

Advance Directive Protocol in the Primary Care Setting

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Date of Submission: July 15, 2019

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Abstract

Background and Review of Literature: Advance directives (AD) are documents that offer patients a way to avoid unwanted care in the event of a serious illness or incapacity. Studies demonstrate the care patients receive at the end-of-life is not often consistent with their preferences, as a result of suboptimal communication between the patient and provider as well as documentation of health care proxies and treatment preferences (Isaac & Curtis, 2016). The lack of a current formal protocol used by primary care providers regarding ADs, particularly towards the young adult patient population, resulting in insufficient discussions of patients' wishes regarding end-of-life healthcare decisions is troubling (Stuart, Volandes, & Moulton, 2017).

Purpose: The purpose of this capstone project was to answer the clinical question, "How does the implementation of an advance directive/advance care planning protocol in a primary care office impact the completion rates of advance directives?"

Methods: This capstone project implemented an evidence-based practice intervention regarding advance care planning (ACP) in a primary care clinic. The project followed a descriptive quality process improvement design. The significance of the project outcome was determined by a hypothesis test based off of quantitative data collected prior to and after the implementation of the capstone intervention.

Results: Twenty-seven of the thirty-four pre-intervention patients, or approximately 79%, did not have any form of an AD and would have been appropriate candidates for the capstone intervention. Post-intervention data resulted in a total of twenty-eight patient chart audits. Fifteen or approximately 54% of the post-intervention population did not have any form of an AD. Out of the fifteen patients that did not have an AD, fourteen individuals were deemed appropriate candidates for the capstone intervention. After receiving information regarding ACP, two individuals opted to promptly schedule an appointment for ACP, eleven reported they would be scheduling an appointment at a later date, and one individual declined AD education and ACP options. A hypothesis test was conducted to determine the effect of the capstone interventions and concluded the findings were statistically significant.

Conclusion: A significantly higher proportion of patients were interested in ACP due to the effect of the capstone intervention as compared to the proportion that could be expected to be interested due to chance alone. This capstone project successfully evaluated the efficacy of an AD protocol in the primary care setting in relation to patients' readiness for ACP and ultimately AD completion.

Keywords: advance care planning, advance directive, primary care provider, end-of-life planning, living will, power of attorney

Advance Directive Protocol in the Primary Care Setting

In 1990, Congress passed the Patient Self-Determination Act (PSDA) in an attempt to promote patient autonomy by requiring health-care institutions and providers to provide information regarding advance directives (AD) and the right to accept or deny treatment to all patients (Miller, 2017). More specifically, facilities and/or providers receiving Medicare and Medicaid reimbursement are required by the PSDA to: (1) inform patients of their rights under state law to make decisions concerning their medical care; (2) periodically inquire as to whether a patient executed an AD and document the patient's wishes regarding their medical care; (3) not discriminate against persons who have executed an AD; (4) ensure that legally valid ADs and documented medical care wishes are implemented to the extent permitted by state law; and (5) provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and ADs (Congressional Research Service, 1990). Advance care planning (ACP) is appropriate for all adults, both young and old, yet has not been implemented equitably in the primary care setting due to a lack in process, which ultimately contributes to healthcare disparities (Yadav et al., 2017).

Background

Advance directives are documents that offer patients a way to avoid unwanted care in the event of a serious illness or incapacity. Specifically, an AD is a formal legal document completed by an individual and authorized by state law to be invoked if the patient is unable to make their own decisions due to an incapacitated health state (Yadav et al., 2017). A durable power of attorney for health care is an individual designated by the patient to serve as a surrogate or proxy under circumstances when the patient is unable to make healthcare decisions. A living

will is a written statement specifying preferences regarding the use of life-sustaining therapies and other medical treatments in the event of incapacity or terminal illness (Yadav et al., 2017).

In the United States, demographic trends document a growing aging population alongside the increasing prevalence of chronic disease amongst individuals 44 years and older (Rao, Anderson, Lin, & Laux, 2014). Evidence revealed social and cultural environments, individual beliefs of the healthcare provider, individual preferences, and family dynamics altogether contribute to the preparation of ADs (del Pozo Puente et al., 2014). In a study conducted by Rao et al. (2014), only 26.3% of the 7,946 respondents aged 18 years and older had an AD in some form or another.

According to Beddows (2017), 58 million people die around the world each year, 60% due to chronic diseases. The magnitude of this fact is demonstrated when considering each death involves at least five other people in caregiving and grieving. By 2030 there will be approximately 74 million deaths per year and 17% of the world will be aged 60 years and over (Beddows, 2017). Numerous studies have documented the care patients receive at the end-of-life is not often consistent with their preferences, as a result of suboptimal communication between the patient and provider as well as documentation of health care proxies and treatment preferences (Isaac & Curtis, 2016). As chronic conditions contribute to poorer health outcomes, morbidity and mortality rates are increasing which only stresses the importance of ACP to be facilitated at an earlier time than currently practiced.

Advance care planning can prevent unnecessary suffering at the end of life, support an individual's decisions and preferences, reduce unnecessary expensive treatment, and ultimately change the view of the public regarding end-of-life. Considering the substantial impact on patient care and cost, Medicare implemented reimbursement to healthcare providers who discuss

ACP with their patients. As of January 1, 2016, Medicare reimburses providers \$86 for an initial 30-minute outpatient consultation on ACP and \$80 for an initial inpatient consultation.

Additionally, Medicare will pay up to \$75 for any supplementary 30 minutes consultations in either setting (Zeitoun, 2015). Therefore, the amount of time allotted for typical visits does not often leave room for these important discussions.

Population and Stakeholders

The goal of healthcare is to provide comprehensive and holistic care to individuals in order to reach the best health state and quality of life while avoiding undesired disparities. The process of ACP is completed when patients and clinicians work together to achieve fully informed consent regarding patients' healthcare desires through shared decision-making (Stuart, Volandes, & Moulton, 2017). Improving the practice model for ACP will ultimately affect the stakeholders of the healthcare system and the targeted population being the primary care providers and patients at a local internal medicine office in the Midwest. Prolonging life for the individual that does not desire to do so only incurs costs for the patient, their family, the health care system, and society as a whole (Sonenberg & Sepulveda-Pacsi, 2018).

Problem Statement

Primary care providers have the opportunity to form rapport with patients over the years due to the unique and well-established patient-provider relationship. The problem is the lack of current formal protocol used by primary care providers regarding ADs, particularly towards the young adult patient population, resulting in insufficient discussions of patients' wishes regarding end-of-life healthcare decisions (Stuart, Volandes, & Moulton, 2017).

Purpose Statement

The purpose of this capstone project was to answer the clinical question, “How does the implementation of an advance directive/advance care planning protocol in a primary care office impact the completion rates of advance directives?”

Outcome

Research has highlighted obstacles interfering with AD completion including: poor provider knowledge regarding prognostic skills and communication related to end-of-life care, limited provider training in end-of-life counseling and care, limited availability to coordinated care models, and overall patient lack of knowledge and understanding related to ACP and end-of-life options (Sonenberg & Sepulveda-Pacsi, 2018). Practitioners are in the position to facilitate ACP for patients in the primary care office by way of providing opportunities for education and discussion regarding end-of-life healthcare options. Ultimately, both the patient and provider hold a role in the completion of an AD. By working in a proactive way rather than reactive, disparities and unnecessary healthcare expenditures will be decreased by giving the patient autonomy over their end-of-life decisions and ultimately increasing their overall quality of life.

Implementation of a formal ACP protocol at the primary care clinic was proposed for the purpose of improving overall ACP occurrence which was hypothesized to increase the completion of AD. The first step in ACP is overcoming the barrier of restriction to time by scheduling an appointment specifically for discussing ADs. To evaluate the success of the protocol in relation to scheduled ACP appointments, quantitative data was collected via a chart audit before and after the implementation of the project intervention. A hypothesis test for

proportions was conducted to determine the significance of the project intervention in relation to scheduled ACP appointments.

Review of Literature

The aim of the literature review was to identify and critically synthesize, analyze, and interpret the literature to be readily adopted and applied in the primary care setting regarding the implementation of an ACP protocol, later impacting the completion rates of ADs for the adult patient. Studies were screened, graded for quality, and analyzed independently; those reporting the barriers and facilitators to engagement in ACP and ADs were included. A comprehensive search of the literature was performed to determine evidence related to effective interventions aimed to answer the determined research-based project question, “How does the implementation of an advance directive/advance care planning protocol in a primary care office impact the completion rates of advance directives?”

Search Strategy

The database sources examined included Cumulative Index of Nursing and Allied Health Literature (CINAHL), Academic Search Elite, MEDLINE, Cochrane Central Register of Controlled Trials, Cochrane database of systematic reviews, Health Source – Consumer Editions, eBook Collection, EBSCOhost, ProQuest Nursing & Allied Health Source, and Cochrane Clinical Answers. Databases were searched using a comprehensive search engine, narrowing literature by applicable key words and phrases. Included key phrases found in the literature title and text included: advance care planning, advance directive, primary care provider, patient attitudes, end-of-life planning, and living will. Search results included systematic reviews, meta-analyses, qualitative studies, and quantitative studies.

Generated articles were further narrowed by applying specific requirements including peer-reviewed, research based, and the date of publication after 2013. Literature was reviewed independently confirming the study population involving the adult population in the United States, with the primary care provider as a substantial variable. References excluded were those addressing ADs for patients in the long-term care setting, disease specific populations, palliative or hospice-based setting, non-measurable outcomes, and recommendations for further research. Five articles were selected for data extraction (see Appendix A).

Literature Search Trail. A literature search trail was created as a guide to recreate a comprehensive, yet specific list of resources concerning the capstone project (see Appendix B). The PICOT components were distinguished in order to identify appropriate synonyms that could be used to reconstruct the literature search and include: primary care, general practice advance* directive, advance* care planning, model, tool, protocol, intervention, completion, engagement, success, and effect. Using a stepwise approach, five comprehensive searches yielded 22 articles (see Appendix C), all which were appropriate resources for the practice change of implementing an AD/ACP protocol in a primary care setting.

To further examine the appropriateness of the articles produced by the literature search trail, ten articles ranging from level I to IV were selected for further examination (see Appendix D). Diverse content was provided by both qualitative and quantitative research including: focus group study, pilot study, cross-sectional analytical study, cross-section survey, systematic literature review, expert opinion, randomized control intervention, and retrospective review. Topics of the research varied from health professionals' experiences in implementing ACP to Medicare payment/reimbursement.

Synthesis of Evidence

Strong evidence regarding barriers to the completion of AD included the lack of skills to deal with patients' vague healthcare related requests, difficulties with defining the right moment, and debate of who should initiate ACP. Facilitators include healthcare providers accumulated skills, ability to foresee a decline in health status, skills to respond to a patient's initiation of ACP, and a longstanding patient-provider relationship (De Vleminck et al., 2013). Nearly three-quarters or 71% of AD were completed one year or more before death, whereas AD completion within three months before death was associated with the younger patient population. Interestingly, minority populations, those with lower education, expected death, and the recent completion of an AD were associated with electing aggressive care (Enguiganos & Ailshire, 2017). Furthermore, Leder et al. (2015) discovered that conditions under which ADs were meant to apply were stated in broad terms and often presented as prewritten blocks of text. Per relatives' report, the majority were aware of the patient's wishes even though the format was predetermined. Assessing the strength of healthcare directive documents during acute situations revealed relatives favored the AD and found it to be more useful than healthcare providers leading the plan of care (Leder et al., 2015). Although intended to help protect patient privacy, legal formalities such as requiring the directive to be signed by two witnesses or be notarized, act as a barrier for vulnerable individuals in the execution and render ADs less clinically useful (Yadav et al., 2017).

The proportion of Americans with an AD has not significantly changed in the past five to ten years, with approximately one in three U.S. adults having completed any type of living will or establishing a durable medical power of attorney (Yadav et al., 2017). Common characteristics of those who prepared an AD include females, persons aged around 50 years, a

high level of education, lifestyles outside of living with a partner, and living in a household with children (del Pozo Puente et al., 2014). Moreover, ACP was often more prevalent in those who took chronic medications, frequently visited the specialist, and have had a long-term relationship with their family provider. Interestingly, having a relative or close friend who has completed an AD positively influenced patients' favor towards discussing end-of-life goals with healthcare providers (del Pozo Puente et al., 2014).

General practice physicians and nurse practitioners can easily engage themselves in ACP with patients, yet the incidence of actual occurrence remains low. Strong evidence was found in regards to primary care providers' attitudes surrounding barriers and facilitating factors associated with ACP. Providers have reported the belief that the patient should in fact initiate the discussion of ACP, which is ultimately a barrier to the completion of ADs. On the contrary, providers have the skills and ability to facilitate patients' desires to discuss AD in the primary care setting (De Vleminck et al., 2013). Studies show that patients believed it was the provider's responsibility to initiate health care planning, suggesting a gap in practice. This difference has been pointed out in previous studies and may explain why ACP consultations were often initiated when end-of-life decisions needed to be made (De Vleminck et al., 2013).

Timing was negatively associated with electing aggressive care, with odds reduced by 0.05% for each month before death the AD was completed (Enguiganos & Ailshire, 2017). Electing aggressive care was significantly higher in minority populations as compared with whites. In the same way, individuals with less than a high school education were associated with greater odds of electing aggressive care while having an expected death reduced the odds by 52% (Enguiganos & Ailshire, 2017). In comparison, Del Pozo Puente et al. (2014) analyzed the factors influencing the decision to prepare ADs, discovering a predominance of women (64.2%)

among those studied, with a mean age of 53.3 years. Higher rates of preparing and completing an AD was associated with secondary or higher education, a single lifestyle, higher than average number of specialist visits, family history of having a living will, and with lower levels of social interaction (del Pozo Puente et al., 2014).

The initiation of ACP in primary care may be improved by targeting the healthcare providers' skills, attitudes, and beliefs (De Vleminck et al., 2013). Open discussions with a primary care provider occurring early in the disease trajectory were found to be beneficial and were highly associated with completing AD before death. In the same way, earlier conversations and documentation in medical records provide clinicians with documented knowledge of the patients' values driving their care preferences (Enguiganos & Ailshire, 2017). In order to support patients' health care decisions, improved AD formats should be developed and the implementation must be incorporated into the training and continuing education for all healthcare providers (Leder et al., 2015).

Advance care planning policies and interventions should not only be directed to populations with low prevalence rates of completion, but also those at high risk for poor end-of-life care outcomes (Yadav et al., 2017). Several factors ranging from socio-demographic situations to health or functional status, affect the decision to formalize an AD. Considering the literature, more research is needed to identify the most appropriate strategies to train healthcare professionals in a way of increase dissemination at a social level regarding the content and purpose of ACP. By initiating the end-of-life conversation, patients may experience better satisfaction simply from being informed of the purpose and strength the legal document can hold in addition to the avoidance of unwanted medical treatment (del Pozo Puente et al., 2014).

Strengths and Limitations. Findings provided by De Vleminck et al. (2013) added to the knowledge of including studies on ACP discussions, yet findings were not generalizable to all countries and health care systems. The qualitative research and observational studies only examined the barriers and facilitators reported by general practitioners, disregarding the patients' perspective. Data collected at one point alone may lead to possible misinterpretation of data, for it was not uncommon for patients to change their care preferences and subsequently their directive over the course of an illness or disease progression (Enguiganos & Ailshire, 2017). Leder et al. (2015) prepared qualitative and quantitative procedures with detailed wording of the clause, making it available for the inquiries. Though the inquiries were potentially limiting, they were conducted in a way of gathering and documenting opinions of patients and providers in the acute care setting. Due to an insensitive search strategy, Yadav et al. (2017) potentially disregarded relevant data although the prevalence of AD among populations with various demographic was collected in a retrospective manner. Lastly, the compromised location and 1-year timeframe in which data was collected by del Pozo Puente et al. (2014) limited the study results to a single health district, hindering generalization of the results to other populations.

A major strength found in the review of literature was the availability of studies addressing multiple dynamics associated with, not only the prevalence of ADs, but also the barriers. A limitation was that the literature search did not provide a generalizable peer-reviewed study that would be suitable for the direct application to the capstone project. Interestingly, most resources found mentioned more information on the provider and relatives' opinion regarding ADs rather than the patients' outlook, satisfaction, and completion rate.

Summary of Findings

In summary, not only does an AD benefit the individual, research has shown the significant impact associated with ACP. Strong evidence was found for the crucial role health care providers' play in the initiation of ACP and completion of ADs for adult patients. These findings justified the need for the initiation of a formal protocol in the primary care setting in order to improve patient satisfaction, quality of life, and health care organization expenses.

Theoretical Framework

The Iowa Model of Research-Based Practice to Promote Quality Care (see Figure 1) was developed by a team of nurses from the University of Iowa Hospitals and Clinics (UIHC) and College of Nursing in the early 1990s intended to guide clinicians in evaluating and incorporating research findings into patient care. The idea for the Iowa model stemmed from a theory developed in 1983 known as Roger's Diffusion of Innovations (Buckwalter et al., 2017). As research developed alongside clinical practice, it became clear that using the best evidence to guide clinical decisions positively affected patient outcomes. The Iowa model was recently revised in 2012 to incorporate the use of multiple levels of evidence and reflect the expansion of evidence-based practice into the infusion of practice change (Buckwalter et al., 2017). Furthermore, the Iowa model has been recognized for its applicability in a variety of settings to address day-to-day clinical issues and promote quality of care (Fencl & Matthews, 2017).

The Iowa model framework begins with identifying a practice question or trigger. The practice question for this project was: "How does the implementation of an advance directive/advance care planning protocol in a primary care office impact the completion rate of advance directives in a 30-day time period?" The next step involved the nurse or team determining whether the problem at hand was a priority for the organization, department, or even

individual provider. An assessment of the community would help determine the significance and overall priority of the practice problem.

Higher priority may be given to topics that address high-volume or high-cost situations (Dang et al., 2015). In relation to prioritization and effect on stakeholders, it was hypothesized that the implementation of the capstone project would increase organizational profit as well as benefit the patient and provider. With a commitment from stakeholders to address the practice question, a plan was developed, implemented, and evaluated in regards to practice change. The final steps involved in the Iowa model framework include piloting a practice change, evaluating the pilot, evaluating practice changes, and dissemination of results (Dang et al., 2015). Although these are essentially final steps, the model was built in a way that incorporates a feedback loop that allows for constant evaluation and modification of implementing evidence-based research into practice (Buckwalter et al., 2017).

The Iowa Model of Research-Based Practice to Promote Quality Care is user driven and differs from other frameworks by way of linking practice changes within the system. The newly revised model is able to capture advances in translational research in addition to patient engagement. As a point of care clinician asking a practice question and seeking a systematic answer, this framework was appropriate for the capstone project.

Organizational Assessment

Founded in 1982 as the first health care system in the Midwest, the organization in which the project was implemented is now a leading regional integrated health care delivery system. Since the beginning, the Midwest health care system has stayed true to their mission: “Improving the health of our communities by the way we care, educate, and innovate.” Committed to providing the best care possible, the organization follows core values encompassing: patient-

centered care, respect and dignity to all, continuing to strive for excellence, teamwork, and dedication to serving the community. The Midwest health system services the regional network of healthcare providers, educators, and support services in the community through three hospitals, 21 health clinic locations, a nursing and allied health college, and a medical supply distributorship.

The particular clinic used from the Midwest health system was the largest, private, not-for-profit, multi-specialty group practice in Nebraska. As evidenced by the accreditation from the National Committee for Quality Assurance (NCQA), the Midwest physicians Family and Internal Medicine clinics strive to improve healthcare quality by working with employers, policymakers, physicians, nurse practitioners, patients, and health plans. The NCQA is an association that represents organizations committed to functioning in a way of making care better through the use of evidence-based practices (National Committee for Quality Assurance, 2018).

In 2017, an initiative incorporating the Nebraska Emergency Treatment Order (NETO) into practice was implemented by six Nebraska health care groups, one of which was the clinical site where the capstone project was executed. The overall goal of the NETO is to help individuals spell out their end-of-life wishes in a way of making patients retain their voice throughout the lifespan (Anderson, 2017). The three-month pilot study involved guidance from the developers of NETO alongside provider education regarding the document itself, conversation tactics, and suggested implementation into practice.

Facilitators and barriers to the change in practice became evident as the NETO pilot trial was conducted at the Midwest Internal Medicine clinic. The healthcare providers selected to participate in the pilot study appreciated the provided NETO documents and educational material. Unfortunately, the necessary time to discuss the components of an AD is not

automatically scheduled for patients without established ADs. Advance care planning is not feasible within the pre-scheduled 15 to 20-minute appointment that was allotted based on the patient's chief complaint alone. Some resistance against using a standardized form was seen, whereas some providers favored the materials in order to start an ACP conversation.

Advance care planning can be facilitated by multiple disciplines such as health coaches or registered nurses, yet these professionals were not involved in the original NETO initiative. Considering that the clinic in which the capstone project was implemented has taken an initiative to change the process of ACP for the patients, the risk of unintended consequences is minimal. Formulating a protocol or recommendation to facilitate ACP will require assistance from multiple departments. In order to avoid resistance and encourage cooperation, education regarding the capstone project was provided to the nurse practitioner, medical assistant, and registered nurse involved in the project prior to implementation.

Methodology

The goal of this capstone project was to implement an evidence-based practice intervention regarding ACP in a primary care clinic. The project followed a descriptive quality process improvement design. The significance of the project outcome was determined by a hypothesis test based off of quantitative data collected prior to and after the implementation of the capstone intervention.

Setting

The Internal Medicine clinic was located in the northwest region of a large metropolitan city in Nebraska. According to the Douglas County Health Department 2015 community health needs assessment, only 31.9% of Metro area adults have a completed AD or living will in place (Professional Research Consultants & Inc., 2015). Although there has been a 2.7% increase in

the completion of ADs from 2011 to 2015, there was still great room for improvement across the Metro area. Further examination of the 2015 demographics of the population with completed ADs reveal 16.3% age from 18 to 39, 35.1% age from 40 to 64, and 64.2% age 65 or greater (Professional Research Consultants & Inc., 2015).

The clinic was staffed with nine physicians that are board certified in Internal Medicine as well as three nurse practitioners. The internists specialize in caring for adolescents and adults by providing a variety of services to include: check-ups and annual exams, evaluations and treatment of acute and chronic illnesses, health screenings, laboratory tests, smoking cessation, disease prevention, and women's health. Written support for the use of the Internal Medicine clinic as the setting for the capstone project was obtained from the Director of Patient Operations.

Sample

The dynamic population of a primary care office consists of many interrelated stakeholders including patients, office managers, medical assistants, nursing assistants, registered nurses, physician assistants, nurse practitioners, physicians, and corporate departments. Although all components ultimately have an effect on implementing an AD practice change, a single provider has the position to make an authoritative decision to change the way ACP is incorporated into routine practice. Ultimately, both the patient and provider play a crucial role in ACP and the completion of an AD document. Providers in the primary care setting have the opportunity to form rapport with patients over the years due to the unique and well-established patient-provider relationship.

The sample population was collected from patients seeking medical care from a nurse practitioner. The population of interest encompassed patients of the Internal Medicine clinic

regardless of socioeconomic characteristics including sex, education level, income level, marital status, occupation, and religion. In addition, a My Accessible Real-Time Trusted Interpreter (MARTTI) was available to facilitate communication between all non-English speaking patients and the healthcare team. Participants were of legal adult age (19 years) in the state of Nebraska and had mental capacity or were accompanied by a legal guardian.

The reason for seeking medical care at the clinic was considered. Qualifying individuals included any patient presenting to the clinic for an annual examination, check-up regarding chronic conditions, hospital follow-up, or any non-emergent medical condition. Individuals with an established AD were included in the sample if they have a desire to make modifications to their living will and/or medical power of attorney. Patients were excluded from the sample population if they were mentally incapacitated without a legal guardian present, already have an established AD and did not desire modifications, or were being seen in office due to an emergent medical condition.

Implementation Procedures

Advance care planning is 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 and end-of-life healthcare preferences (Detering & Silveira, 2018). Prospective studies and randomized trials have shown ACP has significantly improved rates of AD completion, increased the likelihood that clinicians and families understand and comply with a patient's wishes, and ultimately increase the likelihood that a patient will die in their preferred place (Detering & Silveira, 2018). Ultimately, the first step in ACP is overcoming the barrier of restriction to time by scheduling an appointment specifically for discussing fatal health situations, individualized patient conditions, and components of an ADs. The purpose of the

project intervention was to incorporate the already established tools and resources into a protocol, in order to facilitate an opportunity for ACP for patients and their provider.

An office visit was initially scheduled when the patient contacts the office receptionist and provides the reason why they are seeking medical attention. This was often documented as the “chief complaint.” The reason for the visit helped determine potential participants of the intervention, as discussed in the sample population inclusion and exclusion criteria. The patient checked in with the office receptionist, confirmed personal/contact information, and insurance coverage.

Prior to the patient being seen by a provider, the nursing staff assisted the patient to the examination room to complete the check-in process. An ad hoc patient check-in document was used to guide staff in addressing patient information regarding the chief complaint, medical history, social history, immunizations, and medications. In addition, the check-in document addressed patients’ ADs. An image of the check-in document portion regarding ADs is attached for visualization (see Figure 2). The nursing staff was required to ask, “Do you have a living will, power of attorney, or advance directive?” If the patient had any of these documents, they were asked if the documents are already entered in the electronic medical record (EMR) or if they had brought it with them to the hospital/clinic to be scanned into their EMR. If they had an AD that is not already on file, the patient was instructed to provide a copy. Alternative options to document as the patients’ responses included: no, unable to obtain/patient’s condition, and patient is a minor. The clinic has an established method in place to identify and document if patients have an AD, yet the results do not auto-populate a required intervention in the EMR if the patient is without a living will, power of attorney, or advance directive.

Education was provided to the nurse practitioner in agreeance to participate in the project prior to the protocol implementation. Materials reviewed by the nurse practitioner included the NETO provider's guide (see Appendix E) and the NETO patient brochure (see Appendix F). Written permission for the use of these documents was not necessary, for the materials had already been made available in the office setting. In addition, education was provided to the nursing staff involved in the patient check-in process. The nursing staff, nurses and medical assistants, were briefed on project participant selection based off of the established inclusion and exclusion criteria.

Timeline. The capstone project components including pre-intervention data collection, intervention implementation, and post-intervention data collection was completed in a three-month period of time. After IRB approval, staff education was provided in the first month in addition to the collection of pre-intervention data for qualifying patients by the primary investigator. The intervention was implemented throughout the second month and concluded in the third month once the post-intervention sample size had reached at least 20 patients.

Intervention. The protocol was only implemented for patients that met the qualifying criteria. There was no intervention necessary for the patient with an AD in the EMR that did not wish to update the document. If the patient had an AD that was not scanned into the EMR, the nursing staff instructed the patient to provide a copy. Once the check-in process was complete, the nursing staff notified the provider if the patient was an appropriate candidate and answered "no" to the question "Do you have a living will, power of attorney, or advance directive?"

The nurse practitioner provided education to the patient on the importance of ACP during the office visit by briefly explaining the components of an AD and provided the NETO patient brochure (Appendix F). Lastly, the provider encouraged the patient to make an appointment

specifically for ACP. The purpose of scheduling a separate 30-minute appointment was to allow the patient to have an adequate amount of time to review the NETO brochure and for an appropriate amount of time to be allotted for ACP. In order to facilitate the desire to schedule an ACP appointment, patients were directed to the receptionist at the end of the office visit.

Data Collection Procedure

To evaluate the success of the protocol in relation to scheduled ACP appointments for the patients without an AD, data was collected before and after the implementation of the project intervention. A tool was created to document patient responses when asked “Do you have a living will, power of attorney, or advance directive?” (see Appendix G). In order to trend the initial response from check-in to completion of an AD, the patient’s financial institution number/medical record number (FIN/MRN) number was included on the audit tool.

Pre-intervention. Data was collected via a chart audit using the created tool. Patient responses regarding the AD portion of the check-in process were documented in order to determine the prevalence of an AD and scheduled ACP appointment without an intervention. The pre-intervention data was collected for a three-day time period.

Post-intervention. The ACP protocol, or intervention, was then implemented in the primary care office after the pre-intervention data was collected. At that time, data from qualifying patients was documented using the audit tool.

Ethical Considerations

In order to ensure compliance of ethical standards, Institutional Review Board (IRB) approval was obtained prior to data collection and initiation of this project. The Collaborative Institutional Training Initiative (CITI) program regarding social behavioral research investigators and key personnel was completed by the primary investigator, project mentor, and clinical

partner. The risks associated with the participation in this project were minimal, therefore informed consent was not obtained.

Integrity of Data. No personal identifying information was shared during the execution of this project. Patient FIN/MRN were documented on the data collection tool when follow-up investigation was necessary to retrieve intervention outcomes. All data collected was in paper format until entered into an Excel software document on a password protected computer. No patient identifying information was recorded as part of the Excel document. All paper documents collected for the purpose of this project were preserved in a secure location by the primary investigator. Once data collection and analysis was complete, the primary investigator shredded all paper documents used for data collection in a HIPAA approved manner.

Conflict of Interest. The primary investigator had no personal or professional relationships with the facility at which the project was conducted. Investigators were not given an incentive to participate in the development and implementation of the project.

Data Analysis

The project was discussed in detail with the capstone statistician in order to determine the best method for analyzing the data. Quantitative data was recorded pre and post-intervention on the audit tool. The goal sample size for the pre and post-intervention groups were approximately 20 participants in each group. This sample size was selected by the primary investigator and statistician, for the magnitude of the data was more easily determined significant if $p < 0.05$. The data was then entered into an Excel document in an orderly and organized fashion. The comprehensive Excel document containing the project data was provided to the capstone statistician. Considering the data was not analyzed for the same sample pre and post intervention, a hypothesis test for proportions was conducted by the capstone statistician using a

Statistical Package for Social Sciences (SPSS) software to determine the significance of the project.

Results

Pre-intervention data was collected over a three-day timeframe and resulted in a total of thirty-four patient chart audits. Although all the patients were appropriate to participate in ACP or would have benefitted from having an AD, zero of the pre-intervention patients had an AD in the EMR or brought a copy to the office. Five individuals stated they in fact have an AD at home and were therefore instructed to bring a copy to the office. Due to the condition of the patient at the time of check-in to the appointment, the status of ADs was unable to be obtained for two patients. Twenty-seven of the thirty-four pre-intervention patients, or approximately 79%, did not have any form of an AD and would have been appropriate candidates for the capstone intervention.

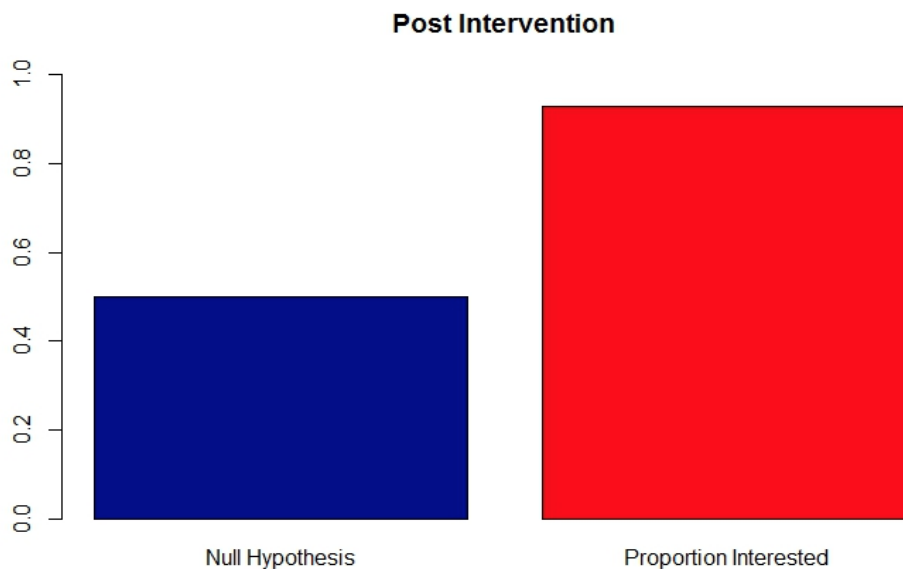
Post-intervention data was collected over a three-day timeframe and resulted in a total of twenty-eight patient chart audits. Three patients had an up-to-date AD that was already scanned into the EMR. After completing the check-in process, ten patients reported they had an AD that was not currently a part of their EMRs. Therefore, the nursing staff instructed these patients to provide a copy to the office in order to be scanned into their medical records. Fifteen or approximately 54% of the post-intervention population did not have any form of an AD. Out of the fifteen patients that did not have an AD, fourteen individuals were deemed appropriate candidates with only 1 individual being removed from the study intervention due to plans of relocation out of state in the near future. After receiving information regarding ACP, two individuals opted to promptly schedule an appointment for ACP, eleven reported they would be scheduling an appointment at a later date, and one individual declined AD education and ACP

options. In order to determine if the capstone intervention had an effect, a hypothesis test was conducted and concluded $\chi^2 = 8.6429$, $df = 1$, and $p\text{-value} = 0.003283$.

Discussion

The project evaluated the efficacy of an AD protocol in the primary care setting in relation to patients' readiness for ACP and ultimately AD completion. As shown in Table 1, the results suggest that a significantly higher proportion of patients were interested in ACP due to the effect of the intervention ($\chi^2 = 8.624$, $p < .05$) as compared to the proportion that could be expected to be interested due to chance alone.

Table 1. Post Intervention Results of Advance Directive Protocol



Beyond increasing readiness for ACP and AD completion, opportunities became available to address confusion regarding the components of AD and the overall completion process. Multiple participants believed that the AD document had to be completed by an attorney or were unaware that the documents could be updated as often as desired. It became relevant that there was confusion regarding the difference between legal and medical directives.

In regards to initiation of the intervention, the nurse practitioner was very aware of the components of an AD and the importance of addressing the needs routinely with the patients. There was observed inconsistency with the nursing staff regarding how thorough the check-in document components were reviewed with the patient. For example, when completing chart audits, it was found that some patients' responses were documented as "patient is a minor" although the patient was of the legal adult age. Moreover, if the patient was established in the office, the previous answer to the AD question auto populated which did not require the staff to re-address. Due to this alone, patients and staff are not required to discuss AD at every office visit. Lastly, the office had no method of tracking, documenting, and following-up with patients that informed they had an AD at home but were instructed to provide a copy to the office. A closed loop process for ADs would provide benefit for the patients and providers of the primary care office by way of following up with those individuals who suggested interest in ACP and/or updated the AD documents in the EMR.

Limitations

Limitations to the study included a small time period for data collection and interaction with the population which may have limited the diversity of study results. All participants were English speaking with a strong majority of the participants being Caucasian, which may affect the application of the results to a culturally diverse population. Inconsistency amongst nursing assistant staff was observed, as the nurse practitioner and/or primary investigator were not involved in the initial patient check-in process, which may have affected the pre-intervention data.

Plan for Sustainability

As previously discussed, research has determined the importance of ADs yet the implementation of ACP into practice lacks structure. This project was created to act as a pilot study for future research and to serve as a foundation for a potential change in practice. In order to encourage continuance of the project and the intervention itself, a summary of this project was presented to the office manager, nurse practitioners, and physicians of the office in which the project was conducted. Project and subsequent materials were condensed into a brief poster board presentation to serve as an educational resource for the purpose of encouraging providers to include ACP as part of a routine healthcare service.

Implications for Practice

As chronic conditions contribute to poorer health outcomes, morbidity and mortality rates are increasing which only stresses the importance of ACP to be facilitated at an earlier time than currently practiced (Hubbell, 2017). Often times, ADs and/or ACP are addressed at the time of admission to the hospital or when the patient is experiencing a fatal change in status. Both situations are suboptimal times for “planning” due to the acuity of illness alongside other acute factors altering the patient's ability to participate in the conversation or make decisions with a sound mind. At the end-of-life, making these difficult decisions is stressful and not always appropriate to do when critically ill.

Practitioners in the primary care setting have the opportunity to facilitate ACP by way of providing opportunities for education and discussion on care options and ADs (Hubbell, 2017). Advance care planning discussions occurring early in the disease trajectory are found to be beneficial, particularly as studies have found that open discussion with a primary care provider is highly associated with completing an AD before death (Enguiganos & Ailshire, 2017). In the

same way, earlier conversations and documentation in medical records provide clinicians with documented knowledge of the patients' values driving their care preferences (Enguiganos & Ailshire, 2017).

Conclusion

An AD is a legal document that has the ability to prevent unnecessary suffering at the end of life, to support an individual's decisions and preferences, and to reduce unnecessary expensive treatment. As previously mentioned, literature has shown the significant role ACP has on completion rates of ADs, yet has not been implemented equitably in the primary care setting (Yadav et al., 2017). The purpose of the project intervention was to incorporate the already established tools and resources into routine practice, in order to overcome the barrier of restriction to time by facilitating an opportunity for ACP for patients and their provider. In conclusion, a significantly higher proportion of patients were interested in ACP due to the effect of the capstone intervention as compared to the proportion that could be expected to be interested due to chance alone. This capstone project successfully evaluated the efficacy of an AD protocol in the primary care setting in relation to patients' readiness for ACP and ultimately AD completion.

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Appendix A: Review of Literature Matrix

Advance Directive Protocol in the Primary Care Setting					
Approximately One in Three US Adults Completes any Type of Advance Directive for End-of-life Care					
Citation	Purpose / Background	Synthesis	Analysis	Interpretation of Evidence	Strength / Limitations
<p>Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Affairs, 36(7), 1244-1251. doi:10.1377/hlthaff.2017.0175</p> <p>Study Design</p> <p>Systematic review and meta-analysis of studies published in the period 2011–16 that reported a completion proportion of advance directives among US adults.</p>	<p>Systematic review of the data on the prevalence of AD among US adults collected before this policy change (Medicare's reimbursement to physicians for ACP counseling effective Jan 1, 2016), to determine how many Americans had an AD, both overall and specifically among people most likely to benefit from them, and how AD completion rates have changed over time.</p>	<p>-Approximately 1 in 3 US adults has completed any type of AD.</p> <p>-the proportion of Americans with an AD does not seem to have changed (per studies published in the past 6 yrs)</p> <p>-similar directives to better represent the substantive issues discussed in ACP conversations, such as patients' values and goals, in addition to specific care preferences</p> <p>-several legal formalities are required for executing an AD. Legal restriction were put in place to protect patients, in fact they act as a barrier, particularly for vulnerable patients, and render ADs less clinically useful</p> <p>-misperceptions regarding POLST forms may have reduced efforts to increase completion rates for ADs, it remains unclear whether the use of POLST forms improves the likelihood that the delivery of care matches what patients desire</p>	<p>Among the 795,909 people in the 150 studies we analyzed, 36.7% had completed an AD, including 29.3 % with living wills. These proportions were similar across the years reviewed. Similar proportions of patients with chronic illnesses (38.2%) and healthy adults (32.7%) had completed AD.</p>	<p>-Comprehensive and robust evidence to date on the prevalence of AD in the US and suggests that the prevalence is low and static</p> <p>-AD remain a key component of high-quality ACP, increasing their completion rates remains a national priority</p> <p>-Policies and interventions should focus on populations with low AD prevalence rates and at high risk for poor end-of-life care outcomes</p> <p>-Results provide an important baseline prevalence rate against which to measure future initiatives aimed at promoting adoption of ADs among such populations</p> <p>-Efforts to increase completion rates of ADs should be targeted to those most likely to benefit from the directives, to maximize their value and efficacy</p>	<p>-designed to assess the recent prevalence of AD among US adults, may have missed studies reporting relevant data because the electronic search strategy was not fully sensitive</p> <p>-Quality and manner of data reporting for participants' characteristics across the studies limited our ability to assess AD prevalence among populations with various demographic characteristics</p> <p>-All data regarding the presence of an AD in the studies analyzed were collected in a retrospective manner (by patient or surrogate recall or medical chart review)</p>
Barriers and Facilitators for General Practitioners to Engage in Advance Care Planning: A Systematic Review					
Citation	Purpose / Background	Synthesis	Analysis	Interpretation of Evidence	Strength / Limitations
<p>De Vleminck, A., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove,</p>	<p>To identify the perceived factors that hinder or facilitate GPs in engaging in ACP</p>	<p>Strong evidence regarding barriers: lack of skills to deal with patients' vague requests, difficulties</p>	<p>GPs can easily engage themselves in ACP but the incidence of GPs engaging their</p>	<p>Initiation of ACP in GP may be improved by targeting the GPs' skills, attitudes, and beliefs but change in</p>	<p>-review adds to the knowledge by including studies on ACP discussions</p> <p>Limitations:</p>

Appendix A: Review of Literature Matrix (Cont.)

<p>C., Vander Stichele, R., & Deliens, L. (2013). Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. <i>Scandinavian Journal of Primary Health Care, 31</i>(4), 215-226. doi:10.3109/02813432.2013.854590</p>	<p>with their patients about care at the end of life.</p>	<p>with defining the right moment, the attitude that it is the patient who should initiate ACP, fear of depriving patients hope Strong evidence regarding facilitators: accumulated skills, the ability to foresee health problems in the future, skills to respond to a patient's initiation of ACP, personal convictions about who to involve in ACP, a longstanding patient-GP relationship, the home setting</p>	<p>patients in ACP remains low. Strong evidence was found for the GP attitude that patients should initiate discussions being a barrier and for having the skill to address a patient's initiation of discussion as a facilitator. Many studies show that patients believe it is the physician's responsibility to initiate ACP, which suggests that there is a gap in the expectation between patients and GPs. This difference has been pointed out in previous studies and may explain why ACP consultations are often initiated tardily when end-of-life decisions need to be made.</p>	<p>health care organization and financing could also contribute. Understanding these barriers and facilitators is important for the development of interventions and training programs aimed to facilitating ACP in general practice.</p>	<p>-given the variation in how ACP is implemented and documented and the variation in GP practice, findings may not be generalizable to all countries and health care systems -only barriers and facilitators reported by GPs were considered -retrieved only qualitative research and observational studies</p>
<p>Study Design Systematic literature review; Studies from 1990-2011, found in 4 electronic databases (PubMed, CINAHL, EMBASE, PsycINFO)</p>	Study of the Factors Influencing the Preparation of Advance Directives				
<p>Citation</p>	<p>Purpose / Background</p>	<p>Synthesis</p>	<p>Analysis</p>	<p>Interpretation of Evidence</p>	<p>Strength / Limitations</p>
<p>del Pozo Punte, K., Hidalgo, J. L., Herrandez, M., Bravo, B. N., Rodriguez, J. O., & Guillan, V. G. (2014). Study of the factors influencing the preparation of advance directives. <i>Archives of Gerontology and Geriatrics, 58</i>(1), 20-24. doi:10.1016/j.archger.2013.07.009</p>	<p>analyze the factors influencing the decision to prepare advance directives (AD) related to socio-demographic situation, health status, degree of dependence, healthcare characteristics and psychosocial aspects</p>	<p>Among subjects who prepared an AD there is a predominance of women, persons aged around 50 years, a high level of education, and lifestyles other than living with a partner or with children in the home. They are more often chronic medication users, more frequently visit the specialist, and have usually had longer-term relationships with their family doctor. Most are independent to carry out their ADs and have lower levels of social interaction. They also more often have relatives who have already made an AD and a more favorable</p>	<p>predominance of women (64.2%) among those who prepared AD, with a mean age of 53.3 years. Preparing AD was associated with secondary or higher education, a lifestyle other than living with a partner and with children, chronic medication use, higher than average number of specialist visits, a longer-term relationship with the family physician, a family history of having AD and with lower levels of social interaction</p>	<p>The results suggest that several factors, resulting from both the socio-demographic situation and health or functional status, can affect the decision to formalize AD. Further research is needed to identify the most appropriate strategies to train healthcare professionals in AD as a way to increase dissemination at a social level regarding the content and purpose of the AD. Results of this study highlight the factors involved in the decision to carry out AD. Different factors, resulting from the socio-demographic</p>	<p>The collection of data during just one year and the limitation to a single health district may hinder generalization of the results to other populations with different characteristics. Potential bias derived from the collection of information and the difficulty estimating the effect of age and sex on the implementation of AD also represent a limitation of the results as these variables were matched in both groups.</p>
<p>Study Design analytical observational case-control</p>					

Appendix A: Review of Literature Matrix (Cont.)

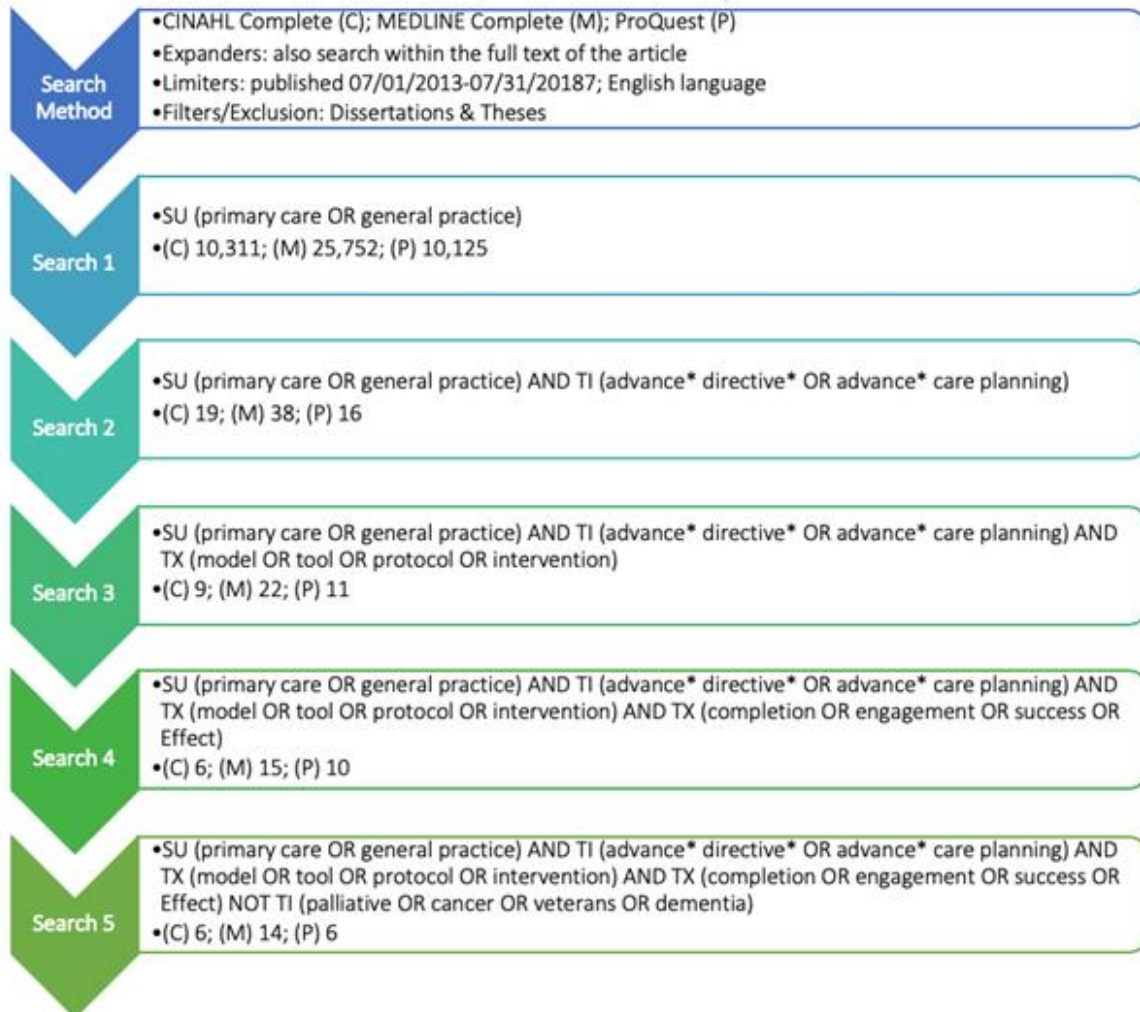
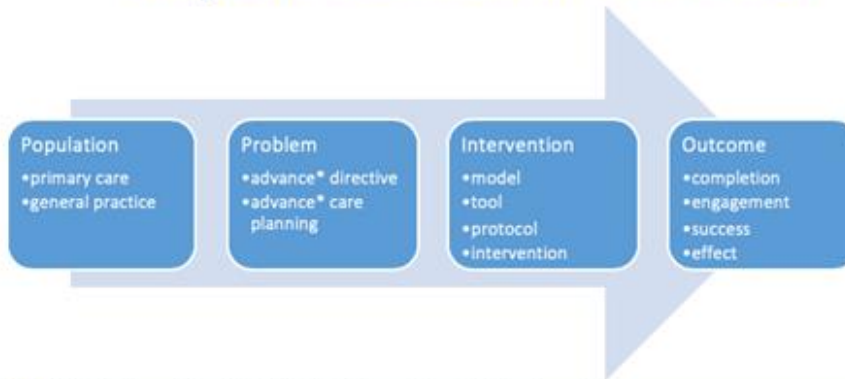
study was conducted by personal interview		opinion toward the usefulness of AD at the time of death of someone close.		situation and the health or functional status can influence the decision to make an AD. Family and personal experiences influence decisions about care at the end of life.	
The Validity of Advance Directives in Acute Situations					
Citation	Purpose / Background	Synthesis	Analysis	Interpretation of Evidence	Strength / Limitations
Leder, N., Schwarzkopf, D., Reinhart, K., Witte, O. W., Pfeifer, R., & Hartog, C. S. (2015). The validity of advance directives in acute situations. <i>Deutsches Arzteblatt International</i> , 112(43), 723-729. doi: http://dx.doi.org/10.3238/arztebl.2015.0723	Studied the extent to which doctors and patients' relatives agree on the applicability of advance directives in the acute setting.	In most of the AD, the conditions under which they were meant to apply were stated in broad, general terms in prewritten blocks of text. All relatives stated that they were very familiar with the patients' wishes. In assessing whether the AD was applicable to the situation at hand, the strength of agreement between physicians and relatives as well as between the two groups of physicians was only fair and non-significant. The relatives found the AD more useful than the doctors did and favored their literal application.	The findings of this study suggest it would be desirable for individuals to prepare AD that are assessed in the same way by all those involved in the event of ICU treatment and are directly applicable. Advance care planning (ACP) may be suitable for developing informed preferences for specific scenarios, discussing them with relatives, and documenting them.	Differing assessments of the applicability of AD imply that the currently most common types of AD are not suitable for use in intensive care. In order to support patients' relatives in their role as surrogate participants in decision-making, improved AD should be developed, and their implementation should be incorporated into the training and continuing medical education of intensive-care physicians	-Inquiries made are limited, as they were conducted in only one hospital -documented opinions provide only a snapshot at a single point in time, and subsequent changes resulting from clinical alterations have not been considered -use of qualitative and quantitative procedures -the summary of the wording of the clauses were prepared and made available for the inquiries
Study Design	Prospective mixed-method study, by questionnaire among physicians and relatives of 50 patients with ADs, hospitalized on 4 different multidisciplinary ICUs. Answers analyzed quantitatively and qualitatively.				
Timing of Advanced Directive Completion and Relationship to Care Preferences					
Citation	Purpose / Background	Synthesis	Analysis	Interpretation of Evidence	Strength / Limitations
Enguidanos, S., & Ailshire, J. (2017). Timing of advanced directive completion and	The purpose of this study was to investigate patterns in timing of AD completion and the	Nearly three-quarters (71%) of ADs were completed a year or more before death. Being younger or a racial/ethnic minority,	Timing was negatively associated with electing aggressive care, with odds of electing aggressive care reduced by	-Study suggests that early advance care planning and documentation of care wishes through ADs may not be associated	-study examines written documentation of care preferences that may include documents other than advance directives

Appendix A: Review of Literature Matrix (Cont.)

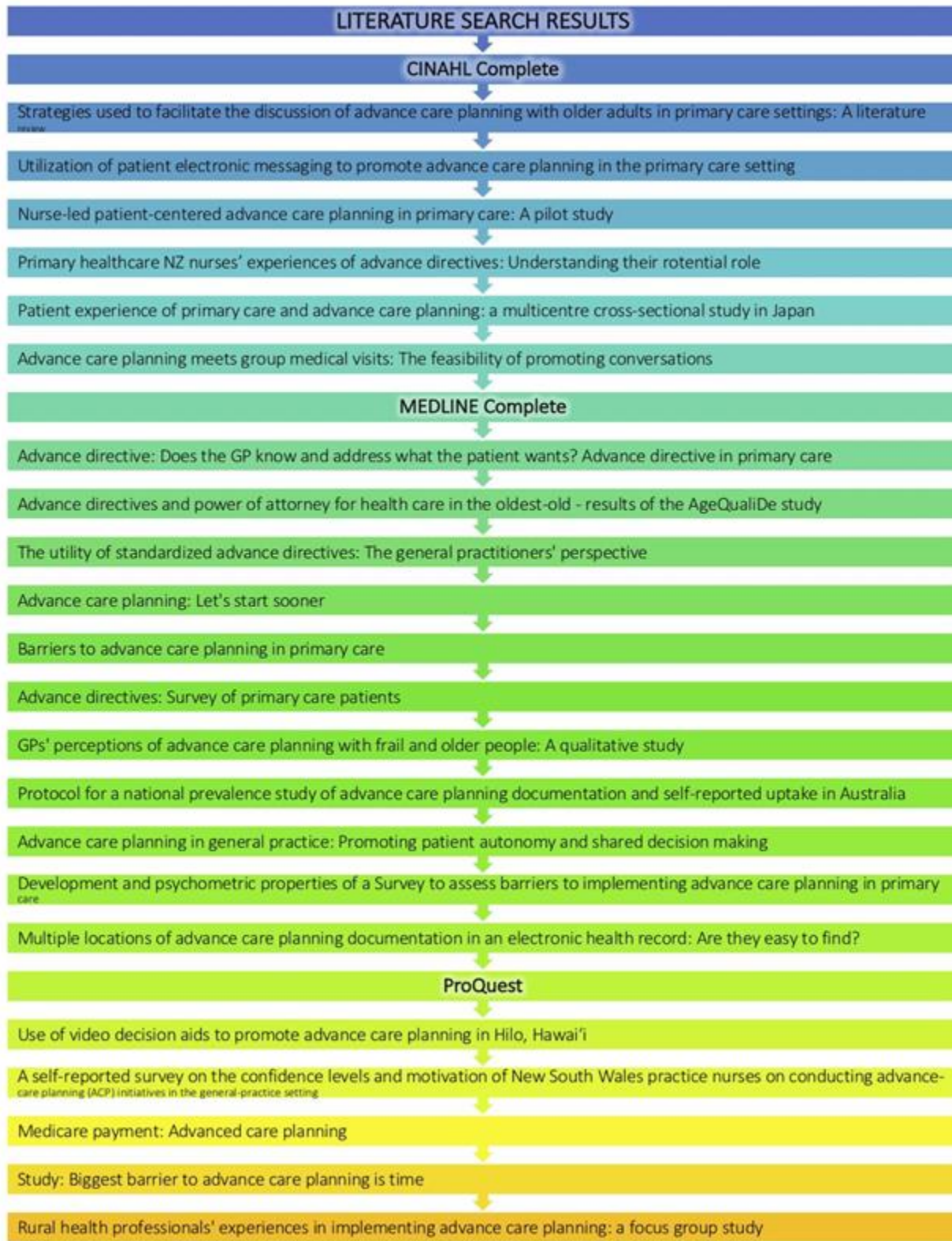
<p>relationship to care preferences. <i>Journal of Pain and Symptom Management</i>, 53(1), 49-56. doi:10.1016/j.jpainsymman.2016.08.008</p>	<p>relationship between timing and documented care preferences.</p>	<p>and having lower education, a diagnosis of cancer or lung disease, and an expected death were associated with completing an AD within the three months before death, while having the lowest quartile of assets and memory problems were inversely associated with AD completion. Minorities, those with lower education, expected death, and timing of AD completion were associated with electing aggressive care.</p>	<p>0.05% for each month before death the AD was completed. Minorities had significantly higher odds of electing aggressive care as compared with whites. Having less than a high school education was associated with greater odds of electing aggressive care while having an expected death reduced the odds of electing aggressive care by 52%.</p>	<p>with greater election of aggressive care and that late ADs completed in the last months of life are associated with higher rates of preferences for aggressive care. -Finding supports recommendations to begin advance care planning discussions early in the disease trajectory, particularly as studies have found that having an advance care discussion with a physician is highly associated with completing an AD before death. -Earlier conversations and documentation in medical records or through completion of ADs provides clinicians with documented knowledge of the patients' values driving their care preferences.</p>	<p>-it is not uncommon for patients to change their care preferences and subsequently their directive over the course of an illness and as illness progresses -study does not include information about changes patients (or proxies) may have made in ADs over time nor does it delineate whether the AD was an original or revised document -studies suggest that changes in health and psychological status influence changes in care preferences -study relies on proxy reports of ADs and documented care preferences gathered after the death of a family member and may be biased due to emotional factors and memory limitations in recalling past events</p>
<p>Study Design</p>					
<p>Retrospective study using multivariate logistic regressions to analyze data from the Health and Retirement Study (ages 51 or older)</p>					

Appendix B: Literature Search Trail

“How does the implementation of an advanced directive/advanced care planning protocol in a primary care office impact the completion rates of advanced directives?”



Appendix C: Literature Search Results



Appendix D: Literature Search Matrix

<p style="text-align: center;">“How does the implementation of an advance directive/advance care planning protocol in a primary care office impact the completion rate of advance directives?”</p> <p style="text-align: center;">Rural Health Professionals’ Experiences in Implementing Advance Care Planning: A Focus Group Study</p>					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
<p>Fletcher, S., Sinclair, C., Rhee, J., Goh, D., & Auret, K. (2016). Rural health professionals' experiences in implementing advance care planning: A focus group study. <i>Australian Journal of Primary Care</i>, 22(1), 423-427. doi:http://dx.doi.org/10.1071/PY15004</p> <p>Level of Evidence</p> <p>Level II: Focus Group Study; Qualitative Research</p>	<p>Study took place in south-western regions of Western Australia between Jan and Oct 2014. Participants were recruited from both the primary care and hospital settings.</p> <p>10 focus groups were conducted, with a total of 55 rural participants including: general practitioners (n=15), general practice registrars (n=6), practice nurses (n=18), community nurses (n=4) and hospital nurses (n=12).</p>	<p>Legislation supporting ACP in Western Australia is relatively new and HCPs are still learning about the process and implementation.</p> <p>This study aimed to provide a rich description of rural health professionals' perceptions and experiences with ACP within the context of their professional role and to identify systemic issues and training needs.</p>	<p>A qualitative, descriptive framework was used alongside thematic analysis to identify the following themes: benefits to patients and families, HCP's role in ACP, barriers and enablers, and systems for communicating ACP.</p> <p>A definition of ACP was introduced at the beginning of each discussion. Focus group discussions were semi-structured, using a discussion guide developed following literature review. Groups were facilitated by an academic GP registrar, discussions were audio-recorded, transcribed verbatim and organized with the aid of NVivo Version 10. Demographic data were obtained via a written questionnaire.</p>	<p>The study highlights significant differences in how rural HCPs conceptualize the process of ACP and their respective roles in it. There is a lack of clarity and understanding of the roles in ACP, which may lead to gaps in the process and implementation in patient care. There is a need for role clarification and a standardized system for distributing ACP documents, which may require the oversight of a coordinator. Research suggests that nurses have attributes that make them appropriate to perform ACP. However, this study identified barriers to nurses' involvement, including the perception that ACP was 'a medical issue', lack of confidence, lack of time and concerns related to the legal aspects of ACP.</p>	<p>If practice nurses are going to expand their role in the ACP process, they require either previous experience, as shown in the study, or support and significant investment in training and mentorship from experienced ACP facilitators. By doing so, nurses could potentially work in a collaborative way with GPs to coordinate ACP processes and provide enhanced care for patients.</p>
<p>Nurse-Led Patient-Centered Advance Care Planning in Primary Care</p>					

Appendix D: Literature Search Matrix (Cont.)

Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths /Weakness	Applicability to Own Research
Holland, D. E., Vanderboom, C. E., Dose, A. M., Ingram, C. J., Delado, A., Austin, C. M.,...Levi, B. (2017). Nurse-led patient-centered advance care planning in primary care. <i>Journal of Hospice & Palliative Nursing</i> , 19(4), 368-375. doi:10.1097/NJH.0000000000000358	<p>Target population was community-dwelling adults with multiple chronic health conditions.</p> <p>The study setting was a large primary care clinic in the upper Midwest with 20 NCCs. 208 patients screened for eligibility, 168 were excluded, 40 patients enrolled but 2 withdrew before intervention was complete. Final sample size: 38 patients.</p>	<p>Rates of advance care planning remain low, indicating a need to identify an approach that promotes acceptance of, and participation in, high-quality advance care planning by clinicians, patients, and families.</p> <p>Primary aim of this pilot study was to determine the feasibility and acceptability of study procedures in comparing the effectiveness of 4 ACP decision aids when used in ACP conversations by primary care NCCs and patients. The secondary aim was to estimate effect size differences among the 4 ACP groups using variables from the ACP engagement survey</p>	<p>Pilot study was conducted to evaluate the feasibility and acceptability of a nurse-led advance care planning intervention in primary care, comparing 4 advance care planning decision aids to help patients consider options; a 4-arm, prospective, comparative design was used with scripted discussions between 4 nurses and 40 patients in a large Midwestern clinic.</p>	<p>Study results provide preliminary evidence that the use of nurses in a primary care setting to conduct ACP conversations with patients is feasible and acceptable to both patients and nurses. Some flexibility with the intervention is required to keep it patient centered while adhering to the integrity of the ACP topics and objectives One attribute of the sample that may misperceive the delivery of the intervention is participants who had previously contemplated ACP, were organized, and had already formed opinions on treatment preferences</p>	<p>Evidence indicates that AD completion rates improve when clinicians provide ACP support and assistance in multiple sessions.</p> <p>The use of nurses to facilitate advance care planning with patients may be an opportunity to improve healthcare and patient outcomes and support full-scope nursing practice in the primary care setting.</p>
Level of Evidence					
Level II: Pilot Study; Quantitative Research					
Advance Directives: Survey of Primary Care Patients					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
O'Sullivan, R., Mailo, K., Angeles, R., & Agarwal, G. (2015). <i>Advance directives: Survey of primary care</i>	<p>The setting of the study was a busy urban family medicine teaching clinic in Hamilton, Ont. Survey population consisted of 800 participants</p>	<p>The primary care office visit is a useful setting for advance care discussions. Past studies have established that many patients prefer to hold</p>	<p>This was a cross-sectional analytical study. A voluntary, anonymous, self-administered questionnaire was developed, informed by review of literature and clinical</p>	<p>The study examined patient impressions regarding planning for end-of-life care. It appears that these discussions are happening more widely than anticipated (43.8%), although they</p>	<p>ACP is occurring largely outside the purview of the family/internal office setting, but rather with a family member, friend, or lawyer. Considering</p>

Appendix D: Literature Search Matrix (Cont.)

<p>patients. Canadian Family Physician, 61(4), 353-356.</p>	<p>(72.5% response rate) well distributed across age groups; 61% of participants were women and a low number of participants aged 80 years or older.</p>	<p>these discussions in the outpatient setting with the PCP initiating the conversation. To date, many studies regarding AD in primary care have been small, retrospective, and/or limited to the elderly or palliative population.</p>	<p>experience. The survey was offered to each adult patient who attended our urban family medicine teaching clinic during the course of a typical business week in November 2011. Data were compiled and analyzed initially using descriptive and nonparametric statistics. Logistic regression was used to determine factors associated with the likelihood of patient preference in having family doctors initiate discussions regarding advance directives.</p>	<p>occur largely outside the purview of the family doctor. It is not routine practice in all clinics to raise the issue of ACP with patients. It is apparent that most patients prefer some control over how and when these issues are approached. As advance directives were rated as more important, having a family doctor initiate the discussion became more desirable.</p>	<p>patient-identified barriers to these discussions, this study could be used to develop a framework for patient-centered ACP conversations in the primary care setting.</p>
<p>Level of Evidence</p>					
<p>Level II: Cross-Sectional Analytical Study; Quantitative Research</p>					
<p>The Utility of Standardized Advance Directives: The General Practitioners' Perspective</p>					
<p>Citation</p>	<p>Participants, Setting, Sample Size</p>	<p>Purpose / Background</p>	<p>Methods, Design, & Limitations</p>	<p>Findings / Summary, Strengths / Weakness</p>	<p>Applicability to Own Research</p>
<p>Otte, I. C., Elger, B., Jung, C., & Bally, K. W. (2016). The utility of standardized advance directives: The general practitioners' perspective. <i>Medicine, Health Care, and Philosophy</i>, 19(1), 199-206. doi:10.1007/s11019-016-9688-3</p>	<p>30 general practitioners were purposively selected from the FMH (Swiss Medical Association) list (proportional quota sampling). Participants were contacted via e-mail outlining the research; 23 physicians agreed to participate (positive response rate of 76 %).</p>	<p>Commonly used pre-printed AD forms have different formats. Some offer space for patients to (a) appoint a surrogate decision maker, and/or (b) to determine future medical treatments and/or (c) give a statement of personal values. So far it is unknown which forms GPs preferably use and why they decide to do so.</p>	<p>Qualitative semi-structured 20 question interview. Interview content: importance of ADs in GPs daily work, which patients are usually interested in drafting an AD, and GPs experiences how ADs are usually drafted. Participants were asked about administering palliative care, their networking with other institutions and stakeholders, and the meaning of ADs for their work.</p>	<p>ADs are an important tool to start a conversation about difficult topics, such as approaching death or death itself. The assessment of the personal values of the patient during this conversation weighs more than the written AD in the end. Interviewees stated concerns that pre-printed forms are too hypothetical to cover all important aspects and therefore offer space for misunderstandings and misinterpretation.</p>	<p>Standardized advance directives are important tools for GPs and offer a good basis for them to start a conversation about patients' preferences and future treatment wishes. When the patient is still not facing the progression of an already existing disease it could be sufficient to only appoint a surrogate decision maker instead of creating a full AD.</p>
<p>Level of Evidence</p>					

Appendix D: Literature Search Matrix (Cont.)

Level II: Qualitative Research	their practices, participants answered questions about administering palliative care in a primary care setting.	The qualitative study was conducted to elaborate on whether GPs use standardized templates, and if so, which version, why, and whether they change/add a patient's individual explanations to the forms. Study sheds light on potential concerns and shortcomings related to the use of templates as well as barriers GPs encounter when assisting their patients in drawing up ADs.	Interviews were recorded from December 2012 to February 2013. The interview guide was pilot tested. All interviews were transcribed verbatim in the original language of the interviewee and were analyzed with the support of the analysis programme atlas.ti, Version 7.0.	GPs in this study shared their concern over making ADs with patients who are still healthy because they fear patients would not be able to consistently anticipate future scenarios and treatment preferences.	since preferences often change during the course of illness. Patients and their relatives should always have the opportunity to ask their GP for medical advice when drafting an AD. It is crucial to regularly verify and update existing ADs within the course of a disease.
Advance Directive: Does the GP Know and Address What the Patient Wants? Advance Directive in Primary Care					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
Scholten, G., Bourguignon, S., Delanote, A., Vermeulen, B., Boxem, G. V., & Schoenmakers, B. (2018). Advance directive: Does the GP know and address what the patient wants? Advance directive in primary care. BMC Medical Ethics, 19(58), 1-7. doi:10.1186/s12910-018-0305-2	The study population consisted of 502 people with an average age of 71 years; no participants were younger than 64 years. An implicit exclusion criterion was as sufficient mastery of the Dutch language. People were approached in public area, by electronic survey, on patient platforms and via senior organizations across Flanders. Patient data was collected between	Due to the rapid changes in the medical world and the aging population, the need for advanced care planning grows. Despite efforts to make this topic discussed, only a minority of patients discusses the advance directive with their general practitioner. This study aimed to map thresholds and examine the barriers GPs and patients experience in preparing and	Quantitative study was conducted with a cross-section of citizens over 65 years and a cross-section of GPs working in Flanders. Questionnaire was designed in a quantitative construction, consisting of multiple choice answers. GP surveys were offered by electronic interface and a Likert scale was used.	The majority of the citizens already heard about an advance directive. Despite this, more than half of the surveyed GPs made 5 or less advance directives last year. These observations confirm previous findings regarding the (low) number of signed advance directives. Citizens expect that the GP plays an informative role and explains what an advance directive stands for. However, the intervention of an external counselor was not further investigated. In contrast to other studies this research	Although the public need is high, the number of formally drafted advance directives remains low. This finding is mainly due to the time-consuming process and inherent to the delicate character of end of life conversations. Further research could examine whether the awareness and information process could be a task for other health care workers.
Level of Evidence					

Appendix D: Literature Search Matrix (Cont.)

Level II: Cross-Section Survey; Quantitative Research	Jan. 17, 2016 and March 7, 2017. GPs were recruited over the Flemish region and without exclusion criteria. 117 physicians participated in the survey. GP data was collected between Jan. 18, 2016 and March 1, 2016.	discussing an advance directive.		shows that the citizens prefer to take initiative themselves in preparing an advance directive. This observation could be explained by a population selection bias.	
GP's Perceptions of Advance Care Planning with Frail and Older People: A Qualitative Study					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
Sharp, T., Malyon, A., & Barclay, S. (2018). GPs' perceptions of advance care planning with frail and older people: A qualitative study. <i>British Journal of General Practice</i> , 68(666), e44-e53. doi: https://doi.org/10.3399/bjgp.17X694145	Focus groups were held with GPs across Cambridgeshire between Sept 2015 and Jan 2016. They were purposively sampled, maximizing participant diversity by sex, practice location, and years in practice. Groups comprised between 3 and 6 GPs and were held following a local commissioning group clinical governance meeting. 21 GPs participated in five focus group discussions from 15 different practices across Cambridgeshire; 20 male and 9	Frail and older people are estimated to account for 40% of deaths. Despite conversations about end-of-life care being an important component of the national End of Life Care Strategy, there is a marked disparity between the majority who would like to discuss advance care plans, and the minority who currently have this opportunity. The purpose of the study was to investigate the attitudes of GPs to advance care planning discussions with frail and older individuals.	Researcher facilitated all the group discussions, adopting a flexible approach to explore group members' experiences and perspectives while ensuring the discussion covered the outline schedule. The focus group enabled free discussion and allowed participants to respond to each other's comments and perspectives. The purpose was not to reach consensus but to understand the range of views and experiences of participants. Discussion lasted between 35 and 45 minutes, were digitally recorded, transcribed verbatim, anonymized, and uploaded into NVivo 10 software for analysis. A Framework analysis	Some GPs were concerned it might cause distress, the majority felt that raising ACP was important, especially as preparation for future emergencies. Knowing the individuals, introducing the idea as part of ongoing discussions, and public awareness campaigns were all facilitators identified. Several considered that service limitations made it difficult to fulfil patients' wishes and risked raising unrealistic patient expectations. Barriers identified included uncertainty over prognosis and difficulties ensuring that individuals' wishes were respected.	Although GPs viewed ACP as important, enthusiasm is tempered by experience. Difficulties for GPs consist of encouraging dialogue and respecting individuals' wishes within the constraints of the existing health and social care system. Publicity campaigns and encouraging patients to prioritize healthcare outcomes could help GPs raise care preferences without causing a detrimental impact on patients or raising unrealistic expectations.
Level of Evidence	Level II: Focus Group Study; Qualitative Research				

Appendix D: Literature Search Matrix (Cont.)

	female, 14 were practice partners and 7 salaried doctors. Time since qualifying as a GP ranged from 4 months to 31 years with a mean of 14 years.		approach was used. Themes were then reviewed and validated by one researcher against the original focus group transcripts and their notes taken at each group discussion.		
Strategies Used to Facilitate the Discussion of Advance Care Planning with Older Adults in Primary Care Settings: A Literature Review					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
<p>Solis, G. R., Mancera, B. M., & Shen, M. J. (2018). Strategies used to facilitate the discussion of advance care planning with older adults in primary care settings: A literature review. <i>Journal of the American Association of Nurse Practitioners</i>, 30(5), 270-279. doi:10.1097/JX.X.0000000000000025</p> <p>Level of Evidence Level II: Systematic Literature Review; Quantitative Research</p>	<p>Systematic literature review approach: review focused on intervention studies evaluating strategies used by PCPs in the primary care setting for discussing ACP and the subsequent completion of ADs. Search included seven Elton B. Stephens Company databases, limited to English language and peer-reviewed publications from 1991 to 2017 using 10 key words.</p> <p>Population of interest was 60 years and older because of the prevalence of multiple chronic illnesses and terminal illnesses with high</p>	<p>Approximately 50% of older adults have an advance directive, yet few talk to their primary care provider about end-of-life wishes. The Institute of Medicine report and recent changes in Medicare reimbursement policies create opportunities for PCPs to address ACP in primary care settings.</p> <p>The purpose of this literature review was to evaluate strategies used in primary care settings to initiate advance care planning conversations leading to the completion of an advance directive.</p>	<p>Systematic review approach: abstracts were appraised with attention to the delineated inclusion and exclusion criteria used for selection. Rationale for the exclusion was based on the primary focus of the study to evaluate the current practice in outpatient settings. Studies that were conducted in acute care, hospice, and palliative care were excluded.</p> <p>Limitations: lack of evaluation of the rigor and quality of the selected publications, group focus age was 60 years and older and may have left out studies that had had a younger population that could contribute to the topic, sought out intervention studies with inclusion of PCPs and patients and may have missed publications</p>	<p>The excluded settings denote a greater acuity level or process at the end of life and recognition of possible impending death, which may have greater urgency for end-of-life decision making.</p> <p>The newly established guidelines and reimbursement for including ACP conversations as part of plan of care challenge PCPs to identify ways in which to address the subject.</p> <p>Effective interventions were educational materials using various methods of delivery, computer-generated triggers for PCPs, inclusion of multidisciplinary professionals for content delivery, and patient preparation for PCP visit.</p>	<p>Considering the significant room for improvement regarding ACP, this literature review serves as a great tool for changing practice. The review provides an array of successful strategies aimed at patients and PCP including: providing patients with educational materials before the clinical visit, personalized message from PCPs, questions for the patient and family to consider to aid in the conversation, and PCP electronic prompts for initiating and documenting the conversation was also effective.</p>

Appendix D: Literature Search Matrix (Cont.)

	utilization of primary care services.		to add to the topic if the PCP or patient were not clearly identified in the publication.		
Medicare Payment: Advance Care Planning					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
Sonenberg, A., & Sepulveda-Pacsi, A. L. (2018). Medicare payment: Advanced care planning. <i>The Journal for Nurse Practitioners</i> , 14(2), 112-116. doi:https://doi.org/10.1016/j.nurpra.2017.11.023	Non-research base article; participants, setting, and sample size are not relevant	Purpose is to describe the potential benefits of the expanded payment of ACP under the recent Medicare policy (effective January 2016) in addition to exploring the impact the payment rule change has on nursing practice. Evidence supports that end-of-life care, beginning with advance care planning, leads to greater patient quality of life and satisfaction, cost savings, and provider satisfaction.	Non-research base article; method, design, and limitations are not relevant	Americans' life expectancy is increasing along with rates of chronic illness and cancer and the concomitant technological advanced that prolong life under those circumstances. End-of-life care, beginning with ACP, leads to greater patient quality of life, satisfaction, cost savings to patients and family caregivers, provider satisfaction, and cost savings to the health care system and society at large.	The study reflected the importance of expanding practitioners' ACP knowledge base and skills. In order to play an instrumental role in advocating for the revision to the Medicare payment rule, obstacles to end-of-life care must be alleviated, beginning with reforming policies to promote ACP.
Level of Evidence					
Level IV: Expert Opinion/Quality Report					
Utilization of Patient Electronic Messaging to Promote Advance Care Planning in the Primary Care Setting					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
Tieu, C., Chaudhry, R., Schroeder, D. R., Bock, F. A., Hanson, G. J., & Tung, E. E. (2017). Utilization of patient electronic messaging to promote	The Setting for the study was the Mayo Clinic's Division of Primary Care Internal Medicine (PCIM) Clinic in Rochester, MN. The study was conducted from May 2015 to July 2015.	Advance care planning is an instrumental mechanism aimed at preserving patient autonomy. Numerous interventions have been proposed to facilitate the implementation of ACP; however,	Randomized control intervention: All primary care patients, aged 65+, who had previously enrolled in a patient electronic messaging system, within the primary care practice, were included for randomization. The	Among primary care patients aged 65 years and older, use of AD-specific electronic messaging statistically significantly increased the rate of AD completion, but the absolute number of completed AD remained relatively low. These data	Patient electronic messaging is an inexpensive and feasible adjunct to many of the current measures in place throughout our healthcare system. Motivational electronic messaging may

Appendix D: Literature Search Matrix (Cont.)

<p>advance care planning in the primary care setting. American Journal of Hospice & Palliative Medicine, 34(7), 665-670. doi:10.1177/1049909116650237</p>	<p>PCIM patients were included if they were 65 years or older, did not have an AD on file within the EMR, and had access to the Mayo Clinic Patient Online Services system. 200 patients were individually, electronically randomized to the intervention group and the remainder of the population comprised the control group.</p>	<p>rates of completed advance directives are universally low. Patient electronic portal messaging is a newer tool in patient-provider communication which has not been studied as a method to promote ACP.</p> <p>The primary aim of the study was to measure the impact of a personalized ACP electronic message on AD completing in a primary care setting.</p>	<p>primary outcome was the proportion of patients in each group who completed an AD, 3 months after intervention. Secondary outcomes included clinical utility of the completed ADs and proportion of patients who viewed their electronic messages.</p>	<p>suggest that this valuable communication tool holds opportunities for further improvement. Older, frailer adults were more likely to complete an AD, and prompted directives were more likely to include a written expression of the individual's health-care values and preference.</p>	<p>allow patients to participate in ACP and complete an AD on their own time, which is significant considering the overall time needed for ACP in office.</p>
<p>Level of Evidence</p> <p>Level I: Randomized Control Intervention</p>					
<p>Multiple Locations of Advance Care Planning Documentation in an Electronic Health Record: Are They Easy to Find?</p>					
Citation	Participants, Setting, Sample Size	Purpose / Background	Methods, Design, & Limitations	Findings / Summary, Strengths / Weakness	Applicability to Own Research
<p>Wilson, C. J., Newman, J., Tapper, S., Lai, S., Cheng, P. H., Wu, F. M., & Tai-Seale, M. (2013). Multiple locations of advance care planning documentation in an electronic health record: Are they easy to find? <i>Journal of Palliative Medicine</i>, 16(9), 1089-1094. doi:10.1089/jp m.2012.0472</p>	<p>Subjects were patients in a multispecialty practice in California age 65 or older who had at least one ACP documentation in the EHR.</p> <p>Participants had to meet all of the following criteria: be an active patient between Sept 2008 and Sept 2011, age 65 or older at the start of the study period, and have at least one ACP documentation in the EHR between Jan 1999 and</p>	<p>The ambulatory care setting is a new frontier for advance care planning. While electronic health records have been expected to make ACP documentation more retrievable, the literature is silent on the locations of ACP documentation in EHRs and how readily they can be found.</p> <p>The purpose of the study was to determine which patient and primary care</p>	<p>The study design is a retrospective review of EpicCare EHR records. The search of terms included advance directives, living will, Physician Orders for Life-Sustaining Treatments, power of attorney, and do-not-resuscitate. Measurements were types and locations of documentation, and characteristics of patients and physicians.</p>	<p>About 50.9% of patients age 65+ had at least 1 ACP documentation in the EHR (n=60,105). About 33.5% of patients with ACP documentation (n=30,566) had an SD. Patients' age, gender, race, illnesses, and when their physician started at the medical group were statistically significantly associated with the probability of having a scanned ACP document. Only 33.5% of patients with ACP documentation somewhere in the EHR had an SD. Older age and female gender</p>	<p>Standardizing the location of advance directive documents should become a priority to improve care. Actions are needed to eliminate disparities and facilitate advance care planning. Practice change surrounding ACP should focus on reducing the already identified disparities associated with AD completion.</p>
<p>Level of Evidence</p>					

Appendix D: Literature Search Matrix (Cont.)

<p>Level II: Retrospective Review; Quantitative Research</p>	<p>Sept 2011. Patients met the criteria of having ACP documentation in the EHR if they had ACP on the problem list, a scanned document containing an ACP decision, or a progress note containing an ACP term.</p>	<p>provider characteristics are associated with having a scanned ACP document. A scanned document is the only documentation containing signatures (unsigned documents are not legally valid).</p>		<p>were associated with higher odds of having an SD, yet being a minority was associated with lower odds.</p>	
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Appendix E: NETO Provider Guide



Help Patients Plan for Emergencies

- Patients present to emergency rooms every day for treatment of unexpected medical emergencies and life-threatening accidents.
- Many patients don't have a basic plan for common events like car accidents, sudden heart attacks or stroke.
- There is a growing number of patients who have some form of advanced, complex illness such as heart failure, COPD, end-stage renal disease, metastatic malignancies or the medical frailty of advanced age. They need guidance to help navigate the utility of various treatment options as their illness progresses and their overall health and quality of life decline.
- Help patients prepare for unexpected health emergencies the way they do for tornados and blizzards. They hope they are never hit, but they have candles and flashlights just in case.

A New Initiative and Tool to Improve Planning

Nebraska Emergency Treatment Orders form (NETO): NETO combines a structured living will (called a "Declaration" under Nebraska law) with standard orders for Emergency Medical Services regarding CPR, intubation and transport.

- NETO is a living will that is clearly actionable in emergency settings.
- NETO is general enough for most patients regardless of their age or illness.
- NETO is a simple form but provides specific direction to emergency personnel when time is crucial.



Although NETO is designed to be used in a medical emergency when patients are unable to speak for themselves, conversations needed to complete the form can also help guide their day-to-day treatment goals.

Decisions are indicated on the NETO form based on the patient's goals and preferences today. If changes in the patient's lifestyle or illnesses impact their choices, you can easily write a new NETO form to reflect those changes.

What is the legal basis for NETO?

Federal law, Nebraska law and U.S. Common Law support a patient's rights to:

- Refuse medical treatment for any reason
- Have their advance directives put into writing
- Have those directives honored across all settings of care

These laws provide protections for proper use, and penalties for misuse. The Joint Commission regularly surveys medical facilities to ensure policies and procedures are in place to utilize these documents.

The NETO form provides orders for EMS or other first responders to initiate or withhold CPR, intubation and transport, in accordance with patient wishes. These out-of-hospital orders are permitted under Nebraska EMS protocols.

Why not let my patient's family or Power of Attorney make healthcare decisions when they can't speak for themselves?

Making decisions about the life and death of a loved one is extremely difficult. Research shows that loved ones are often burdened long after the event, and question decisions that were made. Even those who know what their loved ones want find it difficult to tell doctors to limit treatment when the time comes—especially if it means their loved one may die.

Careful planning and conversations before a crisis can help the patient direct their care within clearly established guidelines, leaving fewer decisions for family.

Appendix E: NETO Provider Guide (Cont.)

NETO: Page One

The Patient Declaration

This is the patient's legal declaration of their acceptance or refusal of treatment:

- The patient initials their specific choices in each section of the declaration.
- The declaration is intended to guide both healthcare professionals and family.
- If the patient is unable to speak for themselves, this declaration should be used in direct care.
- If the patient is able to make decisions, this form may be used as a point of reference when discussing treatment decisions.

Section A: Scope of Initial Treatment Desired

1. INTENSIVE

Patient wants all life-prolonging treatment available.

2. GENERAL/LIMITED:

Patient requests limited general medical interventions (medications, fluids, blood, etc.). Does not want to be intubated. Would like to avoid surgery or ICU if possible.

3. COMFORT:

Patient wants to be allowed to die naturally. Use medical treatment for comfort only.



Section B: Stopping Treatment

NETO separates decisions to START treatment from decisions to STOP treatment.

1. The patient chooses to receive all medical treatment available and would agree to long-term life support as long as medically indicated.

2. The patient indicates the situations they would want medical treatment stopped: If treatment isn't working; if the outcomes of treatment would be unacceptable; and/or allowing family members to outweigh the benefits.

Section D: Long-Term Medically Administered Nutrition & Hydration

This is consent to accept or refuse a PEG tube for long-term nutrition if the patient can't take food or water by mouth. Short-term artificial nutrition is common during active treatment, so it is not part of this decision.

1. The patient wants nutrition provided through a tube surgically into their stomach.
2. The patient does not want a tube surgically placed in their stomach, and refuses medically administered nutrition and hydration.

Section C: Resuscitation status for Cardiopulmonary Arrest

There are only two choices. There is no evidence to support "partial code" options, so none are offered.
 1. Attempt CPR 2. Do not attempt CPR (DNR)

The "average person" who has cardiac (in or out of the hospital) has only 8% to 10% chance of survival with good neurological outcomes. The success rate changes with age and illness.

Of the patients who code in the hospital:



Witnessing the Document:

The patient's signature must be witnessed by a Notary Public OR two adults. One of the witnesses can be a healthcare personnel. Family members are allowed to be witnesses. The physician, physician assistant or nurse practitioner who signs the orders should not serve as a witness.

Appendix E: NETO Provider Guide (Cont.)



NETO: Page Two

Medical Orders & Attestation



Orders:

- EMS must have a physician's, physician's assistant or nurse practitioner's orders to deviate from their standard protocols.
- The medical orders for resuscitation status and intubation status should be completed in NETO in accordance with patient's choices in sections A and C on page one of the form.
- Patients who want only comfort measures may request an order to refuse transportation from their residence.



Attestation:

- This states that you have discussed these decisions with the patient.
- The patient appeared to understand the decisions and they were competent at the time they completed the form with you.

Note: All options include language about treatment that is "medically indicated." It is helpful to remind patients that medicine can't cure everything, especially for people who are already very sick.

While standard procedure is to offer all treatment that will help the patient, there are times when some treatments are not available because they are likely to cause more harm than good.

Patients have a right to refuse any treatment. They have a right to participate in decision making, but they don't have a right to "demand" treatment that isn't medically indicated. They may seek transfer to another doctor or institution who is willing to offer that treatment.



- You are not saying that you agree with their choices; patients have the right to make any choices they wish
- If you, in good conscious, cannot sign the attestation or the requested orders based on your beliefs, you should inform the patient and offer the opportunity to see a different provider to complete the form.
- There are inconsistencies in Nebraska law that give surrogates the right to make decisions, but not to complete a declaration on behalf of the patient. This means a surrogate may not complete a NETO for an incapacitated patient, but they can ask a physician to write orders for that patient. A separate form is available to EMS Stand-Alone Orders only for those patients.
- The attestation is a unique feature of the NETO form. It provides a level of assurance for our colleagues who receive this form that the patient understood the information and was competent when they completed the NETO form.

Appendix E: NETO Provider Guide (Cont.)

Medical Professionals

Getting Paid for Your Work

Advance care planning (ACP) is important and valuable work. Many insurance payers, including Medicare, have created codes for ACP services for patients with serious illnesses. You may combine ACP along with an E&M visit, or you may bill for the ACP code alone if a patient comes in for a planning-only session.

These are time-based codes that pay about \$90 per 16-30 minutes of face-to-face time with the patient or their surrogate.

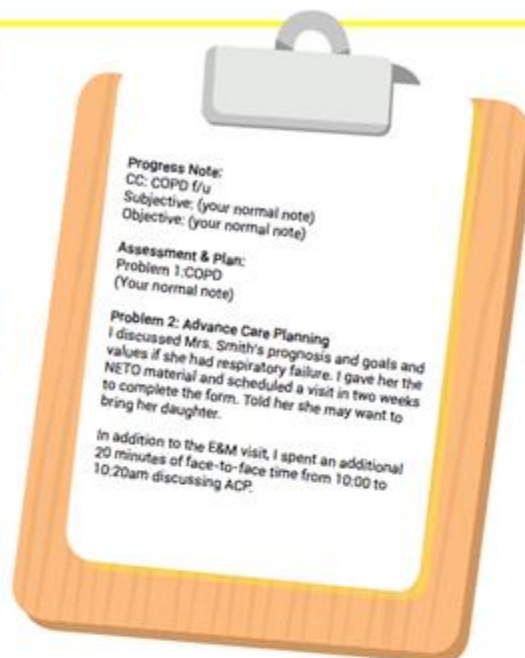
99497 for the first 16-30 minutes

99498 for each unit of 16-30 minutes

If you see a COPD patient for a routine visit, then spend 16 to 46 minutes discussing their Advance Care Planning. You should bill one code for the E&M visit, and code 99497 for the ACP visit. Your note should have a short section that describes the planning (see example).

If you saw the patient ONLY for Advanced Care Planning Problem 2 could serve as a stand-alone note.

- No physical exam is required.
- Document their serious illness diagnosis (i.e. advanced COPD) and the general content of your discussion along with the amount of time spent.



Instructions for transferring patients with NETO forms:

1. Receiving a patient with an existing NETO form:

- The form has two sides: "Orders" and "Declaration." The ORDERS are valid in any out-of-hospital setting. The DECLARATION page is used to direct treatment if the patient is unable to speak for themselves.
- The original NETO form should be posted/kept in a prominent location in the patient's residence.
- A copy of the form should be included in the patient's medical record. It is an advance directive, so it should be filed in that section of the medical or facility record.
- Only the most recent NETO form is valid. Older versions of the form can be marked "revoked/ revised" and/or destroyed by the patient.

2. Transferring a patient with a NETO form:

- When arranging transport, please inform EMS Personnel that the patient has a NETO form.
- The ORIGINAL bright yellow NETO form should be given to EMS or transport personnel.
- The ORIGINAL form should be the top page of the transferring documents.
- The facility may keep a copy of the NETO in their records.

Appendix F: NETO Patient Brochure



what is a

NEBRASKA EMERGENCY TREATMENT ORDER?

Who Should Have a NETO?

- Anyone who wants to make sure their voice is heard in a medical emergency.
- Anyone who wants to relieve their family of making difficult decisions in a medical emergency.
- Older adults or those with a serious illness who may want to limit their treatment options.

What if I Have an Advance Directive?

Completing a NETO will replace an older advance directive or living will. A NETO is different because it's universally recognized and actionable by EMS and local medical teams.

All adults should complete a NETO form in preparation for an unexpected, life-threatening emergency and/or to outline end-of-life wishes.

How do I complete a Nebraska Emergency Treatment Declaration?

You, your family and your health care provider should discuss your health status and care goals. Then you can decide how those goals translate into treatment choices on the NETO form.

When the NETO is signed by you and your doctor or nurse practitioner, your decisions become actionable medical orders that travel with you from one care setting to another.



Appendix F: NETO Patient Brochure (Cont.)



NETO Puts it all Together

A healthcare **DECLARATION** that states what you want if you have a life-limiting emergency and can't speak for yourself.



ORDERS for doctors and Emergency Medical Services (EMS) before you get to the hospital.



Ensures the choices you made in conversation with your doctor will be followed in a medical emergency.



The Nebraska Emergency Treatment Order (NETO) form helps you prepare for a medical emergency.

- NETO will guide your treatment when you can't speak for yourself.
- Your doctors and Emergency Medical Services (EMS) will know the level of treatment to provide that fits your goals and values.
- Your family will know your wishes and can help fine-tune the plan to fit your specific needs in case of a medical emergency.
- NETO can grow and change with you throughout your life. As things change, you can easily revise your plan by talking with your doctor.



Four Decisions

A. Scope of Treatment:

Most people want everything done to try and save their lives. But as people age or become seriously ill, they may want to place limits on treatment. This section considers three levels of treatment: Intensive, General, and Comfort Care.

B. Stopping Medical Treatment

Life-sustaining treatment can be continued if there is a chance that the medical condition will improve. In this section you will decide when to stop or limit treatment.

C. Resuscitation Status:

In this section you will decide if you want the medical team to attempt cardiopulmonary resuscitation (CPR) if your heart stops beating.

D. Long-Term Medically Administered Feeding:

You will decide if you want medically administered nutrition if you are unable to swallow or cannot take food/drink by mouth.

Appendix G: Audit Tool

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Patient (FIN/MRN):

Does the patient have a Living Will, Power of Attorney, or Advance Directive?						
YES			NO			Unknown
<input type="checkbox"/> In EMR	<input type="checkbox"/> Brought to clinic	<input type="checkbox"/> Instructed to provide copy	<input type="checkbox"/> Schedule ACP apt now	<input type="checkbox"/> Schedule ACP apt later	<input type="checkbox"/> Declined ACP	<input type="checkbox"/> Unable to obtain

Figure 1: Iowa Model of Research-Based Practice to Promote Quality Care

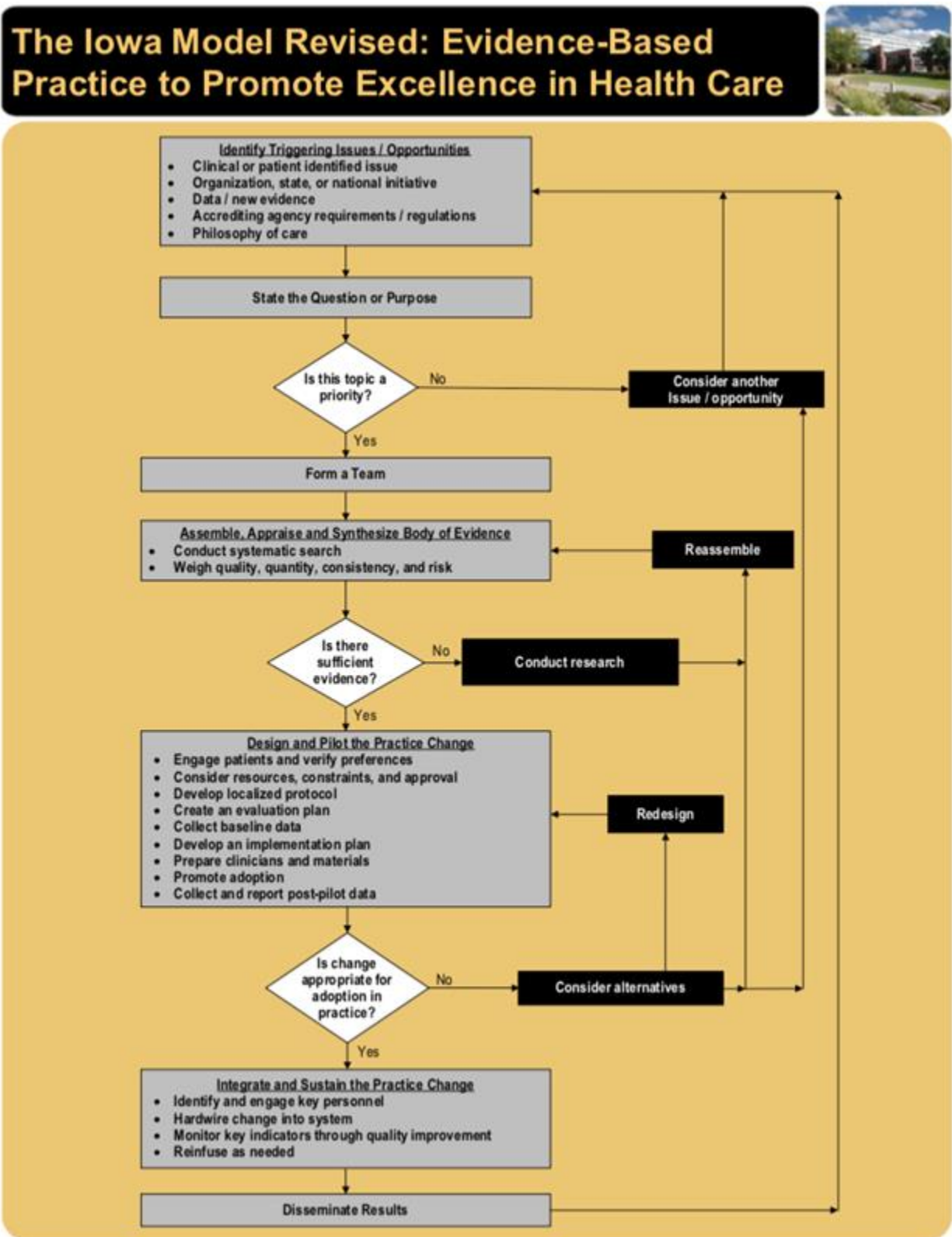


Figure 2: Outpatient Check-in Document

**Does the patient have Living Will,
Power of Attorney or Advance Directive?**

- | | |
|--|--|
| <input type="radio"/> Yes, in EMR | <input type="radio"/> No |
| <input type="radio"/> Yes, Brought to Hospital (MH/WH) | <input type="radio"/> Unable to Obtain/Patient's Condition |
| <input type="radio"/> Yes, Instructed to Provide Copy | <input type="radio"/> Patient is a Minor |