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Advance Care Planning Documentation Practices and Accessibility in the Electronic Health Record: Implications for Patient Safety

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Abstract

Importance—Documenting patients' advance care planning wishes is essential to providing value-aligned care, as is having this documentation readily accessible. Little is known about advance care planning documentation practices in the electronic health record.

Objective—Describe advance care planning documentation practices and the accessibility of documented discussions in the electronic health record.

Design—Cross-sectional study between 2013-2015.

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Acquisition, analysis, or interpretation of data: All authors

Drafting of the manuscript: All authors

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Statistical analysis: Walker, Sudore

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Setting—Primary care clinics at the San Francisco Veterans Affairs Medical Center.

Participants—Veterans 60 years of age with 2 chronic/serious health conditions, 2 primary care visits, and 2 additional clinic/hospital/emergency room visits in the prior year who were participating in an advance care planning trial.

Exposure—Documentation of advance care planning in the electronic health record.

Main Measures—Advance care planning documentation, including all prior legal forms/orders and documented discussions within the prior five years. For discussions, the author's discipline and documentation location in the electronic health record were determined. Discussions were defined as “accessible” if documented in a designated electronic posting location or “not easily accessible” if recorded as free-text in progress notes. Percentages and means were used to describe these measures.

Key Results—The mean age of 414 participants was 71 years (SD ±8), 9% were women, 43% were non-white, and 51% had documented advance care planning including 149 (36%) with forms/orders and 138 (33%) with discussions. Seventy-four participants (50%) with forms/orders did not have accompanying documented discussions. Most (55%) discussions were not easily accessible. Twenty-seven participants had a subsequent discussion documenting changes in treatment preferences from a prior form/order; however, 70% of these discussions were not easily accessible.

Conclusions and Relevance—Half of chronically ill, older participants had documented advance care planning wishes, including one third with documented discussions. However, half of the patients with completed legal forms/orders had no accompanying explanatory discussions. The majority of documented discussions were not easily accessible in the electronic health record, including 70% of those documenting a change in treatment preferences. Ensuring that patients' preferences are documented and easily accessible is an important patient safety and quality improvement target to ensure patients' wishes are honored.

Introduction

Advance care planning (ACP) is a process that supports adults in understanding and sharing their personal values, life goals, and preferences regarding future care.¹ Although the prevalence of ACP documentation is increasing² and may continue to increase with both federal and local reimbursement programs for ACP,³ the rates of ACP documentation are still low,⁴ especially among older and disenfranchised populations. A lack of documented ACP can lead to medical interventions misaligned with patients' wishes⁵ as well as worse quality of life and stress for patients and surrogate decision-makers.^{6–11} Furthermore, ACP is a dynamic process which should be revisited as patients' wishes and clinical context changes. Having up-to-date ACP information at the point of care is essential to providing value aligned care, however, little is known about ACP documentation practices.

The Veterans Affairs (VA) healthcare system, which treats over 10 million Veterans over the age of 65 years,¹² is a leader in ACP quality improvement.¹³ Prior studies at the VA have sought to improve patient education and preparation for informed decision-making as well as increase rates of advance directive completion.^{14–17} The VA has also created ACP note

templates and a centralized posting section for ACP discussion documentation in the electronic health record (EHR) to better capture patient preferences.

While prior studies, and a recent Institute of Medicine report, have stressed the need for standardized and up-to-date documentation of ACP in the medical record,^{18–23} it is unknown how well clinicians are utilizing EHR documentation tools, which disciplines are documenting patients' preferences, and whether this information is easily accessible in the medical record. Better understanding of ACP documentation practices will lead to quality improvement opportunities to ensure patient safety and patients' wishes are honored. This study aimed to quantify the rates and timing of ACP documentation, which disciplines were documenting ACP discussions, and whether ACP discussion information was placed in an easily accessible EHR location that could be retrieved at the point of care. Based on our clinical experience and prior research,¹⁸ we hypothesized that the majority of documented discussions would not be easily accessible in the EHR.

Methods

This is a cross-sectional study of primary care patients at the San Francisco Veterans Affairs Medical Center (SFVAMC). Baseline data were obtained from records of patients enrolled in a randomized controlled trial from 2013-2015 comparing the efficacy of a patient-centered ACP website (www.prepareforyourcare.org) plus an easy-to-read advance directive versus an advance directive alone on ACP documentation. The methods and results of this trial have been published.^{24,25}

Patient Population

Eligibility was defined by chart review, physician assessment, and study staff assessment. Patients at the SFVAMC were eligible if they were at least 60 years of age, fluent in English, had at least two serious/chronic health conditions (defined by ICD-9 codes matching conditions listed in validated measures of comorbidity),^{26,27} had been seen at least twice in the prior year by a primary care provider in the General Medicine, Geriatrics, or Women's Clinics, and had two additional clinic/hospital/emergency visits in the past year. Patients with evidence of dementia, blindness, cognitive impairment, delirium, psychosis, or active substance abuse by chart review or screening were ineligible. We obtained permission from primary care providers to approach their patients and then recruited participants by letters, flyers, phone calls, and in-clinic recruitment. Participants provided informed written consent. The study was approved by the University of California, San Francisco (UCSF) and the SFVAMC institutional review boards.

Measures

Measures included the frequency of ACP documentation, defined as legal forms/orders and documented ACP discussions (Figure 1). Forms/orders included any prior scanned advance directives or living wills, durable power of attorney for healthcare (DPOAHC) forms, and orders including outpatient Do Not Resuscitate/Do Not Intubate (DNR/DNI) orders or Physician Orders for Life Sustaining Treatment (POLST). For ACP discussions, chart notes were reviewed within the prior five years. Two independent coders reviewed all medical

records. Disagreements were resolved by consensus. To qualify as a documented ACP discussion, written evidence of participant engagement and input in a conversation was required; documentation that participants were only provided educational materials was not counted.

For legal forms/orders, we assessed the type (e.g., advance directive, DPOAHC, POLST, and code order), overall frequency, and mean elapsed time between form/order completion and study enrollment. For participants with multiple forms/orders, all types were described and the most recent form/order was used to calculate overall frequency and timing. Also, because patients with completed legal forms/orders should ideally have accompanying ACP discussions to explain their decision-making process, we determined how many patients with a legal form/order had a documented ACP discussion.

For ACP discussions, we assessed the frequency, type, and timing of documented information, the author of the note, and location and accessibility in the EHR. Rates of discussion completion, as a percentage of all study participants, as well as mean elapsed time between discussion completion and study enrollment, were computed. For participants with multiple documented discussions, the most recent discussion was used. The type of documented discussions was categorized as follows: “goals of care” (i.e., a discussion describing participants’ wishes, reasoning, and thought processes), “code status only” (i.e., DNR/DNI or Full Code or Comfort Care noted in discussion documentation without documentation of participants’ reasoning or thought processes), “surrogate decision maker,” and discussions about “legal documents.” Discussions often included multiple categories. Data are presented for each content category as percentages of the total number of participants with discussions. Authorship was categorized by discipline: primary care provider, inpatient/outpatient social worker, inpatient medical team, or outpatient psychologist. The location of each ACP discussion was determined by the note type. The SFVAMC EHR uses note templates for ACP which are captured in a central posting area on the face page of the patients’ medical record. The accessibility of each ACP discussion was determined by whether it could be located in the centralized posting area. If it could, the discussion was deemed “easily accessible.” Documented discussions which could only be found by searching free-text from chart notes, including hospital admission, discharge, emergency department, outpatient primary care, specialty clinic, social work, and surgical/anesthesia pre-operative notes, were deemed “not easily accessible.”

For both ACP forms/orders and ACP discussions, we assessed preferred level of treatment using categories based on POLST and other scope-of-treatment documents.²² Preferences were categorized as “Aggressive” care (i.e., documented Full Code or affirmative to intubation, CPR, and all other life sustaining treatments without evidence of wanting to limit treatments in any situation), “Limited Aggressive” care (i.e., documented Full Code, affirmative to CPR and intubation but not indefinitely and not in every situation), “DNR/DNI-Limited” (i.e., negative response to intubation or CPR, but affirmative to surgery, antibiotics, or feeding tubes), or “DNR/DNI-Comfort” (i.e., negative responses to CPR and intubation with specific documentation of the term “comfort measures only”). The category of “No Wishes Documented” was used if preferences could not be categorized by these

criteria. Rates of each desired level of treatment are presented as percentages of all participants with completed forms or discussions, respectively.

Once treatment preferences were categorized, we determined whether physician orders accompanied DNR/DNI documentation in advance directives or discussions. An accompanying DNR/DNI physician order or POLST is considered appropriate so that patients' wishes can be honored across health settings.²⁸ Thus, we assessed rates of POLST or outpatient DNR/DNI orders for participants whose advance directives and/or ACP discussions were categorized as DNR/DNI.

We also assessed changes in treatment preferences between forms/orders and subsequent ACP discussions with discernible levels of desired treatment (e.g., Aggressive, DNR/DNI-Comfort, etc.). Levels of desired treatment were categorized as "changed" if they differed between forms/orders and subsequent ACP discussions. For these participants, we categorized the changes as "more aggressive" or "less aggressive" based on how their preferences changed in more recent documented ACP discussions relative to prior forms. Determining the accessibility of ACP discussions that document changes in treatment preferences is important so that patients' most updated wishes can be honored. Therefore, we assessed time between form completion and subsequent ACP discussions and the accessibility of the ACP discussion that documented the treatment change.

Statistical Analysis

To describe participant characteristics and our measures, we used percentages and means with standard deviations. Analyses were conducted using SAS statistical software (version 9.4; SAS Institute Inc.).

Results

Participants

The mean age of the 414 participants was 71 years ($SD \pm 8$) (Table 1). Participants were mostly men (91%), 43% were non-white by self-report, 18% had less than a high school education, 20% had limited health literacy, 29% self-rated their health as fair-to-poor on a 5-point Likert scale, and 92% reported having a potential surrogate decision maker. Of the 414 participants, 212 (51%) had some type of ACP documented in the EHR.

ACP legal forms and Physician Orders

One hundred forty-nine participants (36%) had completed ACP legal forms at any time, including 130 advance directives/living wills and 103 DPOAHC forms. These forms were completed an average of 4.6 years ($SD \pm 3.2$) prior to study enrollment (Table 2). Three POLST forms were completed and two participants had outpatient DNR/DNI orders. Of 149 participants with ACP legal forms/orders, 75 (50%) had an accompanying documented ACP discussion.

ACP discussions

In the five years prior to study enrollment, 138 (33%) study participants had documented ACP discussions. These discussions occurred 2.1 years ($SD \pm 1.4$) prior to study enrollment and focused on surrogate decision makers ($n=115$, 83% of participants with discussions), goals of care ($n=45$, 33%), legal documents ($n=36$, 26%), and code status ($n=23$, 17%).

Overall, discussions were documented predominantly by social workers ($n=75$, 54%) and outpatient primary care providers ($n=49$, 36%) (Table 3). Inpatient primary teams documented 12 discussions (9%), while one discussion each was documented by an outpatient palliative care provider, and an outpatient psychologist.

Of 138 ACP discussions, 62 (45%) were easily accessible and 76 (55%) were not easily accessible from the EHR. Of the easily accessible discussions, 58 (94%) were documented by social workers, two by inpatient primary teams, and one each by a primary care provider and an outpatient palliative care provider. Of the not easily accessible discussions, 48 (63%) were documented as free-text by primary care providers in progress notes and 17 (22%) were documented in social work notes. By provider type, 58 (77%) of 75 discussions documented by social workers were easily accessible, while one (2%) of 49 discussions documented by primary care providers was easily accessible.

Treatment Preferences and Physician Orders

Participants expressed preferences for desired level of treatment in 83% of completed ACP forms/orders and 39% of discussions (Table 4). In legal forms/orders, the most frequently desired level of treatment was DNR/DNI-Limited (56%). Among ACP discussions, the most frequently desired level of treatment was Limited Aggressive (46% of those with discernible wishes). Among the 88 participants with DNR/DNI wishes in advance directives, two (2%) had active DNR/DNI orders and two (2%) had completed POLST forms. Of the 15 participants with DNR/DNI wishes in discussions, no participants had active DNR/DNI orders and two (13%) had completed POLST forms.

Changes in Preferences

During the 5-year retrospective review of the EHR, 34 participants had completed a legal form/order and then had a subsequent ACP discussion where levels of preferred treatment were documented. Discussions occurred an average of 3.9 years ($SD \pm 3.4$) after form/order completion. For 27 (79%) of these participants, discussions documented a change in participants' treatment preferences: nine (33%) to more aggressive treatment and 18 (67%) to less aggressive treatment. For 19/27 (70%) participants with changed preferences, the documented ACP discussions were not easily accessible in the EHR: nine (100%) of those documenting more aggressive treatment preferences and 10 (56%) of those documenting less aggressive treatment preferences.

Discussion

To our knowledge, this is the first study to describe the comprehensive type, authorship, location, and accessibility of ACP documentation through detailed electronic chart review.

The VA is an exceptional national model of ACP documentation in that it includes a centralized posting section in the EHR for ACP, is dedicated to ACP initiatives,^{13–17,25,29} and half of chronically ill, older Veterans in this study had documented ACP wishes, well above national norms.³⁰ However, given that many non-VA health systems do not have similar established EHRs and dedicated ACP programs, these study findings point to a likely widely generalizable quality improvement gap for patient safety in ACP. For example, 50% of patients with a completed form or physician order in this study did not have an accompanying documented ACP discussion about that form/order in the EHR. In addition, the majority of ACP discussions were not easily accessible, though they were more up-to-date (i.e., on average two years versus five years prior) and often represented changes in wishes from prior forms/orders. A majority of ACP discussions, including those which were easily accessible, were also documented by social workers rather than primary care providers.

These results are similar to a Canadian study of hospitalized patients demonstrating that patients' and families' wishes were not being documented correctly in the medical record.²² Lack of accurate and accessible ACP documentation represents an important patient safety issue that could have devastating ramifications on patients' care.²³ Having up-to-date, easily accessible descriptions of patients' wishes for medical care in an ACP discussion note in the EHR is essential to ensuring patients engage in fully informed shared decision-making about their preferences, interpreting the meaning behind legal forms/orders, conveying important information to other treating physicians about real-time and ongoing changes in patients' preferences, and ensuring that patients' wishes are honored. The insight provided by documented discussions also provides crucial context for future discussions with additional medical providers.

However, in this study, half of participants with completed ACP legal forms had no accompanying documented discussions. Ensuring all forms/orders are accompanied by a corresponding ACP note may be an important quality improvement metric in addition to advance directive or form/order completion. In addition, the majority of ACP discussions were not easily accessible and were documented as free-text in progress notes without any associated notification or flag in the central posting section of the EHR. This minimizes the likelihood that a future clinician would notice and be able to use this information in an actionable way at the bedside. Although many providers are having detailed ACP discussions with patients, the lack of standardized documentation practices limits the clinical utility of these discussions.

The lack of standardization was most concerning when documented preferences changed between legal forms/orders and subsequent discussions, especially as 70% of these changes in preferences were not easily accessible in the EHR. Future providers who do not notice or cannot find subsequent free-text discussions in the EHR are likely to default to more easily located forms/orders which may contain outdated patient preferences. These forms/orders were, on average, completed five years prior to study enrollment, and more frequent updates are needed as demonstrated by the high rate of changed preferences among those with subsequent discussions. Use of such out-of-date documentation may lead to care misaligned

with patients' preferences. When extrapolated on a population level, these misaligned documented wishes could affect many patients.

ACP discussions were most frequently documented by social workers followed by primary care providers. The involvement of social workers in this process is a strength of the integrated Patient Aligned Care Teams (PACT) in the VA system and likely positively impacts ACP documentation overall. However, in some cases, the additional involvement of the primary care provider to provide context regarding patients' medical conditions and prognoses may also be important. Primary care providers documented only 2% of ACP discussions in an easily accessible location compared to 77% of social workers' documentation. This discrepancy may reflect differences between training curricula and could likely be improved with educational interventions. The extremely low use of POLST and DNR/DNI orders for the subset of patients with preferences for DNR/DNI also reveals an opportunity for improvement of the ACP documentation process.

While prior research has focused on increasing rates of legal form completion³¹⁻³³ or techniques to conduct effective ACP discussions,³⁴⁻³⁶ interventions focusing on appropriate documentation of ACP discussions are less prevalent.¹⁴ Such an intervention could have a large impact on clinical care and patient safety²³ and may require minimal behavioral change from clinicians since our study demonstrated that many are already having and recording rich ACP discussions. In addition, changes to the EHR that would allow clinicians to easily flag goals of care conversations within other progress notes, to be placed in important central EHR posting areas, may negate the need for remembering specific note titles.

The strengths of this study include the comprehensive nature of chart review performed by two independent reviewers. Limitations include the predominantly older and male population of Veterans recruited from a single medical center who were participating in a study of ACP, which may restrict generalizability. However, the study population was diverse in other demographic characteristics. In this cross-sectional study, we were unable to assess changes in behavior over time, nor determine whether patients received care consistent with their most up-to-date preferences. However, our data provide an assessment of the current state of practice which can be used to inform future studies.

Conclusions

These results suggest potential areas for EHR redesign and quality improvement to ensure patient safety and patient-centered care in ACP. Quality improvement targets include clinician education concerning documentation of ACP discussions in an easily accessible location in the EHR, especially to help explain preferences for patients with completed ACP legal forms and changes to patients' preferences over time. More frequent updating of patient's wishes and completion of physician orders for patients with clear and stable DNR/DNI wishes may also be needed. Further study, including the design of the EHR, is needed to better understand how to improve ACP documentation practices and help ensure patients' wishes are honored.

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Key Points

Question

What are the current advance care planning documentation practices at a VA Medical Center and how accessible are documented advance care planning discussions in the electronic health record?

Findings

In this cross-sectional study of 414 chronically ill Veterans, half had documented advance care planning wishes, including one third with documented discussions. Most (55%) discussions were not easily accessible in the medical record, including 70% of those documenting treatment wishes which had changed from prior legal forms/orders.

Meaning

Efforts to improve standardization and accessibility of advance care planning documentation are imperative to ensure patient safety and patients' wishes are honored.

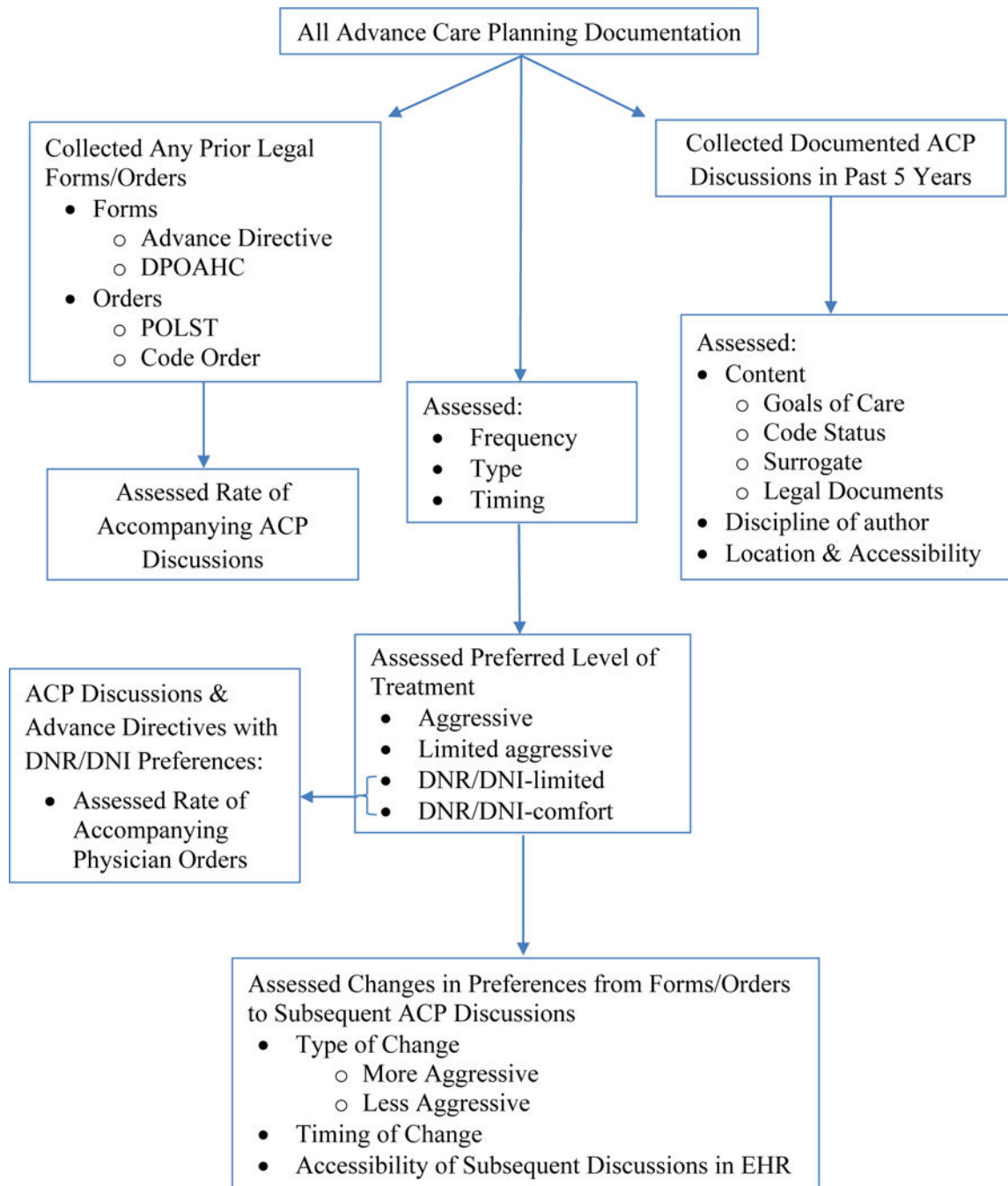


Figure 1. All study measures assessed by chart review

ACP indicates Advance Care Planning; DNR/DNI, Do Not Resuscitate/Do Not Intubate; DPOAHC, Durable Power of Attorney for Health Care; EHR, Electronic Health Record; POLST, Physician Orders for Life Sustaining Treatment.

Table 1

Demographic characteristics of study participants.

Demographic Characteristics	
Age: N=414, mean (SD)	71.1 (7.8)
Sex: Women, N=414, No. (%)	38 (9%)
Race/Ethnicity: N=413, No. (%)	
White	235 (57%)
African American	88 (21%)
Latino/Hispanic	33 (8%)
Native American	5 (1%)
Asian/Pacific Islander	26 (6%)
Multi-ethnic/Other	26 (6%)
Education high school: N=413, No. (%)	74 (18%)
Finances, not enough to make ends meet: N=412, No. (%)	49 (12%)
In a married/long term relationship: N=414, No. (%)	187 (45%)
Have a potential surrogate: N=414, No. (%)	382 (92%)
Self-Rated Health, fair-to-poor: N=412, No. (%)	120 (29%)
Limited Health Literacy, N=411, No. (%)	83 (20%)

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Table 2

ACP legal forms and physician orders.

Type of ACP Forms/Orders	Completed Forms/Orders N=414, No. (%)	Time prior to study enrollment (mean years \pm SD)
Advance Directive	130 (31%)	5.0 \pm 3.3
DPOAHC Form	103 (25%)	5.6 \pm 3.7
POLST	3 (0.7%)	1.9 \pm 1.5
DNR/DNI Order	2 (0.5%)	4.1 \pm 0.7
Any ACP Forms/Orders	149 (36%)	4.6 \pm 3.2

ACP indicates Advance Care Planning; DNR/DNI, Do Not Resuscitate/Do Not Intubate; DPOAHC, Durable Power of Attorney for Health Care; POLST, Physician Orders for Life-Sustaining Treatment.

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Table 3Location and authorship of documented ACP discussions in the EHR^a

Easily Accessible		N = 62 (45%)
Author	Location in EHR	No. (%)
Inpatient Social Worker	ACP Posting ^b	35 (25%)
Outpatient Social Worker	ACP Posting	23 (17%)
Inpatient Medical Team	ACP Posting	2 (1.4%)
Primary Care Provider	ACP Posting	1 (0.7%)
Outpatient Palliative Care Provider	ACP Posting	1 (0.7%)
Not Easily Accessible		N = 76 (55%)
Author	Location in EHR	No. (%)
Primary Care Provider	Outpatient Progress Note	48 (35%)
Inpatient Social Worker	Inpatient Social Work Note	13 (9.4%)
Inpatient Medical Team	Admission Note	5 (3.6%)
Outpatient Social Worker	Outpatient Social Work Note	4 (2.9%)
Inpatient Medical Team	Discharge Summary	2 (1.4%)
Inpatient Medical Team	Inpatient Progress Note	1 (0.7%)
Inpatient Medical Team	Inpatient Progress Note Addendum	1 (0.7%)
Inpatient Medical Team	Inpatient Pre-Operative Note	1 (0.7%)
Outpatient Psychologist	Outpatient Progress Note	1 (0.7%)
Time between ACP discussion documentation and study enrollment (mean years \pm SD)		2.1 \pm 1.4

^a n = 138 documented advance care planning discussions.

^b The ACP posting location is a centralized, easily accessible location on the face page of a participant's electronic health record. ACP indicates Advance Care Planning; EHR, Electronic Health Record.

Table 4

Desired level of treatment documented in legal forms and ACP discussions.

Level of Treatment Desired	ACP legal forms N = 149, No. (%)	ACP discussions N = 138, No. (%)
Aggressive	9 (6%)	14 (10%)
Limited Aggressive	26 (17%)	25 (18%)
DNR/DNI-Limited	83 (56%)	10 (7%)
DNR/DNI-Comfort	5 (3%)	5 (3%)
No Wishes Documented	26 (17%)	84 (61%)

ACP indicates Advance Care Planning; DNR/DNI, Do Not Resuscitate/Do Not Intubate.

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