed a durable power of attorney for health care (6 out of 10). The residents from rural communities were less likely to have an AD on file (4 out of 10).

- What percentage of patients in the Cox Family and Occupational Medicine Clinic of Monett, Missouri, have documented ADs available in their medical records after an educational intervention concerning ADs?

The second audit completed after the intervention has a slight increase of 16.5% from 15% of the patient population having documented ADs in the EMR. The findings are consistent with previous studies involving ACP interventions being analyzed, including simplified discussions, videos, multimedia, written instructions, and clinician training. A literature review implies that most interventions, regardless of the method, improve patient satisfaction and decrease clinician stress (UpToDate, 2023). However, significant results have been negligible.

Most patients that received the intervention are in line with previously collected data indicating that several characteristics are associated with a higher likelihood of completing an AD. Those characteristics include; older age, white race, history of chronic disease, higher socioeconomic status, prior knowledge surrounding ADs, higher levels of education, and higher levels of functional impairment (UpToDate, 2023). Yadav et al. (2017 state that efforts to increase completion rates should be targeted at those most likely to benefit from interventions.

Issues of Concern

Since 1967, ADs have been endorsed as the primary tool for people to communicate their EOL wishes. The proportion of Americans with an AD has mostly stayed the same in the last 25 years (Yadav et al., 2017). This project focused on an intervention to improve AD completion, but several other barriers to completion should have been considered. To enhance compliance with AD completion, it is imperative to understand individual perspectives of why AD completion has been and continues to be underutilized.

The legal formalities required for executing an AD can confuse and intimidate many individuals. The intervention should have thoroughly discussed the legislative requirements in Missouri or any other states that might have been in play. For instance, some states require two witnesses to make the form legal, while others require the AD to be notarized. This can be particularly intimidating for vulnerable patients who lack the financial resources to consult an attorney. Some states only acknowledge living wills and healthcare proxies in a hospital location. Some states require EMS providers to deliver resuscitative care unless state-approved AD documents are presented (Baker & Marco, 2020). Some communities are geographically located near other states, and crossing the borders to receive medical care can void an AD if it does not meet said state's requirements. Future legislation that simplifies regulations around ADs may be warranted to improve compliance.

Advance directives fall in the category of medical ethics. Medical ethics raise concerns for not only the patient and loved ones but the healthcare staff must understand personal beneficence and morals. Time limitations for the project did not allow for discussions of ethics and morality with the APRN or to participants. End-of-life scenarios can conflict between ethical principles and personal wishes (House et al., 2022). Including the AAFP *Core Principles for End-of-Life Care* might have addressed some questions surrounding ethics and ACP. According to the American Academy of Family Physicians (2023), care at the end of life should embody the following principles:

- Respect the dignity of both patients and caregivers
- Be sensitive to and respectful of the patient's and family's wishes.
- Use the most appropriate measures consistent with patient and surrogate choices.
- Ensure that pain alleviation and management of other physical symptoms are a high priority.
- Recognize, assess, and address the associated psychological, social, and spiritual religious issues and cultural taboos, realizing that different cultures may require significantly different approaches.
- Ensure appropriate continuity of care by the patient's family clinician and consultants.
- Advocate for the patient's right to choose any therapy that may reasonably be expected to improve the patient's quality of life, including alternative or nontraditional treatments.
- Provide access to palliative care and hospice care.
- Respect the clinician's professional judgment and recommendations, with consideration for both patient and family preferences.
- Consider clinical and evidence-based research and education relative to providing care at the EOL.

Social Isolation or lack of a proxy was not approached in the intervention. The assumption

was made that “everyone has someone.” Many elderly individuals are limited in their choice of health proxy simply because of loved ones that have died before them or are isolated geographically. It should also be mentioned that the project was implemented during the Covid-19 pandemic. The pandemic created shutdowns and stay-at-home orders and prevented most community events. The elderly tended to experience higher levels of social isolation than any other age cohort.

Cultural, racial, and ethnic factors were not considered in the intervention roll-out. Monett, Missouri, has a population of 9,035, and 32.37% identify as Hispanic (Data USA, 2023). One of the inclusion criteria was that the participants must be fluent in English, essentially ruling out a large portion of patients that could have received the intervention. Although it is important not to stereotype patients, culturally, Hispanic and Asian patients rely more on family members for decisions rooted in tradition and spiritual beliefs. They thus may not believe that an AD is needed (Spoelhof & Elliot, 2012).

The most successful interactive interventions include repeated conversations about the completion of ADs over time, providing opportunities to ask questions, and receiving assistance from a knowledgeable person is more effective than instructive interventions (Bravo, Bubois, & Wagneur, 2008). The interactions with participants of this project were very limited. The APRN that participated in the project is very thorough and has anywhere from 15-30 minute time slots for her patients, depending on the nature of the appointment. The intervention had to be presented when time allowed before or after their actual appointment. This time crunch left the intervention hurried in some situations, and often the patient did not have enough time to absorb the information or to ask questions.

Observations

The project has strengths and weaknesses associated with the rollout of the intervention strategies.

Strengths

Even though the percentage increase was minimal, this study has value. The APRN that took part in the intervention received extensive education regarding ACP. The education portion for the APRN was adapted from *The Conversation Project.* Materials included a PowerPoint presentation, online course work *Having the Conversation: Basic Skills for Conversations about End-of-Life Care*, and a toolkit for clinicians to talk to patients about EOL care. The tools utilized for the project were created using evidence-based research, increasing the validity and reliability of the information provided to the participants. The APRN states that she feels far more knowledgeable and has a greater self-confidence when approaching her older patients.

Limitations

The project was presented at a single clinic, and only one provider's patients were included among the participants. Utilizing only one clinic and one provider does not allow for a complete representation of the population. For instance, most patients seen at the clinic have some type of medical insurance, leaving those without insurance unrepresented in the study. Hispanic individuals were the only minority represented in the project. Convenience sampling did not allow for other minority representation.

The project results could have been affected by the short five-month time constraint. A longitudinal study would have been more helpful. Several systematic reviews have shown evidence that the most effective AD interventions involve interactive discussions between the patient and physician over multiple visits (Bravo et al., 2008; Jezewski et al., 2007; Ramsaroop et al., 2007). Attrition bias is always considered when conducting longitudinal studies; however, there is no way to track if participants started seeing another provider during the five months of data collection at this clinic.

The pre-arranged script was not always the same with each interaction. The script did change slightly between presentations, depending on how the patient directed the conversation or the unique questions that would be asked.

The APRN could not always be present during the ACP discussions because of her busy schedule. Leaving the patients to discuss EOL care with the presentation's author, who sometimes had no prior interaction with participants, negated the plan to have someone they trusted to deliver the information.

Evaluation of Theoretical Framework

This project used the Jean Watson Philosophy and Science of Caring Theory as the theoretical framework to guide this project and aid in creating the intervention. Overall, the results of this project support Watson's theory. Watson's theory emphasizes the importance of treating patients as individuals and treating them holistically to improve patient comfort surrounding EOL care. Jean Watson describes goals and objectives to "deepen and expand Caring Science."

- Change the prevalent model of medical science to a model of Caring Science by restoring the ethic, philosophy, and diverse practices of caring and love necessary for healing.
- Deepen the original Caring-Healing relationships between caregiver and patient/family to rebuild love and compassion as the ethical values foundation of healthcare.
- Translate the model of Caring-Healing into fully incorporated programs and services to help transform healthcare one nurse, caregiver, educator, leader, and system at a time.
- Ensure caring and healing for the community, improve nurse and care provider retention, enhance patient outcomes, promote safe practices, and decrease costs to the system.

These objectives all coincide with the primary goal of ACP. Collaboration of ACP demands that the clinician be responsible for compassionate patient autonomy, improving the quality of care, strengthening relationships, and reducing overtreatment.

The participants can identify the need for ACP and early involvement through educational intervention. This ultimately leads to the implementation of Watson's Caring theory. Improving ACP conversation gives the healthcare team the tools to assess patients and their concerns and understand how holistically treating patients can improve AD compliance rates.

Evaluation of the Logic Model

The results of this project were not as apparent as hypothesized, although the data still supports the logic model introduced in chapter one. The logic model assumed the following:

1. The staff is underprepared for ACP planning.
2. The staff is not comfortable discussing ACP.
3. The community will benefit from conversations directed toward ACP.
4. The clinic's existing policies can be improved.

Assumptions 1, 2, and 4 of the logic model can be proven by comparing the data collected from the first audit, demonstrating that AD completion rates in the clinic are far below the national average. The third assumption that the community will benefit from ACP conversations is subjective and cannot be proven. The APRN is more aware of the necessity of ACP in her daily interactions with patients, and her confidence level when discussing EOL issues has self-admittedly improved. The project could have benefitted from a before and after test of the APRN's ACP knowledge.

Recommendations for Future Projects and Research

Future research to address ACP and ADs needs to be ongoing. Nurses must understand the PSDA and the laws in the state they work. Healthcare facilities' policies and procedures can be brutal to find depending on the hospital system. When they are located, the lentiginous information can be cumbersome at best. In the future, research will focus on understanding if the nursing staff knows where to access the information needed and if they understand the reading.

Secondly, longitudinal studies that follow the participants through multiple appointments and stages of life would be beneficial. This project's influence on patients cannot be summed up in five months. Starting the discussion and planting a seed in the minds of those participants may encourage individuals to create an AD sometime down the line. Thirdly, studies that educate multiple clinicians in a clinic to encourage discussing EOL care would be advantageous. Having the clinicians compare notes and understand why one provider does or doesn't have more patients completing ADs would be of great significance. Fourthly, surveys or telephone interviews are a great way of gathering information from patients themselves as to why they are not following through with ACP. The data could then be compiled into an intervention based on the findings. Lastly, there is much information regarding nursing knowledge and interventions that may improve scores among the nursing staff. There does need to be a larger focus on pushing providers to talk about death and ACP with their patients and families.

Conclusion

This project aimed to improve the percentages of patients completing an AD and documenting it in their EMR. Although this study did not significantly improve the percentages of ADs in the clinic, this project provided evidence-based information to the APRN and many patients. Ultimately, this project sets the arena for future research projects and demonstrates the significant need for interventions geared toward improving AD compliance.

Due to the aging population and technology allowing for longer life spans, hospitals should consider expanding research to evaluate how ACP can help decrease hospital expenses, unwanted procedures, and extended hospital stays in the last years of life. Improving ACP and AD compliance will help set up the hospital, collaborative members, patients, and families for success. Overall, the educational intervention implemented within this scholarly project positively impacted knowledge and encouraged patients to consider ACP and ADs.

References

Advanced Care Planning Decisions. (2020). *19 Evidence-Based benefits of advance care planning.* https://www.acpdecisions.org/19-evidence-based-benefits-of-advance-care-planning/

Agency for Healthcare Research and Quality (2023). *Disparities.* Retrieved at www.ahrq.gov/topics/disparities.html

American Academy of Family Physicians. (2023). *Ethics and planning for health care decisions.* https://www.aafp.org/about/policies/all/ethics-advance-planning.

American Association of Colleges of Nursing. (2021). *End-of-life-care (ELNEC).* http://www.aacnnursing.org/ELNEC/About

American Cancer Society. (2019). *What is an advance directive?* http://www.cancer.org/treatment/findingandpayingfortreatment/understanding

Baker, E. F., & Marco, C. A. (2020). Advance directives in the emergency department. *Journal of the American College of Emergency Physicians open, 1*(3), 270–275. https://doi.org/10.1002/emp2.12021

Bravo, G., Dubois, M. F., & Wagneur, B. (2008). Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science & Medicine. 67*(7), 1122-1132

Buchanan, R. J., Bolin, J., Wang, S., Zhu, L., & Kim, M. (2004). Urban/rural differences in decision-making and the use of advance directives among nursing home residents at admission. *The Journal of Rural Health, 20*(2), 131–135. https://doi.org/10.1111/j.1748-0361. 2004.tb00019.x

Cambridge Dictionary. (2023). *Acute.* https://dictionary.cambridge.org/us/dictionary/english/acute

Carr, D. & Luth, E. A. (2017). Advance care planning: Contemporary issues and future directions. *Innovation in Aging*, *1*(1), 1–10. https://doi:10.1093/geroni/igx012

Centers for Disease Control. (2023). *Systematic Reviews.* Retrieved at https://cdc.gov/library/researchguides/systematicreviews.html

Centers for Medicare and Medicaid. (2018). HHS. *HHS FY 2018 budget in brief-CMS-overview.* https://www.hhs.gov/about/budget/fy2018/budget/budget-in-brief/cms/index

The Conversation Project. (2022). *Your guide to choosing a health care proxy.* theconversationproject.org

Daily Caring. (2021). *End of life conversations with seniors: A guide for caregivers.* https://www.dailycaring.com/how-to-talk-about-end-of-life-with-seniors/

Dartmouth Atlas Project. (2017). *End-of-life cancer care.* https://www.dartmouthatlas.org/interactive-apps/end-of-life-cancer-care/

DataUSA. (2023). *Monett, MO.* https://datausa.io/profile/geo/monett-mo/#.~.:text=32.4%

Donaldson, M. S., Proquest (Firm), Institute of Medicine (U.S.). Division of Health Care Services & Committee on the Future of Primary Care. (2000). *Primary care: America's health in a new era.* National Academy Press. https://doi.org/10.17226/5152

Federal Emergency Management Agency. (2023). *Glossary.* Retrieved at https://www.fema.gov

Five Wishes. (2021). *Helping people talk about what matters most.* Five Wishes.

https://fivewishes.org/five-wishes/who-we-are/about-us/our-history-and-mission

Free Medical Dictionary. (n.d.). *End-of-life* https://medical-dictionary.thefreedictionary.com/end-of-life

Free Medical Dictionary. (n.d.). *Healthcare provider.* https://medical-dictionary.thefreedictionary.com/healthcare

Free Medical Dictionary. (n.d.). *Primary care provider.* https://medical-dictionary.thefreedictionary.com/Primarycareprovider

DataUSA. (2023). *Monett, MO.* https://datausa.io/profile/geo/monett-mo/#.~.:text=32.4%

Federal Emergency Management Agency. (2023). *Glossary.* Retrieved at https://www.fema.gov

Five Wishes. (2021). *Helping people talk about what matters most.* Five Wishes. https://fivewishes.org/five-wishes/who-we-are/about-us/our-history-and-mission

Free Medical Dictionary. (n.d.). *End-of-life.* https://medical-dictionary.thefreedictionary.com/end-of-life

Free Medical Dictionary. (n.d.). *Healthcare provider.* https://medical-dictionary.thefreedictionary.com/healthcare

Free Medical Dictionary. (n.d.). *Primary care provider.* https://medical-dictionary.thefreedictionary.com/Primarycareprovider

Hemsley, B., Meredith, J., Bryant, L., Wilson, N. J., Higgins, I., Georgiou, A., Hill, S., Balandin, S., & McCarthy, S. (2018). An integrative review of stakeholder views on advance care directives (ACD): Barriers and facilitators to initiation, documentation, storage, and implementation. *Patient Education and Counseling, 102*(6), 1067–1079. http://doi.org/10.1016/j.pec.2019.01.007

Hospitalist. (2015). *New Medicare rule will reimburse physicians for advance care planning*. https://www.the-hospitalist.org/hospitalist/article/122030/health-policy/new-medicare-rule-will-reimburse-physicians-advance-care

House, S. A., School, C., Ogilvie, W. A. (2022). Advance directives. National Library of Medicine. https://www.ncbi.nlm.nih.gov/books/NBK459133/

Howard, M., Bernard, C., Klein, D., Elston, D., Tan, A., Slaven, M., Barwich, D.,You, J. J. & Heyland, D. K. (2018). Barriers to and enablers of advance care planning with patients in primary care: Survey of health care providers. *Canadian Family Physician, 64*(4), e190-e198

Patient Self Determination Act, H.R. 4449, 101st Congress. (1990, July2) https://www.congress.gov/bill/101st-congress/house-bill/4449

Institute of Medicine (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life.* National Academies Press.

IvyPanda. (2020, December 16). *Watson's caring theory for nurse practitioners.* https://ivypanda.com/essays/watsons-caring-theory-for-nurse-practitioners/

Jezewski, M. A., Meeker, M. A., Sessanna, L., & Finnell, D. S. (2007). The effectiveness of interventions to increase advance directive completion rates. *The Journal of Aging Health, 19*(3), 519-536

Johnson, C. E., Singer, R., Masso, M., Sellars, M., & Silvester, W. (2015). Palliative healthcare professionals' experiences of caring for patients with advance care directives. *Australian Health Review, 39*, 154-159. http://dx.doi.org/10.1071/AH14119

Knight, K. (2021). 50 years of advance care planning: What do we call success? *Monash Bioethics Review 39,* 28-50. https://doi.org/10.1007/s40592-021-00127-3

Kunte, V., Johansen, M. L., & Isenberg-Cohen, S. (2017). Improving long-term care residents'outcomes by educating nursing staff on end-of-life communication. *The Journal of Hospice & Palliative Nursing, 19*(6). https://doi:-10.1097/NJH.0000000000000386

McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017). "I'm still here": What matters to people with intellectual disability during advance care planning. *JARID*, *30*(6), 1089-1098. http://dx.doi.org/10.1111/jar.12355

McQuown, C. M., Frey, J. A., Amireh, A., & Chaudhar, A. (2017). Transfer of DNR orders to the ED from extended care facilities. *American Journal of Emergency Medicine, 35*(7), 983-985. https://doi.org/10.1016/j.ajem.2017.02.007.

Merriam-Webster. (n.d.). *Cardiopulmonary Resuscitation.* https://www.merriam-webster.com/dictionary/cardiopulmonary%20resuscitation

Merriam-Webster. (n.d.). *Intubation.* https://www.merriam-webster.com/dictionary/intubation

Merriam-Webster. (n.d.). *Invasive Procedure*. https://www.merriam-webster.com/dictionary/invasive%20procedure

Merriam-Webster. (n.d.). *Living Will.* https://www.merriam-webster.com/dictionary/living%20will

Missouri Revisor of Statutes. (2021). *Revised Statues of Missouri, RSMo section 190.603.*

Lawserver. https://www.lawserver.com/law/state/missouri/mo-laws/missouri_laws_190-603

Missouri Revisor of Statutes. (1991). *Durable power of attorney for health care act, RSMo Section 404.800-872).* https://revisor.mo.gov

Missouri Revisor of Statutes. (1985). *Declaration operative, when, RSMo section 459.025*. https://revisor.mo.gov

Murphy, D. J., & Cluff, L. E. (1990). The SUPPORT study. *Journal of Clinical Epidemiology, 43 Suppl*, v-x. https://www.doi.org/10.1016/0895-4356(90)90210-G

Nagarajan, S. V., Lewis, V., Halcomb, E., Rhee, J., Morton, R. L., Mitchell, G. K., Tieman, J., Phillips, J. L., Detering, K., Gavin, J., & Clayton, J. M. (2022). Barriers and facilitators to nurse-led advance care planning and palliative care practice change in primary healthcare: A qualitative study. *Australian Journal of Primary Health, 28*(2), 151–157. https://doi.org/10.1071/PY21081

National Institute of Health (2018). *Advance care planning: Healthcare directives*. NIH. https://www.nia.nih.gov/health/advance-care-planning-health-care-directives

National POLST. (2021). *POLST for healthcare professionals.* Polst. https://polst.org/proffesionals-page/?pro=1

Neubauer, M. A., Taniguchi, C. B., & Hoverman, J. R. (2015). Improving incidence of code status documentation through process and discipline. *Journal of Oncology Practice, 11*(2), e263-266.

Nursing Theory. (2020). *Watson's philosophy and science of caring.* Nursing Theory.

https://nursing-theory.org/theories-and-models/watson-philosophy-and-science-of-caring

Nursing World (2020). *ANA position statement: Nursing care and do-not-resuscitate (DNR) decisions.* https://ojin.nursingworld.or/MainMenuCategories/

Patient's Rights Council. (2015). *POLST: Important questions & answers.* https://patientsrightscouncil.org/site/polst-important-questions-answers/

Perry, S., & Lawand, C. (2017). A snapshot of advance directives in long-term care: How Often is "do not" done? *Healthcare Quarterly 19*(4), 10.

Pirinea, H., Simunich, T., Wehner, D., & Ashurst, J. (2016). Patient and healthcare provider interpretation of do not resuscitate and do not intubate. *Indian Journal of Palliative Care 22*(4), 432–436. http://wwwjpalliativecare.com.doi.10.4103/0973-1075.191784

Ramsaroop, S. D., Reid, M. C. & Adelman, R. D. (2007). Completing an advance directive in the primary care setting: What do we need for success? *Journal of American Geriatric Society, 55*(2), 277-283

Rando-Matos, Y., Vives-Argilagos, T., Rodero-Perez, E., Solsona-Diaz, L, Ballve-Moreno, J. L., Moreno-Farres, N., Sorando-Alastruey, R., Adroer-Martori, R., Sanfelui-Soto, N., & Almeda-Ortega, J. (2020). *Effectiveness of a brief advance directive intervention in primary care: A randomized clinical trial.* https://doi.org/10.1016/j.pec.2020.06.018

Rolnick, J. A., Shea, J. A., Hart, J. L., & Halpern, S. D. (2019). Patients' perspectives on approaches to facilitate completion of advance directives. *American Journal of Hospice 36*(6), 526-532. https://doi:10.1177/1049909118824548

Sabatino C. P. (2010). The evolution of health care advance planning law and policy. *The Milbank Quarterly*, *88*(2), 211-239. https://doi.org/10.1111/j.1468-0009.2010.00596.x

Sehgal, N. L., & Wachter, R. M. (2007). Identification of inpatient DNR status: A safety hazard begging for standardization. *Journal of Hospital Medicine*, *2*(6), 366-371. http://doi.10.1002/jhm.283.

Skrocki, M. (2013). Standardization needs for effective interoperability. *Transactions of the International Conference on Health Information Technology Advancement,* *2*(1), 76-83. http://scholarworks.wmich.edu/cgi/viewcontent.cgi?article=1039&context=ichita_transactions

Sizoo, E. M., Pasman, H. R., Buttolo J., Heimans, J. J., Klein, M., Deliens, L., Reijneveld, & J. C., Taphoorn, M. J. (2012). Decision-making in the end-of-life phase of high grade Glioma patients. *European Journal of Cancer 48,* 226-232. http://dx.doi.org/10.1016/j.ejca.2011.11.010

Spoelhof, G. D. & Elliott, B. (2012). Implementing advance directives in office practice. *American Family Physician*, *85*(5), 461-466

Statology. (2023). *When to use a Chi-Square test (With examples).* https://www.statology.org/when-to-use-chi-square-test/

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R.D., & Heyland, D. K. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*, *53*(5), 821–832. https://doi.org/10.1016.12.331

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments. *Jama*, 274(20), 1591-1598.

Thiese, M. S. (2014). Observational and interventional study design types: An overview. *Biochemia Medica, 24*(2), 199-210. https://doi.org/10.11613/BM.2014.022

Trees, A. R., Ohs, J. E., & Murray, M. C. (2017). Family communication about end-of-life decisions and the enactment of the decision-maker role. *Behavioral Sciences 7*(2), 36-49. https://doi.org/10.3390/bs7020036

United States Census Bureau. (2021). *Quick facts Monett City, Missouri.* https://www.census.gov/quickfacts/monettcitymissouri

United States Department of Health and Human Services. (2008). *Advance directives and advance care planning: Report to Congress.* https://aspe.hhs.gov/sites/default/files/private/pdf/75811/ADCongRpt.pdf

United States Legal Definitions. (n.d.). *Durable power of attorney.* https://definitions.uslegal.com/d/durable-power-of-attorney/

UpToDate. (2023). Advance care planning and advance directives. https://www.uptodate.com/contents/advance-care-planning-and-advance-directives#H2095034

Wissow, L. S., Belote, A., Phillips, A. Kritzler, R., & Weiner, J. P. (2004). Promoting advance directives among elderly primary care patients. *General Internal Medicine, 19*, 944-951. http://dx.doi.org/10.1111/j.1525-1497.2004.30117x

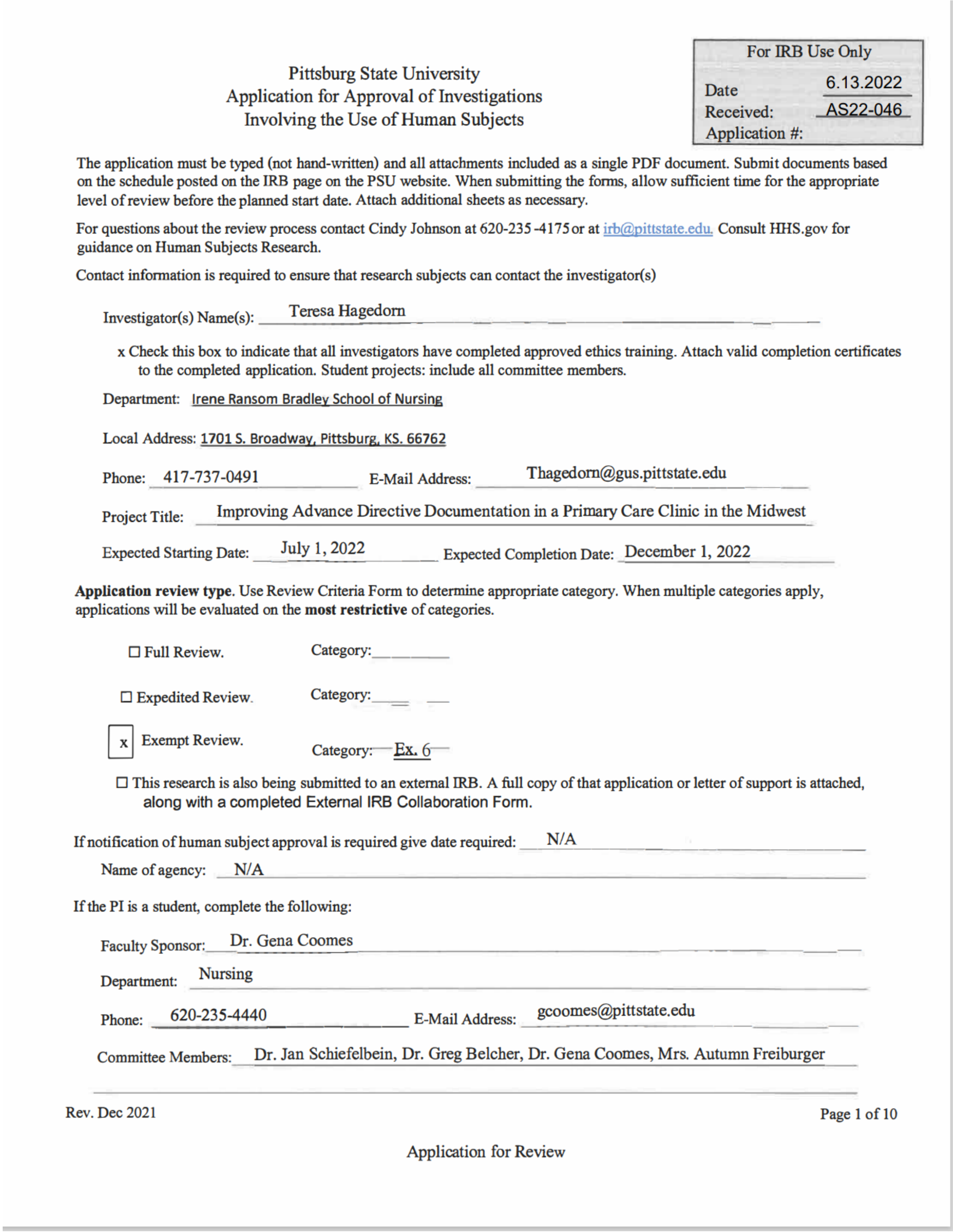
Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., Mante, A., Halpern, S. D., & Coutright, K. R. (2017). Approximately one in three US adults completes any advance directive for end-of-life care. *Health Affairs, 36*(7), 1244–1251.

Yung, V. Y., Walling, A. M., Min, L., Wenger, N. S., & Ganz, D. A. (2010). Documentation of advance care planning for community-dwelling elders. *Journal of Palliative Medicine, 13*(7), 861–867.

Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., & Laciejewski, M. L. (2009). Health care costs in the last week of life. *Archives of Internal Medicine 2009, 169*(5), 480-488. https://www.doi.org/10.1001/archinternmed.2008.587

APPENDICES

Appendix A



For IRB Use Only	
Date Received:	6.13.2022
Application #:	AS22-046

Pittsburg State University
Application for Approval of Investigations
Involving the Use of Human Subjects

The application must be typed (not hand-written) and all attachments included as a single PDF document. Submit documents based on the schedule posted on the IRB page on the PSU website. When submitting the forms, allow sufficient time for the appropriate level of review before the planned start date. Attach additional sheets as necessary.

For questions about the review process contact Cindy Johnson at 620-235-4175 or at irb@pittstate.edu. Consult HHS.gov for guidance on Human Subjects Research.

Contact information is required to ensure that research subjects can contact the investigator(s)

Investigator(s) Name(s): Teresa Hagedorn

x Check this box to indicate that all investigators have completed approved ethics training. Attach valid completion certificates to the completed application. Student projects: include all committee members.

Department: Irene Ransom Bradley School of Nursing

Local Address: 1701 S. Broadway, Pittsburg, KS. 66762

Phone: 417-737-0491 E-Mail Address: Thagedorn@gus.pittstate.edu

Project Title: Improving Advance Directive Documentation in a Primary Care Clinic in the Midwest

Expected Starting Date: July 1, 2022 Expected Completion Date: December 1, 2022

Application review type. Use Review Criteria Form to determine appropriate category. When multiple categories apply, applications will be evaluated on the **most restrictive** of categories.

☐ Full Review. Category:

☐ Expedited Review. Category:

☒ Exempt Review. Category: Ex. 6

☐ This research is also being submitted to an external IRB. A full copy of that application or letter of support is attached, along with a completed External IRB Collaboration Form.

If notification of human subject approval is required give date required: N/A

Name of agency: N/A

If the PI is a student, complete the following:

Faculty Sponsor: Dr. Gena Coomes

Department: Nursing

Phone: 620-235-4440 E-Mail Address: gcoomes@pittstate.edu

Committee Members: Dr. Jan Schiefelbein, Dr. Greg Belcher, Dr. Gena Coomes, Mrs. Autumn Freiburger

Rev. Dec 2021 Page 1 of 10

Application for Review

I. **Description of the Subjects**

A. How many subjects will be involved? A minimum of 144

B. Subject Population (check all that apply):

▪ Adults ☐ Prisoners ☐ Minors ☐ Intellectual Disability

☐ Physically Ill ☐ Disabled ☐ Special Education

☐ Other (explain): N/A

C. For projects conducted in schools or school settings, written approval from the School Administrator must be obtained. Please attach to end of this application.

Location: N/A

Name of School: N/A

What grade are the students in? N/A Approximate Age of Students? N/A

How many classes involved? N/A What subject: (secondary)? N/A

D. Does this research require participation from an organization other than PSU? If Yes, please attach a letter of support/understanding or documentation from that organization demonstrating approval or willingness to participate. *See attached letter from Autumn Freiburger*

E. What criteria will be used to select subjects AND/OR what criteria will be used to exclude individuals? (e.g., age, sex, race, ethnic origin, religion, or any social or economic qualifications)? State why the selection will be made on the basis or bases given.

Inclusion Criteria: Established clinic patients, 18 years of age and older, cognitively able to understand the information provided, and must understand the English language.

Exclusion Criteria: New patients, younger than 18 years of age, cognitive disability, do not understand the English language

II. Abstract: Summarize the strategies used to collect data and protect participants. Discuss what will be the purpose of collecting the data (e.g. is the data for an improvement project, is the data solely for a peer reviewed publication, is it a pilot for a larger study, etc.). Attach additional sheets as necessary.

Since the 1970's, advance directives (ADs) in healthcare have been available to make sure one's end-of-life wishes are known. However, the data shows that modest improvement of documentation of ADs has been gained. Awareness of end-of-life preferences allows respect and autonomy of self along with a sense of peace for the loved ones in mourning. The purpose of this quality improvement project is to:

1. Identify the percentage of a selected providers patients that have documented ADs in their electronic medical records without any identifying information. Autumn Freiburger (Cox Monett clinic manager) can assist in procuring this information, so the investigator never has access.

2. Prepare a PowerPoint presentation for select provider that will build on her current knowledge of ADs and how to communicate end-of-life information with her patient population.

3. The select provider will then offer patients that meet criteria with this information. This intervention will last over a 5-month period with the outcome of reaching a minimum of 144 patients.

4. Identifying the percentage of the select providers patients that have documented ADs in their electronic medical records will then be reassessed. The same care will be maintained in assuring patient privacy and no identifying information will be released to the investigator.

III. Procedure: Activities Involving Human Subjects. Attach additional sheets as needed.

A. Give a brief description or outline of your research procedures as they relate to the use of human subjects.

1. Who will be the subjects? How will you recruit participants into the study? If advertising for subjects, include a copy of the proposed advertisement.
After project approval is obtained from Irene Ransom Bradley School of Nursing, Pittsburg State University, and Cox Health System, the clinic manager (Autumn Frieburger) will be responsible for obtaining chart percentages prior to the educational intervention of patients that have a documented advanced directive in their electronic medical record. The primary care provider (Melissa Hitchcock, FNP-C) will also be provided with educational materials regarding advanced care planning and any questions she may have will be answered. The patients will be chosen daily for a 5-month period and receive information from Melissa and the principal investigator regarding advanced care planning. The clinic manager will then proceed with obtaining chart percentages of patients that have documented advanced directives in their electronic medical records after the five-month intervention period. The principal investigator will not have access to any patient charts/information.

The subjects will be the established patients of a single provider (Melissa Hitchcock, FNP-C) that meet the inclusion criteria listed above. Convenience sampling will be utilized for recruitment. No advertising will be needed.

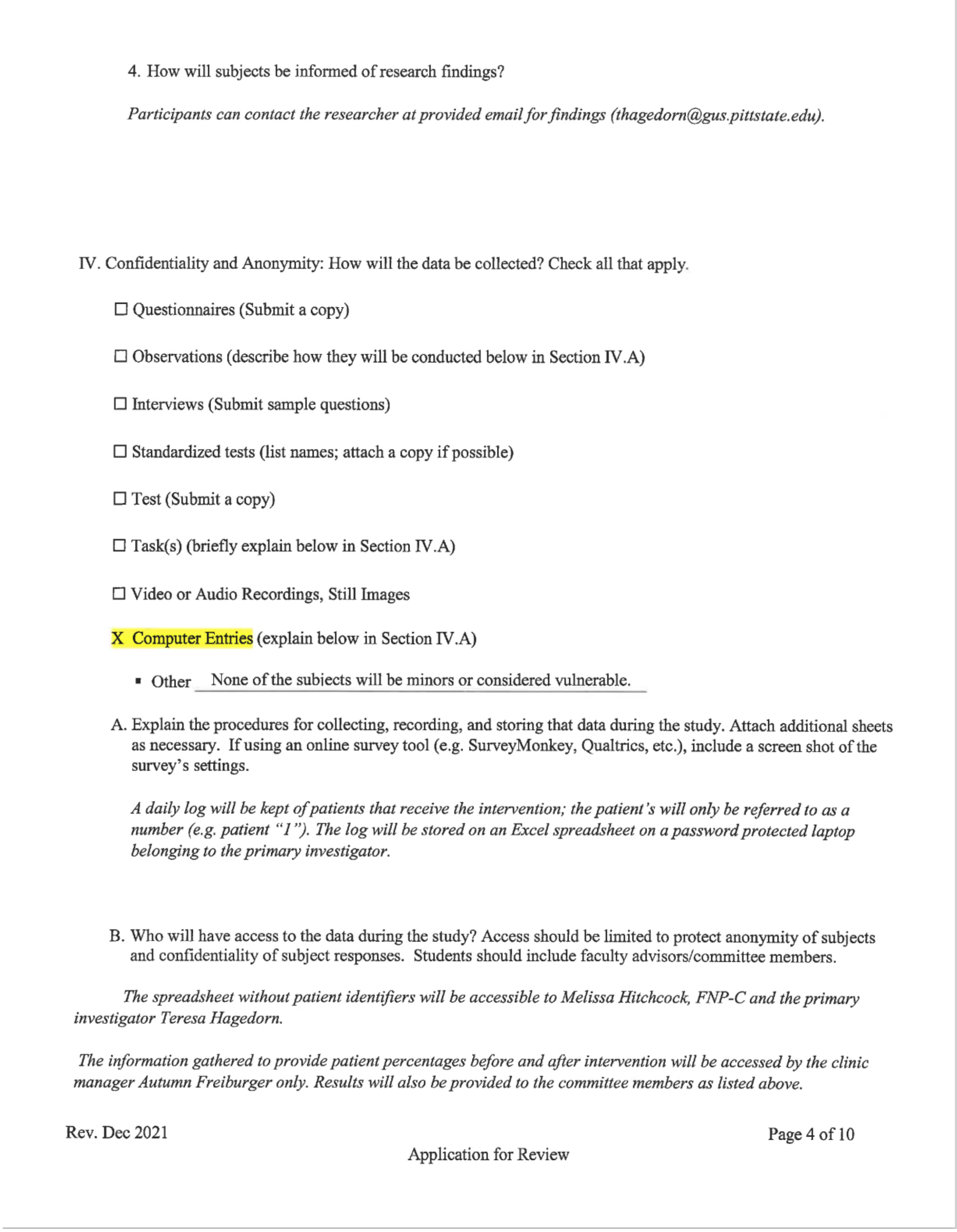
2. What precisely will be done to the subjects? State instructions given to the subjects and activities in which they will engage. If you are using questionnaires or handouts, please include a copy as an attachment to this application.

The provider will interact with the subjects whom she has developed a trusted provider/patient relationship with and discuss end-of-life decision making, why advance directives are important, choosing who they would like to speak for them if needed, and how to go about documenting an advance directive.

No questionnaires or handouts will be distributed.

3. If any of the subjects are minors or "vulnerable" (e.g. children, prisoners, mentally or physically disabled, pregnant women) discuss how their special condition will be handled.

None of the subjects will be minors or considered vulnerable.



4. How will subjects be informed of research findings?

Participants can contact the researcher at provided email for findings (thagedorn@gus.pittstate.edu).

IV. Confidentiality and Anonymity: How will the data be collected? Check all that apply.

☐ Questionnaires (Submit a copy)

☐ Observations (describe how they will be conducted below in Section IV.A)

☐ Interviews (Submit sample questions)

☐ Standardized tests (list names; attach a copy if possible)

☐ Test (Submit a copy)

☐ Task(s) (briefly explain below in Section IV.A)

☐ Video or Audio Recordings, Still Images

X Computer Entries (explain below in Section IV.A)

- Other None of the subjects will be minors or considered vulnerable.

A. Explain the procedures for collecting, recording, and storing that data during the study. Attach additional sheets as necessary. If using an online survey tool (e.g. SurveyMonkey, Qualtrics, etc.), include a screen shot of the survey's settings.

A daily log will be kept of patients that receive the intervention; the patient's will only be referred to as a number (e.g. patient "1"). The log will be stored on an Excel spreadsheet on a password protected laptop belonging to the primary investigator.

B. Who will have access to the data during the study? Access should be limited to protect anonymity of subjects and confidentiality of subject responses. Students should include faculty advisors/committee members.

The spreadsheet without patient identifiers will be accessible to Melissa Hitchcock, FNP-C and the primary investigator Teresa Hagedorn.

The information gathered to provide patient percentages before and after intervention will be accessed by the clinic manager Autumn Freiburger only. Results will also be provided to the committee members as listed above.

C. Explain what will happen to the data once the study is completed. Federal regulations require that data be kept for at least three years after completion of the research (45 CFR 46.115(b)). How will the data be protected during this time? Is there a need to keep the data beyond that or will it be destroyed? If kept, how long and where will it be stored, how will confidentiality be ensured, who will have access to it?

The spreadsheet data will be stored and kept on the primary investigator's personal laptop. The laptop will be secured in her home and pass code protected. At the end of the project, the data will be placed on a secure flash drive and placed in the committee chairperson's office for three years. The data will be deleted from investigator's personal laptop at that time. The information will be destroyed after the three-year period requirement. Confidentiality is ensured as no patient identifiers will be collected and stored.

D. Explain the level of confidentiality you are guaranteeing the participants. Include data privacy policies for all external tools being used.

No patient identifiers will be stored in data collection producing a minimal risk of confidentiality breach.

V. Benefits, Risks, and Costs of this Study

A. What are the potential benefits to the subjects, to the field or discipline, or to the University?

Potential psychological consequences such as emotional responses of anxiety or guilt from previous lived experiences are a minor risk involved.

B. Will compensation (money, extra credit, etc.) be offered to the subjects? If so, what specifically will be offered, and how will it be dispersed?

No compensation will be offered to the subjects.

C. What risks, discomforts, or other adverse reactions are most likely to be encountered by the subjects? Please consider carefully.

☐ Employability

☐ Financial or personal reputation

■ Emotional stress or discomfort

☐ Loss of confidentiality

☐ Physical stress or discomfort

☐ Other (explain): N/A

☐ Deception (benevolent misdirection)

☐ Embarrassment

☐ Psychological stress or discomfort

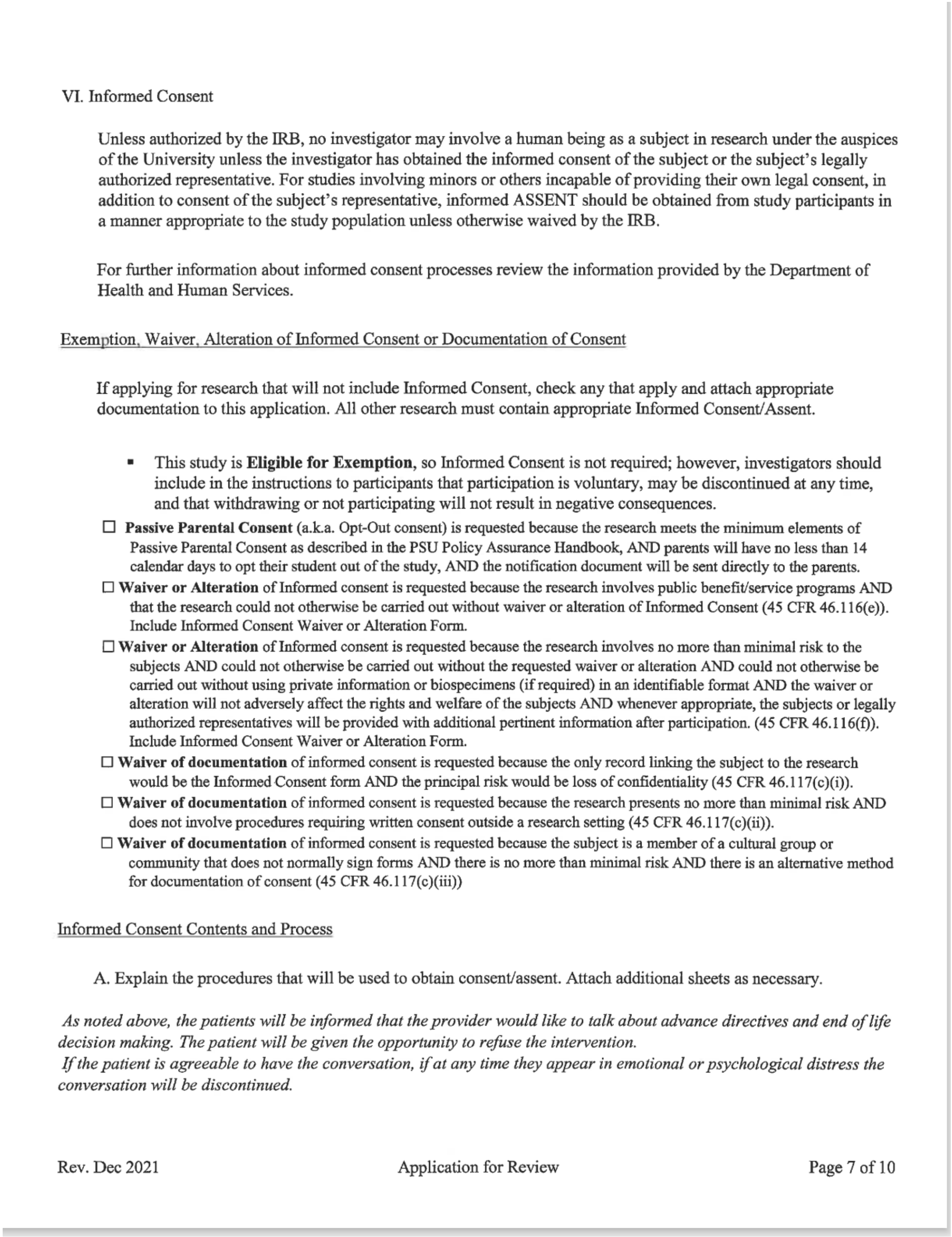
☐ Criminal or civil liability

D. What safeguards will you use to eliminate or minimize these risks? If there is the possibility of adverse reactions by the subjects, explain where the subjects can receive help.

The patients will be informed that the provider would like to talk about advance directives and end of life decision making. The patient will be given the opportunity to refuse the intervention. If the patient is agreeable to have the conversation, if at any time they appear in emotional or psychological distress the conversation will be discontinued. The participants may also stop participating in the conversation at any time without penalty or impact in their healthcare.

E. In your opinion, does the research involve more than minimal risk to subjects? "Minimal risk" means "the risks of harm anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine or psychological examinations or tests." (45 CFR 46.102(j)) Please explain.

It is my opinion that the quality improvement project does not involve more than minimal risk to subjects.



VI. Informed Consent

Unless authorized by the IRB, no investigator may involve a human being as a subject in research under the auspices of the University unless the investigator has obtained the informed consent of the subject or the subject's legally authorized representative. For studies involving minors or others incapable of providing their own legal consent, in addition to consent of the subject's representative, informed ASSENT should be obtained from study participants in a manner appropriate to the study population unless otherwise waived by the IRB.

For further information about informed consent processes review the information provided by the Department of Health and Human Services.

Exemption, Waiver, Alteration of Informed Consent or Documentation of Consent

If applying for research that will not include Informed Consent, check any that apply and attach appropriate documentation to this application. All other research must contain appropriate Informed Consent/Assent.

- This study is **Eligible for Exemption**, so Informed Consent is not required; however, investigators should include in the instructions to participants that participation is voluntary, may be discontinued at any time, and that withdrawing or not participating will not result in negative consequences.

☐ **Passive Parental Consent** (a.k.a. Opt-Out consent) is requested because the research meets the minimum elements of Passive Parental Consent as described in the PSU Policy Assurance Handbook, AND parents will have no less than 14 calendar days to opt their student out of the study, AND the notification document will be sent directly to the parents.

☐ **Waiver or Alteration** of Informed consent is requested because the research involves public benefit/service programs AND that the research could not otherwise be carried out without waiver or alteration of Informed Consent (45 CFR 46.116(e)). Include Informed Consent Waiver or Alteration Form.

☐ **Waiver or Alteration** of Informed consent is requested because the research involves no more than minimal risk to the subjects AND could not otherwise be carried out without the requested waiver or alteration AND could not otherwise be carried out without using private information or biospecimens (if required) in an identifiable format AND the waiver or alteration will not adversely affect the rights and welfare of the subjects AND whenever appropriate, the subjects or legally authorized representatives will be provided with additional pertinent information after participation. (45 CFR 46.116(f)). Include Informed Consent Waiver or Alteration Form.

☐ **Waiver of documentation** of informed consent is requested because the only record linking the subject to the research would be the Informed Consent form AND the principal risk would be loss of confidentiality (45 CFR 46.117(c)(i)).

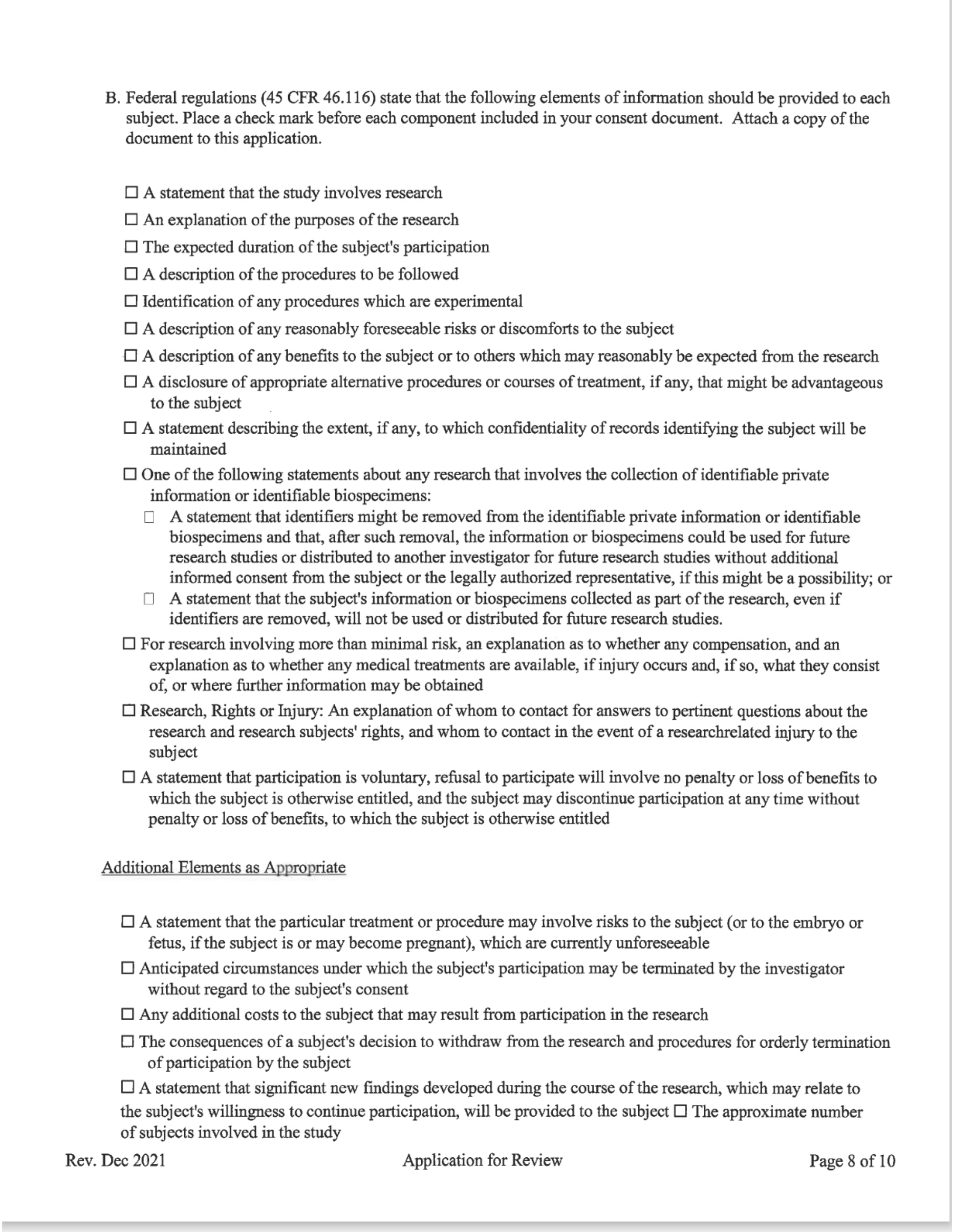
☐ **Waiver of documentation** of informed consent is requested because the research presents no more than minimal risk AND does not involve procedures requiring written consent outside a research setting (45 CFR 46.117(c)(ii)).

☐ **Waiver of documentation** of informed consent is requested because the subject is a member of a cultural group or community that does not normally sign forms AND there is no more than minimal risk AND there is an alternative method for documentation of consent (45 CFR 46.117(c)(iii))

Informed Consent Contents and Process

A. Explain the procedures that will be used to obtain consent/assent. Attach additional sheets as necessary.

As noted above, the patients will be informed that the provider would like to talk about advance directives and end of life decision making. The patient will be given the opportunity to refuse the intervention.
If the patient is agreeable to have the conversation, if at any time they appear in emotional or psychological distress the conversation will be discontinued.



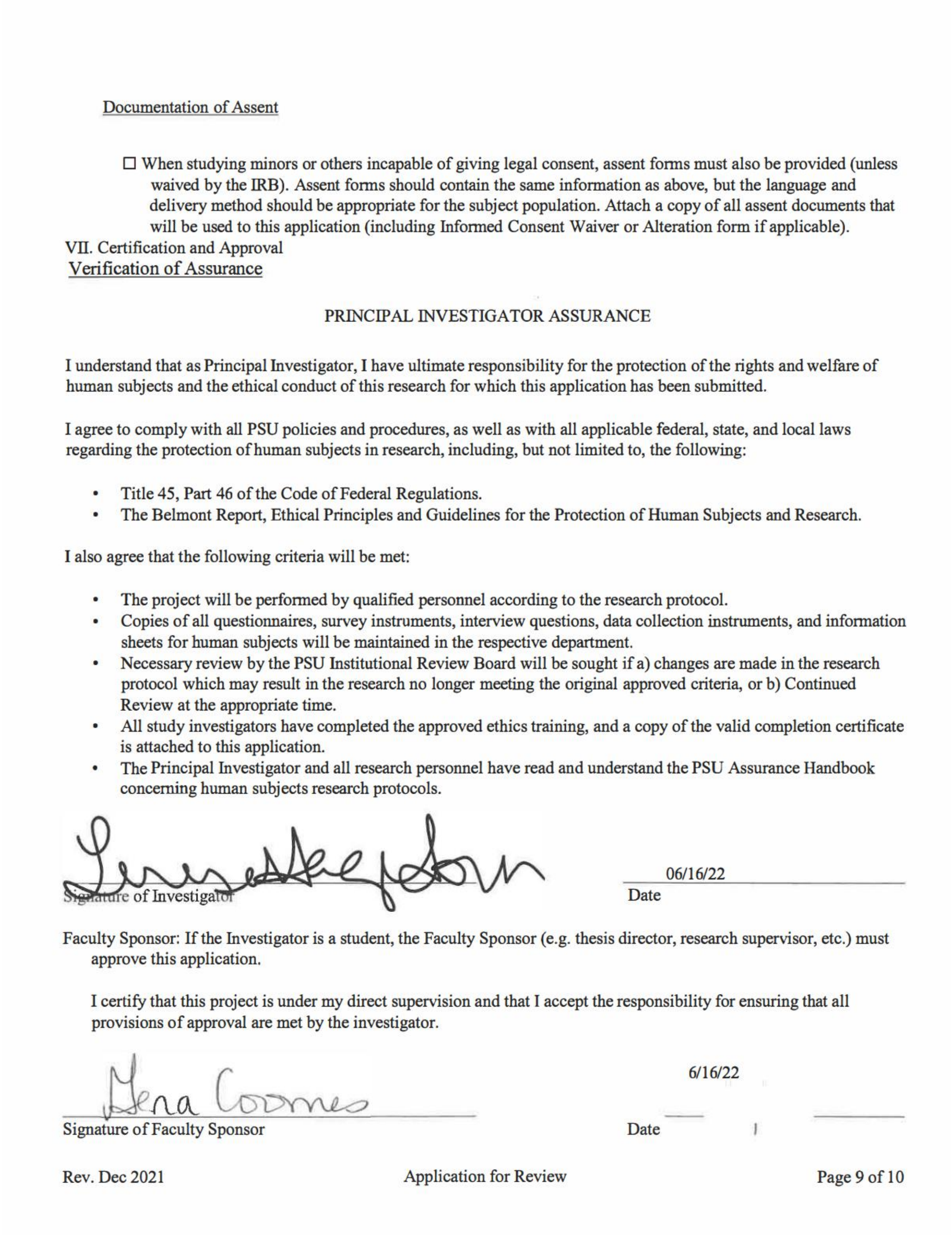
B. Federal regulations (45 CFR 46.116) state that the following elements of information should be provided to each subject. Place a check mark before each component included in your consent document. Attach a copy of the document to this application.

- ☐ A statement that the study involves research
- ☐ An explanation of the purposes of the research
- ☐ The expected duration of the subject's participation
- ☐ A description of the procedures to be followed
- ☐ Identification of any procedures which are experimental
- ☐ A description of any reasonably foreseeable risks or discomforts to the subject
- ☐ A description of any benefits to the subject or to others which may reasonably be expected from the research
- ☐ A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject
- ☐ A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained
- ☐ One of the following statements about any research that involves the collection of identifiable private information or identifiable biospecimens:
    - ☐ A statement that identifiers might be removed from the identifiable private information or identifiable biospecimens and that, after such removal, the information or biospecimens could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from the subject or the legally authorized representative, if this might be a possibility; or
    - ☐ A statement that the subject's information or biospecimens collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies.
- ☐ For research involving more than minimal risk, an explanation as to whether any compensation, and an explanation as to whether any medical treatments are available, if injury occurs and, if so, what they consist of, or where further information may be obtained
- ☐ Research, Rights or Injury: An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a researchrelated injury to the subject
- ☐ A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and the subject may discontinue participation at any time without penalty or loss of benefits, to which the subject is otherwise entitled

Additional Elements as Appropriate

- ☐ A statement that the particular treatment or procedure may involve risks to the subject (or to the embryo or fetus, if the subject is or may become pregnant), which are currently unforeseeable
- ☐ Anticipated circumstances under which the subject's participation may be terminated by the investigator without regard to the subject's consent
- ☐ Any additional costs to the subject that may result from participation in the research
- ☐ The consequences of a subject's decision to withdraw from the research and procedures for orderly termination of participation by the subject

☐ A statement that significant new findings developed during the course of the research, which may relate to the subject's willingness to continue participation, will be provided to the subject ☐ The approximate number of subjects involved in the study



Documentation of Assent

☐ When studying minors or others incapable of giving legal consent, assent forms must also be provided (unless waived by the IRB). Assent forms should contain the same information as above, but the language and delivery method should be appropriate for the subject population. Attach a copy of all assent documents that will be used to this application (including Informed Consent Waiver or Alteration form if applicable).

VII. Certification and Approval

Verification of Assurance

PRINCIPAL INVESTIGATOR ASSURANCE

I understand that as Principal Investigator, I have ultimate responsibility for the protection of the rights and welfare of human subjects and the ethical conduct of this research for which this application has been submitted.

I agree to comply with all PSU policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects in research, including, but not limited to, the following:

- Title 45, Part 46 of the Code of Federal Regulations.
- The Belmont Report, Ethical Principles and Guidelines for the Protection of Human Subjects and Research.

I also agree that the following criteria will be met:

- The project will be performed by qualified personnel according to the research protocol.
- Copies of all questionnaires, survey instruments, interview questions, data collection instruments, and information sheets for human subjects will be maintained in the respective department.
- Necessary review by the PSU Institutional Review Board will be sought if a) changes are made in the research protocol which may result in the research no longer meeting the original approved criteria, or b) Continued Review at the appropriate time.
- All study investigators have completed the approved ethics training, and a copy of the valid completion certificate is attached to this application.
- The Principal Investigator and all research personnel have read and understand the PSU Assurance Handbook concerning human subjects research protocols.

Signature of Investigator

06/16/22
Date

Faculty Sponsor: If the Investigator is a student, the Faculty Sponsor (e.g. thesis director, research supervisor, etc.) must approve this application.

I certify that this project is under my direct supervision and that I accept the responsibility for ensuring that all provisions of approval are met by the investigator.

Gena Coomes
Signature of Faculty Sponsor

6/16/22
Date

Rev. Dec 2021 Application for Review Page 9 of 10

Department Reviewer: I acknowledge that this research is in keeping with the standards set by our department, university, state and federal agencies. I assure that the principal investigator has met all departmental requirements for review and approval of this research, and that this application is complete and correct.

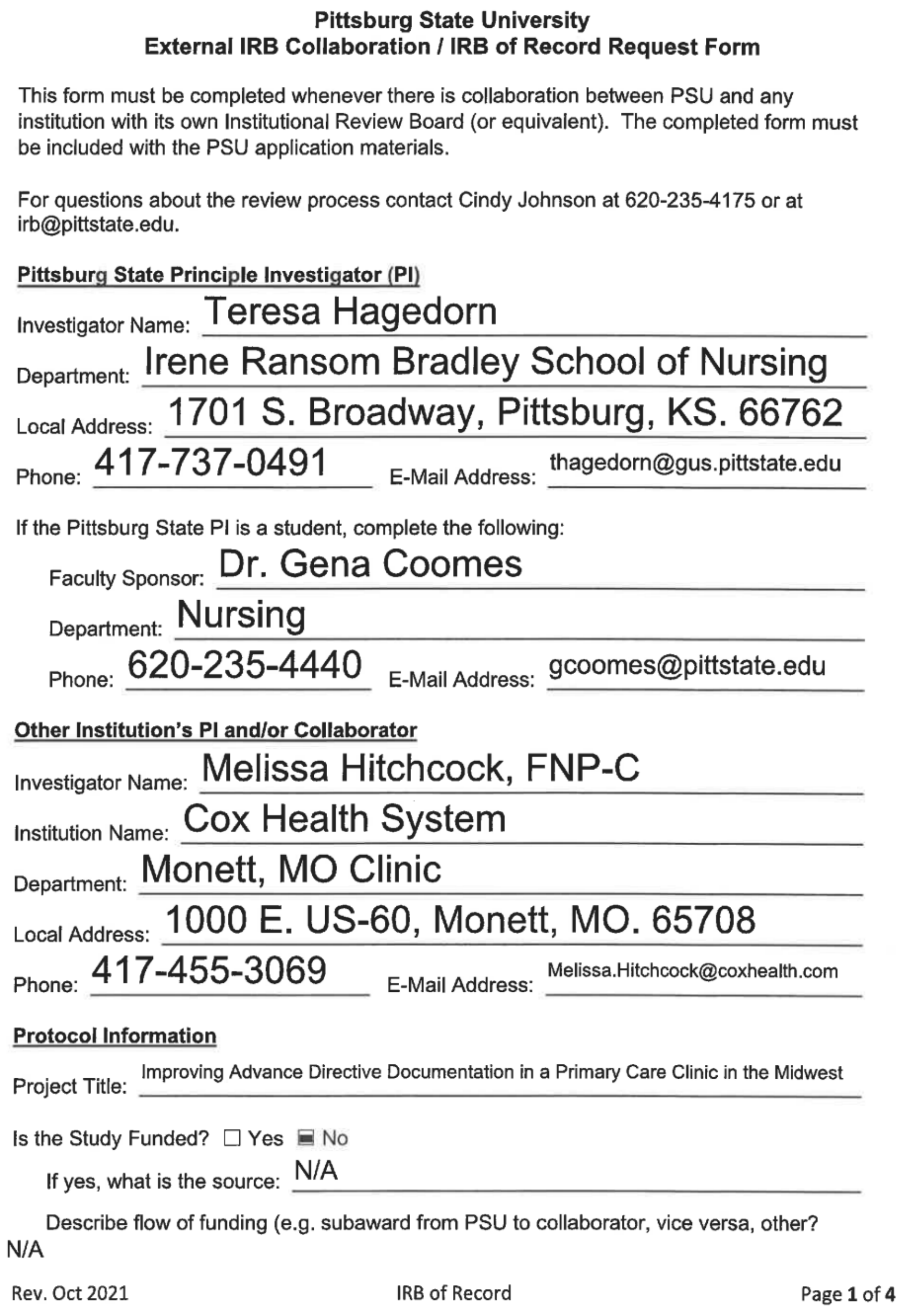
Amanda Alonzo

6/16/22

Signature of Department Representative

Date

Appendix B



Pittsburg State University
External IRB Collaboration / IRB of Record Request Form

This form must be completed whenever there is collaboration between PSU and any institution with its own Institutional Review Board (or equivalent). The completed form must be included with the PSU application materials.

For questions about the review process contact Cindy Johnson at 620-235-4175 or at irb@pittstate.edu.

Pittsburg State Principle Investigator (PI)

Investigator Name: Teresa Hagedorn
Department: Irene Ransom Bradley School of Nursing
Local Address: 1701 S. Broadway, Pittsburg, KS. 66762
Phone: 417-737-0491 E-Mail Address: thagedorn@gus.pittstate.edu

If the Pittsburg State PI is a student, complete the following:

Faculty Sponsor: Dr. Gena Coomes
Department: Nursing
Phone: 620-235-4440 E-Mail Address: gcoomes@pittstate.edu

Other Institution's PI and/or Collaborator

Investigator Name: Melissa Hitchcock, FNP-C
Institution Name: Cox Health System
Department: Monett, MO Clinic
Local Address: 1000 E. US-60, Monett, MO. 65708
Phone: 417-455-3069 E-Mail Address: Melissa.Hitchcock@coxhealth.com

Protocol Information

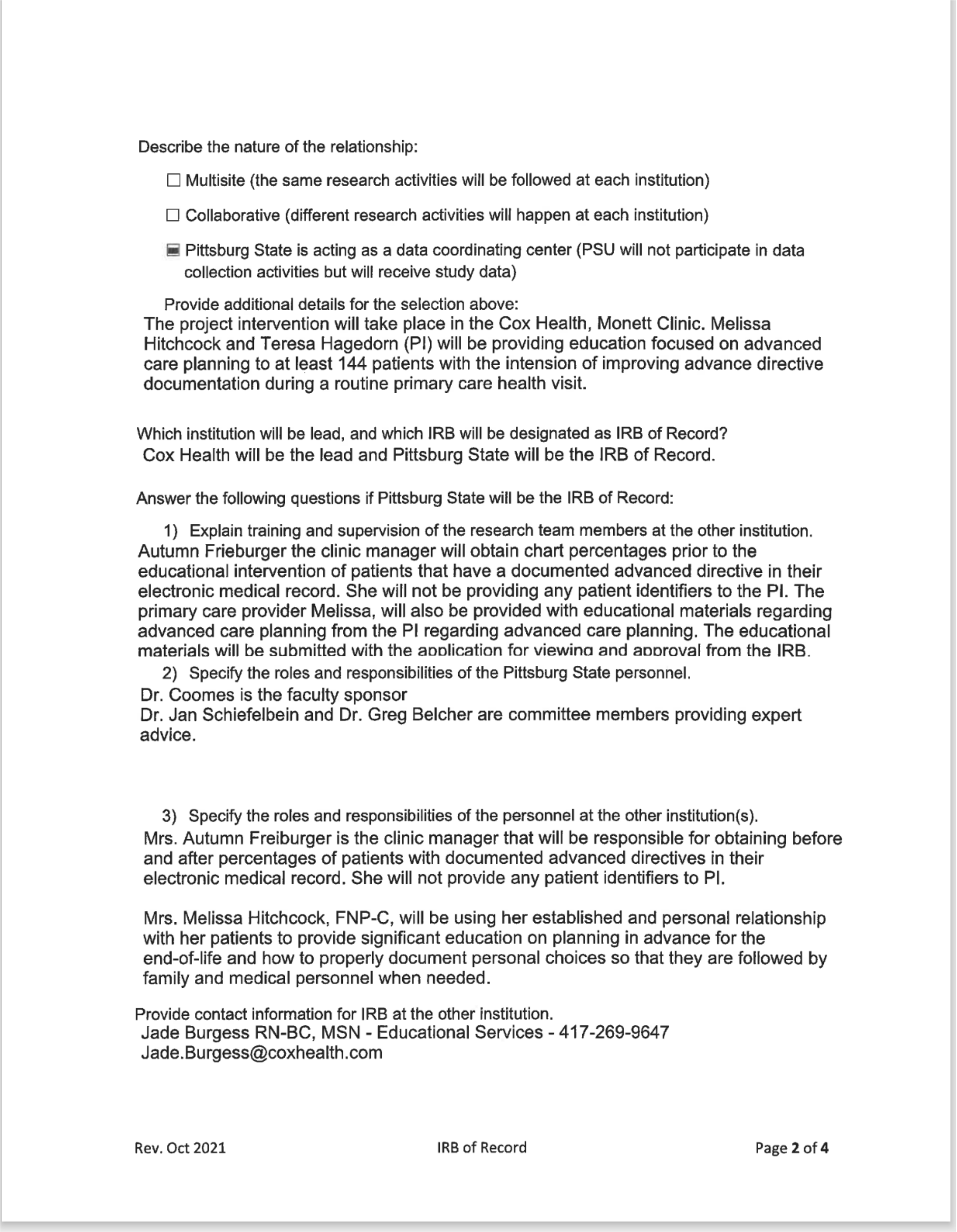
Project Title: Improving Advance Directive Documentation in a Primary Care Clinic in the Midwest

Is the Study Funded? ☐ Yes ☒ No

If yes, what is the source: N/A

Describe flow of funding (e.g. subaward from PSU to collaborator, vice versa, other?
N/A

Rev. Oct 2021 IRB of Record Page **1** of **4**



Describe the nature of the relationship:

☐ Multisite (the same research activities will be followed at each institution)

☐ Collaborative (different research activities will happen at each institution)

☒ Pittsburg State is acting as a data coordinating center (PSU will not participate in data collection activities but will receive study data)

Provide additional details for the selection above:

The project intervention will take place in the Cox Health, Monett Clinic. Melissa Hitchcock and Teresa Hagedorn (PI) will be providing education focused on advanced care planning to at least 144 patients with the intension of improving advance directive documentation during a routine primary care health visit.

Which institution will be lead, and which IRB will be designated as IRB of Record?

Cox Health will be the lead and Pittsburg State will be the IRB of Record.

Answer the following questions if Pittsburg State will be the IRB of Record:

1) Explain training and supervision of the research team members at the other institution.

Autumn Frieburger the clinic manager will obtain chart percentages prior to the educational intervention of patients that have a documented advanced directive in their electronic medical record. She will not be providing any patient identifiers to the PI. The primary care provider Melissa, will also be provided with educational materials regarding advanced care planning from the PI regarding advanced care planning. The educational materials will be submitted with the application for viewing and approval from the IRB.

2) Specify the roles and responsibilities of the Pittsburg State personnel.

Dr. Coomes is the faculty sponsor

Dr. Jan Schiefelbein and Dr. Greg Belcher are committee members providing expert advice.

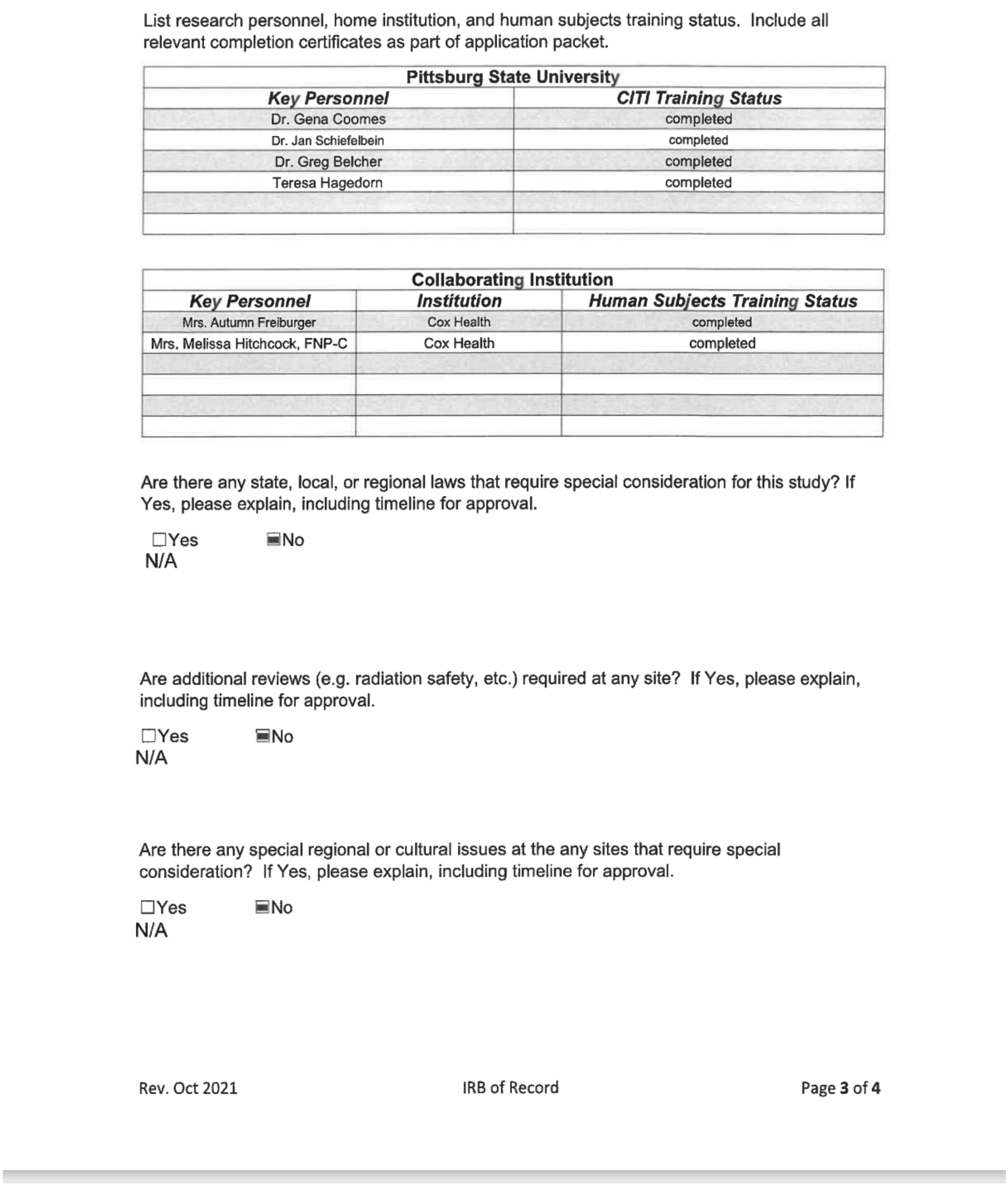
3) Specify the roles and responsibilities of the personnel at the other institution(s).

Mrs. Autumn Freiburger is the clinic manager that will be responsible for obtaining before and after percentages of patients with documented advanced directives in their electronic medical record. She will not provide any patient identifiers to PI.

Mrs. Melissa Hitchcock, FNP-C, will be using her established and personal relationship with her patients to provide significant education on planning in advance for the end-of-life and how to properly document personal choices so that they are followed by family and medical personnel when needed.

Provide contact information for IRB at the other institution.

Jade Burgess RN-BC, MSN - Educational Services - 417-269-9647
Jade.Burgess@coxhealth.com



List research personnel, home institution, and human subjects training status. Include all relevant completion certificates as part of application packet.

Pittsburg State University	
Key Personnel	***CITI Training Status***
Dr. Gena Coomes	completed
Dr. Jan Schiefelbein	completed
Dr. Greg Belcher	completed
Teresa Hagedorn	completed

Collaborating Institution		
Key Personnel	***Institution***	***Human Subjects Training Status***
Mrs. Autumn Freiburger	Cox Health	completed
Mrs. Melissa Hitchcock, FNP-C	Cox Health	completed

Are there any state, local, or regional laws that require special consideration for this study? If Yes, please explain, including timeline for approval.

☐Yes ☒No

N/A

Are additional reviews (e.g. radiation safety, etc.) required at any site? If Yes, please explain, including timeline for approval.

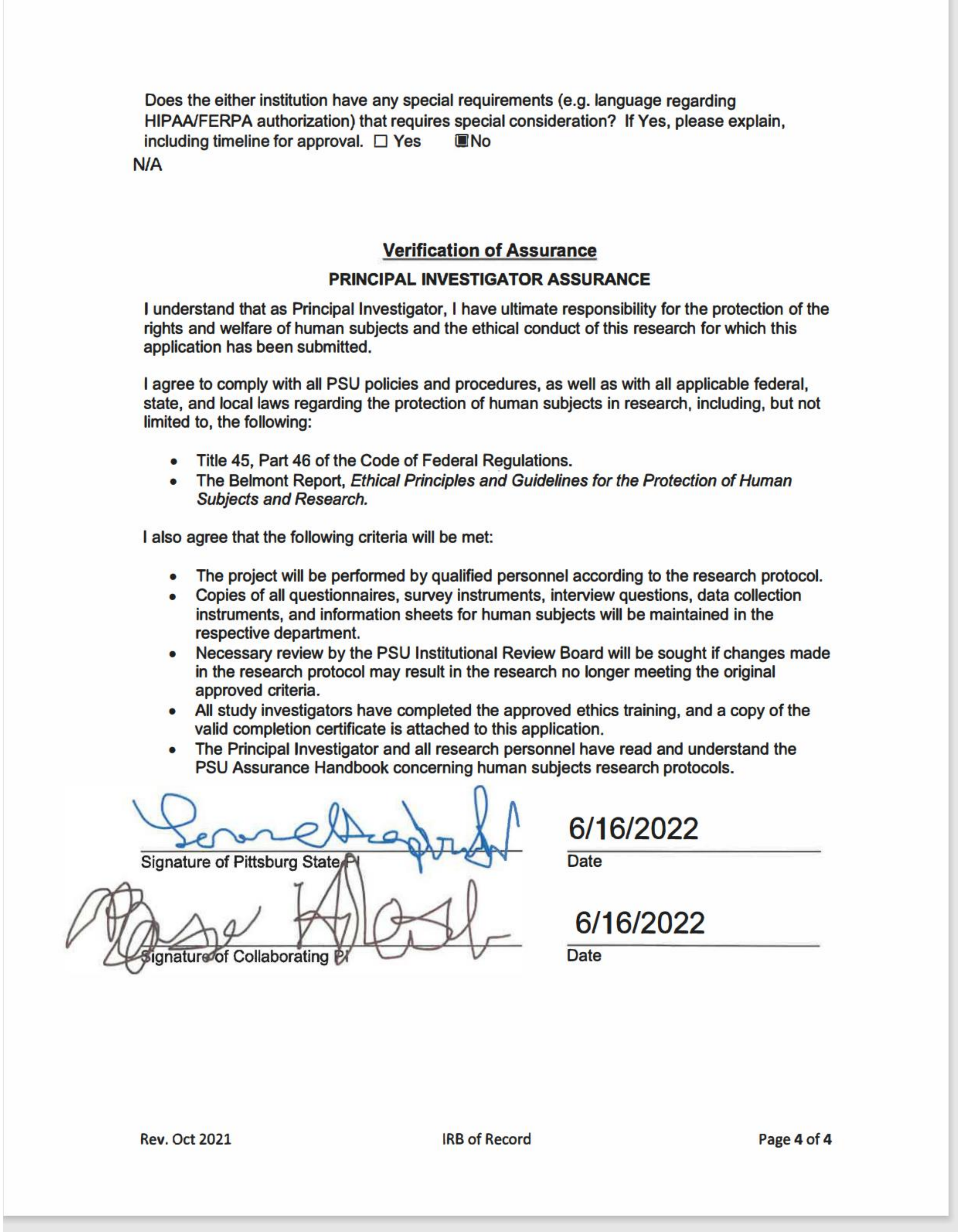
☐Yes ☒No

N/A

Are there any special regional or cultural issues at the any sites that require special consideration? If Yes, please explain, including timeline for approval.

☐Yes ☒No

N/A



Does the either institution have any special requirements (e.g. language regarding HIPAA/FERPA authorization) that requires special consideration? If Yes, please explain, including timeline for approval. ☐ Yes ☒ No

N/A

Verification of Assurance

PRINCIPAL INVESTIGATOR ASSURANCE

I understand that as Principal Investigator, I have ultimate responsibility for the protection of the rights and welfare of human subjects and the ethical conduct of this research for which this application has been submitted.

I agree to comply with all PSU policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects in research, including, but not limited to, the following:

- Title 45, Part 46 of the Code of Federal Regulations.
- The Belmont Report, *Ethical Principles and Guidelines for the Protection of Human Subjects and Research.*

I also agree that the following criteria will be met:

- The project will be performed by qualified personnel according to the research protocol.
- Copies of all questionnaires, survey instruments, interview questions, data collection instruments, and information sheets for human subjects will be maintained in the respective department.
- Necessary review by the PSU Institutional Review Board will be sought if changes made in the research protocol may result in the research no longer meeting the original approved criteria.
- All study investigators have completed the approved ethics training, and a copy of the valid completion certificate is attached to this application.
- The Principal Investigator and all research personnel have read and understand the PSU Assurance Handbook concerning human subjects research protocols.

Signature of Pittsburg State PI

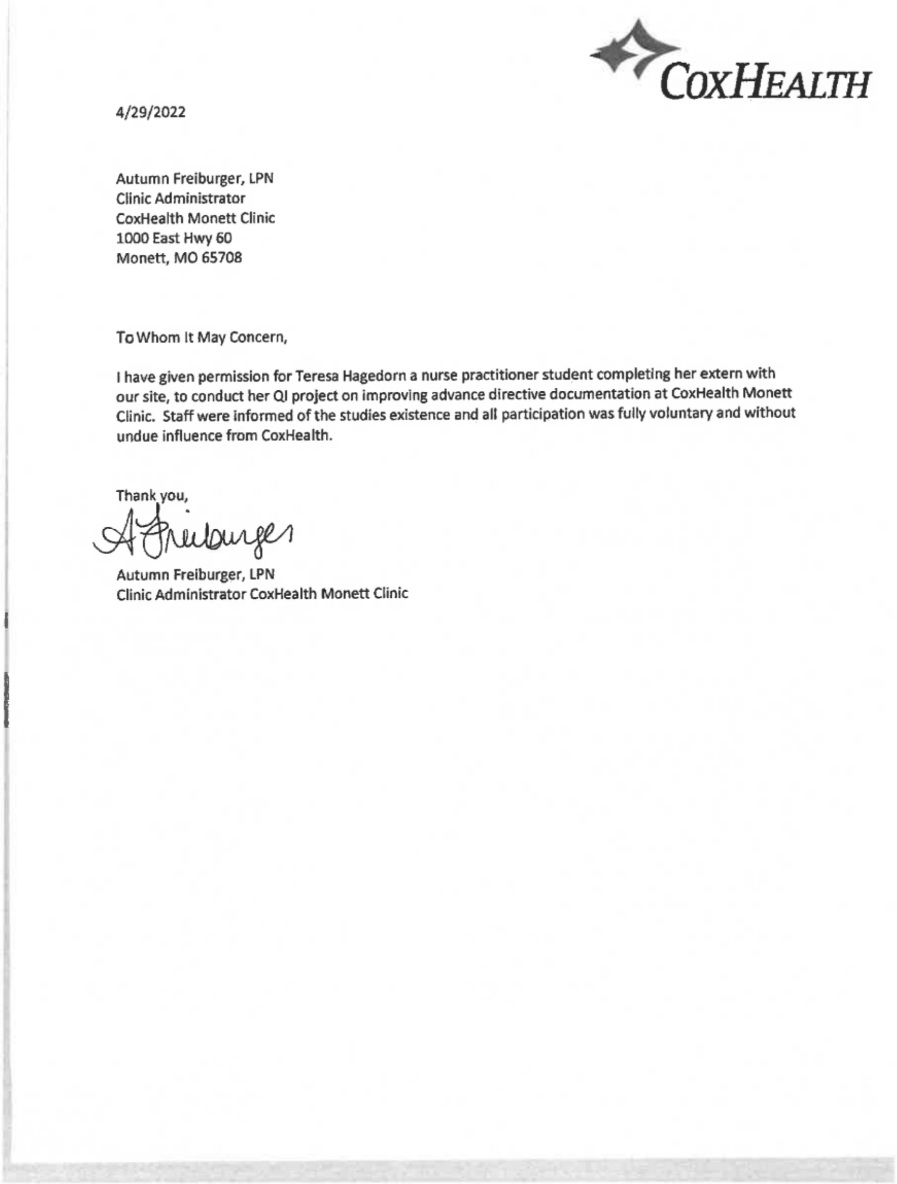
6/16/2022

Date

Signature of Collaborating PI

6/16/2022

Date



CoxHealth

4/29/2022

Autumn Freiburger, LPN
Clinic Administrator
CoxHealth Monett Clinic
1000 East Hwy 60
Monett, MO 65708

To Whom It May Concern,

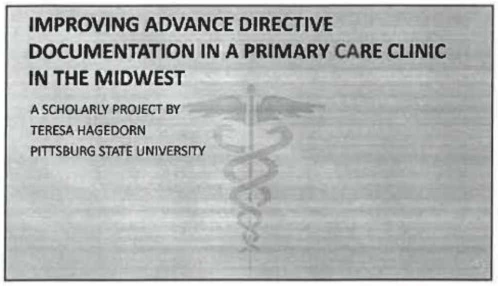
I have given permission for Teresa Hagedorn a nurse practitioner student completing her extern with our site, to conduct her QI project on improving advance directive documentation at CoxHealth Monett Clinic. Staff were informed of the studies existence and all participation was fully voluntary and without undue influence from CoxHealth.

Thank you,

A Freiburger

Autumn Freiburger, LPN
Clinic Administrator CoxHealth Monett Clinic

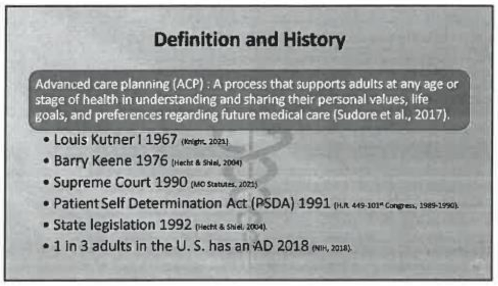
Appendix C



IMPROVING ADVANCE DIRECTIVE DOCUMENTATION IN A PRIMARY CARE CLINIC IN THE MIDWEST

A SCHOLARLY PROJECT BY
TERESA HAGEDORN
PITTSBURG STATE UNIVERSITY

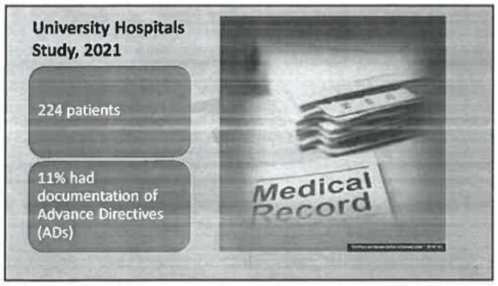
Provided as a YouTube video presentation for Melissa Hitchcock, NP.



Definition and History

Advanced care planning (ACP) : A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care (Sudore et al., 2017).

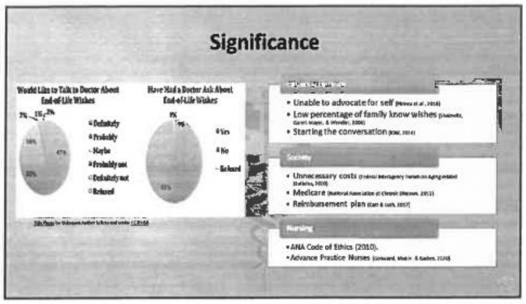
- Louis Kutner I 1967 (Knight, 2021)
- Barry Keene 1976 (Hecht & Shiel, 2004)
- Supreme Court 1990 (MO Statutes, 2021)
- Patient Self Determination Act (PSDA) 1991 (H.R. 449-101st Congress, 1989-1990).
- State legislation 1992 (Hecht & Shiel, 2004).
- 1 in 3 adults in the U. S. has an AD 2018 (NIH, 2018).



University Hospitals Study, 2021

224 patients

11% had documentation of Advance Directives (ADs)



Significance

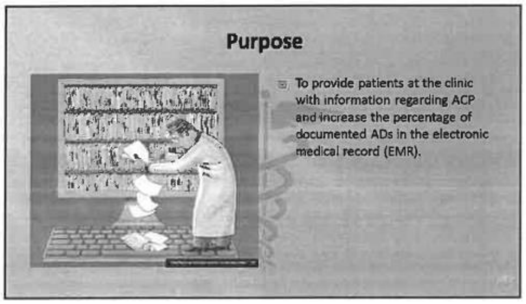
- Unable to advocate for self
- Low percentage of family know wishes
- Starting the conversation

Society

- Unnecessary costs
- Medicare
- Reimbursement plan

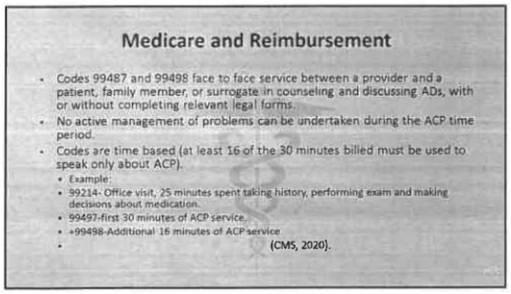
Nursing

- ANA Code of Ethics (2010).
- Advance Practice Nurses



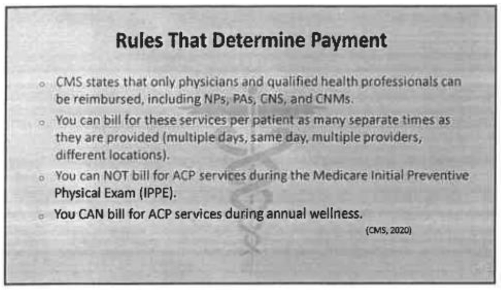
Purpose

- To provide patients at the clinic with information regarding ACP and increase the percentage of documented ADs in the electronic medical record (EMR).



Medicare and Reimbursement

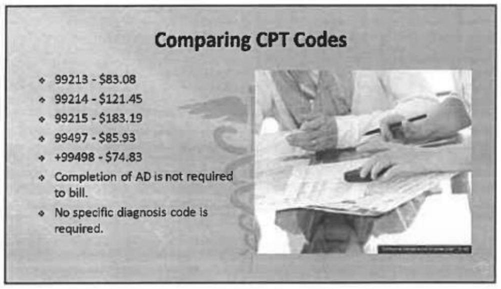
- Codes 99487 and 99498 face to face service between a provider and a patient, family member, or surrogate in counseling and discussing ADs, with or without completing relevant legal forms.
- No active management of problems can be undertaken during the ACP time period.
- Codes are time based (at least 16 of the 30 minutes billed must be used to speak only about ACP).
  - Example:
  - 99214- Office visit, 25 minutes spent taking history, performing exam and making decisions about medication.
  - 99497-first 30 minutes of ACP service.
  - +99498-Additional 16 minutes of ACP service
  - (CMS, 2020).



Rules That Determine Payment

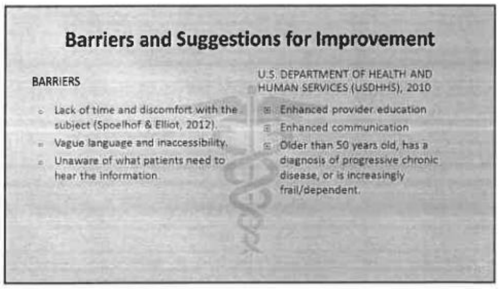
- CMS states that only physicians and qualified health professionals can be reimbursed, including NPs, PAs, CNS, and CNMs.
- You can bill for these services per patient as many separate times as they are provided (multiple days, same day, multiple providers, different locations).
- You can NOT bill for ACP services during the Medicare Initial Preventive Physical Exam (IPPE).
- You CAN bill for ACP services during annual wellness.

(CMS, 2020)



Comparing CPT Codes

- 99213 - $83.08
- 99214 - $121.45
- 99215 - $183.19
- 99497 - $85.93
- +99498 - $74.83
- Completion of AD is not required to bill.
- No specific diagnosis code is required.



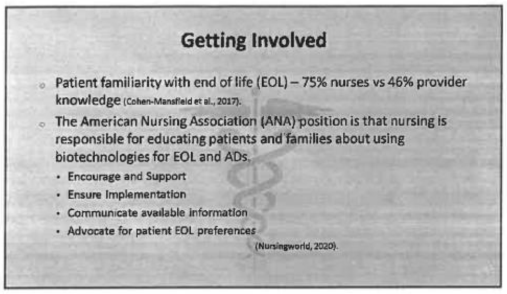
Barriers and Suggestions for Improvement

BARRIERS

- Lack of time and discomfort with the subject (Spoelhof & Elliot, 2012).
- Vague language and inaccessibility.
- Unaware of what patients need to hear the information.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (USDHHS), 2010

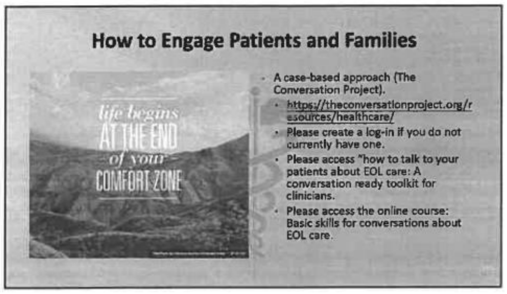
- Enhanced provider education
- Enhanced communication
- Older than 50 years old, has a diagnosis of progressive chronic disease, or is increasingly frail/dependent.



Getting Involved

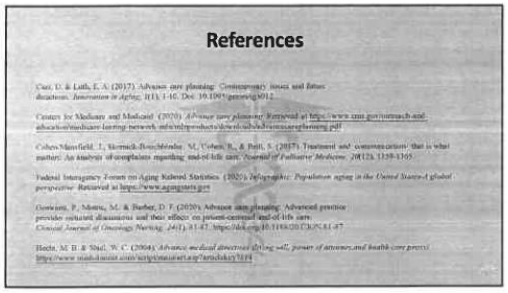
- Patient familiarity with end of life (EOL) – 75% nurses vs 46% provider knowledge (Cohen-Mansfield et al., 2017).
- The American Nursing Association (ANA) position is that nursing is responsible for educating patients and families about using biotechnologies for EOL and ADs.
  - Encourage and Support
  - Ensure Implementation
  - Communicate available information
  - Advocate for patient EOL preferences

(Nursingworld, 2020).

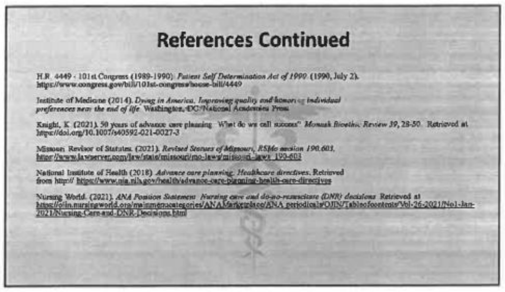


How to Engage Patients and Families

- A case-based approach (The Conversation Project).
  - https://theconversationproject.org/resources/healthcare/
  - Please create a log-in if you do not currently have one.
  - Please access "how to talk to your patients about EOL care: A conversation ready toolkit for clinicians.
  - Please access the online course: Basic skills for conversations about EOL care.



References



References Continued

H.R. 4449 - 101st Congress (1989-1990). *Patient Self Determination Act of 1990.* (1990, July 2). https://www.congress.gov/bill/101st-congress/house-bill/4449

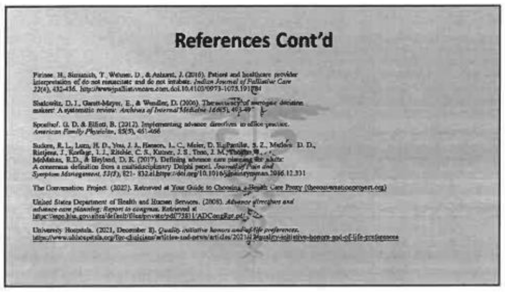
Institute of Medicine (2014). *Dying in America. Improving quality and honoring individual preferences near the end of life.* Washington, DC: National Academies Press.

Knight, K. (2021). 50 years of advance care planning: What do we call success? *Monash Bioethics Review 39*, 28-50. Retrieved at https://doi.org/10.1007/s40592-021-0027-3

Missouri Revisor of Statutes. (2021). *Revised Statutes of Missouri, RSMo section 190.603.* https://www.lawserver.com/law/state/missouri/mo-laws/missouri_laws_190-603

National Institute of Health (2018). *Advance care planning: Healthcare directives.* Retrieved from http:// https://www.nia.nih.gov/health/advance-care-planning-health-care-directives

Nursing World. (2021). *ANA Position Statement: Nursing care and do-not-resuscitate (DNR) decisions.* Retrieved at https://ojin.nursingworld.org/mainmenucategories/ANAMarketplace/ANAperiodicals/OJIN/TableofContents/Vol-26-2021/No1-Jan-2021/Nursing-Care-and-DNR-Decisions.html



References Cont'd

Pirinea, H., Simunich, T., Wehner, D., & Ashurst, J. (2016). Patient and healthcare provider interpretation of do not resuscitate and do not intubate. *Indian Journal of Palliative Care 22*(4), 432-436. http://www.jpalliativecare.com. doi:10.4103/0973-1075.191784

Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine 166*(5), 493-497.

Spoelhof, G. D. & Elliott, B. (2012). Implementing advance directives in office practice. *American Family Physician*, 85(5), 461-466

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R.D., & Heyland, D. K. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management, 53*(5), 821- 832.e1 https://doi.org/10.1016/j.jpainsymman.2016.12.331

The Conversation Project. (2022). Retrieved at Your Guide to Choosing a Health Care Proxy (theconversationproject.org)

United States Department of Health and Human Services. (2008). *Advance directives and advance care planning: Report to congress.* Retrieved at https://aspe.hhs.gov/sites/default/files/private/pdf/75811/ADCongRpt.pdf

University Hospitals. (2021, December 8). *Quality initiative honors end-of-life preferences.* https://www.uhhospitals.org/for-clinicians/articles-and-news/articles/2021/12/quality-initiative-honors-end-of-life-preferences