

Conversation Starters:
Research Insights from Clinicians
and Patients on Conversations About
End-of-Life Care and Wishes

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Contents

3 Introduction and Methods

3 Summary

5 Insights from Patients

Patients' Ideas for Conversation Starters

Patients' Past Experiences with Advance Care Planning Conversations

8 Insights from Clinicians

Clinicians' Ideas for Conversation Starters

Early Advance Care Planning Discussions: Prior to an Illness

Advance Care Planning Discussions After a Diagnosis

13 Conclusion

Introduction and Methods

The John A. Hartford Foundation, Cambia Health Foundation, and California Health Care Foundation commissioned PerryUndem Research/Communication to conduct focus groups among health care clinicians and patients on the topic of end-of-life care and wishes.

This qualitative research comes on the heels of a national survey we conducted in spring 2016 among primary care providers and specialists who regularly see patients 65 and older. The national survey showed that nearly all physicians consider advance care planning conversations important, while, as of early March 2016, only a fraction had billed Medicare for such conversations using a new Medicare reimbursement code implemented in January 2016. The national survey identified key barriers to having these conversations, such as not having a formal assessment process in place, feeling uncertain about what to say in conversations with patients, feeling unsure when to have the conversations, and having difficulty dealing with family disagreements. Detailed findings can be found at: www.johnhartford.org/newsroom/view/advance-care-planning-poll.

The goal of the qualitative research was to explore experiences and ideas from both clinicians and patients around starting and having quality conversations about advance care planning and end of life. This qualitative research focused on various types of clinicians in contrast to the spring 2016 national survey, which only included primary care physicians and specialists.

Six focus groups with health care clinicians were conducted June 7–29, 2016:

Atlanta, GA:

- ▶ 8 Family/General Practice Physicians and Internists
- ▶ 9 Advance Nurse Practitioners and Physician Assistants

Chicago, IL:

- ▶ 7 Specialists (Oncologists, Cardiologists, and Pulmonologists)
- ▶ 8 Advance Nurse Practitioners and Physician Assistants

Los Angeles, CA:

- ▶ 11 Family/General Practice Physicians and Internists
- ▶ 5 Specialists (Oncologists and Pulmonologists)

The research also included one online focus group with 31 adults over age 40 who have an advance care plan and have talked with clinicians about their wishes within the last five years. Participants were diverse in terms of race/ethnicity, gender, education level, income, and region of the country. The online focus group was conducted September 8, 2016.

This report includes an overall summary of key findings, followed by insights from patients and clinicians.

Summary

Following are key insights from the research:

1 Clinicians talk about two distinct types of advance care planning conversations: (1) early advance care planning with relatively healthy patients and (2) later advance care planning discussions with patients who have a serious illness diagnosis. Early advance care planning conversations tend to be procedural and simply involve raising the topic with relatively healthy patients. Clinicians say later advance care planning conversations are much more difficult, start arbitrarily, and are difficult to navigate.

2 Starting the early advance care planning conversation prior to a diagnosis is routine and fairly easy for clinicians who have assessment questions integrated in a formal system. Often, questions about an advance care plan are integrated into the EHR and asked in routine visits among relatively healthy patients. With prompting from the EHR, clinicians ask patients whether they have a plan in place, and if not, provide introductory information about the topic. This initial conversation does not tend to be in-depth or lengthy.

3 While raising the topic is fairly easy for clinicians with a formal assessment system, patients say this conversation is not very helpful when it comes to the actual planning and decisionmaking process. Many patients in the study say their provider was

not helpful in the decisionmaking process. Most did not have in-depth discussions with providers to help them decide their wishes for care. As a result, these patients did not have an opportunity to weigh all of the probable scenarios, treatments, and options for care with their provider.

4 Patients are much more likely to have had in-depth planning conversations with family members and attorneys, than with their health care providers. When asked who they talked to in the planning process, most respondents say their spouses, followed by children. About half had conversations with attorneys during the process.

5 Patients say they want clinicians to be direct, honest, and sensitive, and to explain why advance care plans are important. Patients want a combination of direct, honest talk with a sensitive and considerate tone. Talking about the importance of plans – such as the ramifications of not having their wishes documented – is also important.

6 After the patient is diagnosed with a serious illness – or when the patient is near the end of life – clinicians say the most productive conversations occur if an early advance care plan is already in place. Clinicians agree that having end-of-life discussions, particularly with family members, are much easier when they can start from the patient’s wishes documented in an advance care plan.

7 Both clinicians and patients say the planning process should start at an early age. Clinicians say conversations are much easier to have when patients are young, healthy, and cognizant. Patients agree – most say conversations with health care providers should start when adults are in their 20s and 30s.

A Snapshot of Conversation Starters

| FROM PATIENTS | FROM CLINICIANS |
|--|---|
| Start early advance care planning conversations with young adults. | Start early advance care planning conversations with young adults. |
| Be direct, honest, and sensitive, and explain why plans are important. | Have a routine set of questions integrated in a formal assessment system. |
| Have advance care plan forms to give patients. | Treat advance care planning as routine and not singled out as about death. |
| Have staff that can help fill out paper work. | Know that end-of-life conversations are an iterative, ongoing process rather than a one-time event. |
| Integrate end-of-life wishes during a visit that covers other issues. | Use palliative care teams to help facilitate conversations and care. |
| Check in with patients occasionally about their wishes. | Have background knowledge about racial/ethnic/cultural communities. |
| Provide advice and input on treatment possibilities, recovery, possible outcomes, and help patients think through options. | Have an advance care plan or “living will” already in place – a #1 conversation starter near end of life. |
| Create opportunities for community groups to come together and facilitate discussions about end-of-life issues among populations they serve. | Create opportunities for training and talking with colleagues. |

Insights from Patients

Patients' Ideas for Conversation Starters

Advance care planning conversation starters: Be direct, honest, and sensitive, and explain why plans are important. Many participants want their health care providers to be direct and honest with them in conversations about planning for end-of-life care. Several participants also say they want their provider to be sensitive, considerate, understanding, and compassionate. A few say they want providers to be open to the patient's wishes and they want to hear that their wishes will be followed.

Other advice for providers:

- ▶ Explain why plans are important: saving grief and the weight of decisions on others, the ramifications of not having a plan.
- ▶ Remind patients why advance care plans are necessary at any age.
- ▶ Have advance care planning forms to give to patients.
- ▶ Have staff that can help fill out paperwork.
- ▶ Tell patients they should not be offended by the conversation because everyone must have a plan.
- ▶ Be straightforward about reasonable expectations.

"Be direct, sensitive, and honest."

"Explain in logical terms the possibility of accidents and disease to make it logical to not put that burden on the family."

"Let me know exactly what is end of life and explain gently what needs to be done."

"Give the person the actual papers and offer your nurse or assistant or social workers to help you fill it out."

Half of participants would like their health care providers to check in with them occasionally about their wishes; others feel that this follow up is unnecessary. Participants who would like occasional check-ins say it would be helpful to assess whether their feelings have changed and to "double check." Several also say check-ins would be helpful when their health changes. A few say these inquiries would be a sign that their provider cared about them and would build trust.

Others feel check-ins with providers may be unnecessary because their plans are their responsibility alone or because they do not think they will change their minds.

Most participants say integrating questions about end-of-life care into routine visits is a good idea. They say the questions will prompt patients to think about the issue and be proactive about getting their wishes in writing. No participants feel that the practice is a bad idea – a few say it is unnecessary for them because they already have a plan in place.

*"Several things need to be discussed.
Will I recover completely? If not,
what will I not be able to do?
How much pain, if any, will I be in?"*

"Because I would want his input to help decide what's the best course to take."

If their health changed, 24 of 31 participants would want to have a conversation with a health care provider. Many participants say they would want their health care provider's advice on treatment, input on recovery scenarios and possible outcomes, and help in thinking through options. A few participants would want to make sure "everything is covered" and "everyone is on the same page."

Participants who would not want a conversation tend to say it is a personal or private decision that has already been made.

"I don't think I would need to talk with my health care provider about this issue because I think that me and my spouse could make the decision on our own."

Twenty-four of 31 participants prefer a conversation about end-of-life wishes during a visit that covers other issues. Participants prefer the convenience of combining an end-of-life care discussion with a visit for another health issue, rather than having a separate meeting just to discuss end-of-life care wishes. Several allude to a full separate visit being unnecessary since they already have plans in place. A few who would want a separate visit say it would allow more time and fewer distractions.

"Why make an appointment just to talk about death? ... This can be done at a regular appointment... Why pay for an additional office visit anyway?"

"Since you're there for a complete physical, it is the perfect time to revisit. It's also perfect because I may have found out some other medical issue."

Twenty-four of 31 participants feel "very confident" that their wishes will be followed when the time comes. Seven are somewhat confident. Most are confident either because they have talked with designated family members or because copies of their documented wishes are with doctors and attorneys.

Those who only feel "somewhat" confident hope their children would follow wishes or feel that as long as their files are not lost, there should not be a problem.

When asked directly, 18 of 31 participants feel their children and immediate family members will "definitely" feel comfortable following their wishes. Another nine say their family members will "probably" feel comfortable. Participants feel their family members will want to follow their wishes, and several say they have discussed wishes already with key family members.

"We have discussed it and agreed on it already. My son will follow my wishes."

"Copies are with all my doctors, my hospital and my wife and son. I feel confident that these people will respect my wishes."

"I think my son will be so overwhelmed that he will need some help to carry out my requests."

Participants say the most important thing they could do to make sure family members follow their wishes is to discuss their wishes and give them copies of their plan. Reiterating their wishes every once in a while, reassuring them, and explaining their choices may also help.

The majority of participants say providers and patients should begin having advance care planning conversations when patients are in their 20s and 30s. Only six participants say conversations should begin after age 45.

There are mixed reactions to the concept of community groups bringing people together to talk about end-of-life issues. Many participants feel these types of events are a good idea to get people thinking about the issue, hearing others talk face to face, increasing awareness, and helping people get more comfortable with the idea. Several say churches would be a good place to start. Others mention workplaces, colleges, social groups, lesbian gay bisexual transgender community centers, organizations that work on issues of aging, and local government.

Several participants, however, feel that the issue is too personal, private, or confidential to discuss openly in a group setting.

"[Community events] are a good idea to get the subject out there to every age and circumstance – so people are more comfortable talking about it and doing something about it."

"It's too intimate of a subject for me to feel comfortable discussing in a group forum."

Patients' Past Experiences with Advance Care Planning Conversations

As previously described in the methods section, these insights come from adults around the country who either have a living will or an advance care plan, and have talked to a health care provider about the topic.

While all participants had some type of interaction with health care clinicians, more critical conversations happened with family members and attorneys. Virtually all married participants say they talked with their spouses to help plan out their wishes around end-of-life care. Those who are divorced or widowed mention children. Many participants have talked to attorneys. Only about five of 31 participants say their health care providers were part of discussions to help them plan out end-of-life care wishes.

"My mate and I sat down. He was very guarded and didn't want to talk about death. I persisted."

"[I talked with] my wife and kids. They are the most important people in my life. And they had the right answers."

Half of the participants say their attorneys helped them put their directives in writing. Two say a health care provider helped them and two mention a social worker. Others say they put wishes in writing themselves or with the help of a spouse or child. However, it's important to note that lower-income patients may not have the same access to legal assistance as higher-income patients.

"I just told my primary care provider that I wanted to have a living will on file and he stated that it was a great idea."

"My wife and I had seen many friends die without directions. So our lawyer was aware of this and asked many questions."

Participants are more likely to have initiated a conversation with their health care provider than vice versa. Twenty-two of 31 participants say they initiated the topic of end-of-life care with their health care provider. Fourteen participants say their provider initiated the conversation. Nine say both they and their health care provider had initiated conversations at different times.

Many say their conversations with clinicians were transactional and not helpful in making decisions or putting plans in writing. During these conversations, providers ask whether the patient had an advance directive or living will or the patient gives the provider a copy. When asked specifically what the health care provider said or did to help get their wishes in writing, 14 of 31 participants say “nothing.”

A few participants allude to more in-depth conversations with providers, such as discussing options for recovery in various circumstances. One participant describes a conversation with her provider who “tried to plan for every contingency.” Another participant’s provider sent her to a social work team, which she described as “awesome.”

“[My provider did not say] much. It was more general and they wanted the copies.”

“He just indicated that it was a good thing to do. And said he would hate see me do like so many other people he had cared for and how ugly their situations ended.”

“My health care provider did not help. I provided them with completed forms.”

“It was the hospital where they insisted I have a living will. No talking about it at all [with my primary care provider.]”

Insights from Clinicians

Clinicians’ Ideas for Conversation Starters

Several ideas emerge around ways health care systems can help clinicians initiate and engage in quality end-of-life care conversations. These include:

- ▶ Formalize questions or prompts for a discussion in the Medicare annual wellness visit EHR “checklist.”
- ▶ Implement a flagging system in EHRs for follow-up reminders with patients.
- ▶ Track the number of completed POLST¹ forms a physician has on average and notify the provider when the number is lower than expected.
- ▶ Provide opportunities for clinicians to share with and learn from each other.
- ▶ Hold workshops or provide training to learn more about how to have quality conversations.
- ▶ Integrate help and support from social workers and palliative care teams.
- ▶ Implement a protocol for giving every patient the opportunity to complete a POLST form.
- ▶ Have reading and patient education materials in waiting rooms.
- ▶ Address situations that lead to patients’ wishes being ignored, such as not sharing records or reading documents (some clinicians feel pessimistic about getting patients’ wishes in writing when barriers can make those wishes irrelevant).

“I found talking to colleagues... extremely helpful... They are able to really explain to me how they see it; how it’s seen from that cultural group”

1. A Physician Orders for Life Sustaining Treatment (POLST) form is a set of medical orders, similar to the do-not-resuscitate order, intended for those who are seriously ill or frail.

“You will get a notification [to ask about advance care plans in the EHR] So it makes you just more conscious.”

“I like having workshops. When I was going to med school there was no discussion like this, not even during fellowship. I think it’d be helpful to be educated somewhat by the professionals – the people who are really good at communication and sensitivity issues.”

Clinicians also have a number of ideas, reminders, and tips for talking with patients. These include:

- ▶ Treat advance care planning as a routine part of the health care continuum and not just about death.
- ▶ Start and continue the conversation with the understanding that the process is iterative: Initiate a planning conversation, follow up regularly, and discuss wishes and options as health or treatment changes.
- ▶ Ease into the conversation and use empathetic language, such as: “We ask this of everyone;” “I’m going to say something that may be difficult...”
- ▶ Be at or below eye level with the patient.
- ▶ Be present and authentic.
- ▶ Acknowledge emotions.
- ▶ Take as much time as necessary, allowing patients to adjust to the information.
- ▶ Reassure patients they can change their minds.
- ▶ Give choices – but also your recommendation.
- ▶ Identify the family decisionmaker to be the main liaison with care providers.
- ▶ Focus on the patient’s suffering and wishes during family disagreements.

Clinicians also discuss challenges and opportunities around talking with diverse populations about end-of-life care. Many physicians point out the different cultural beliefs and reactions to conversations about end-of-life and advance care planning. For example, some patients fear that talking about death will invite death. Others are uncomfortable and want to avoid the topic. Some distrust the clinician. Religious beliefs, gender, and family roles can all factor into conversations.

Ideas for improving discussions with diverse patients include:

- ▶ Have some background knowledge about the racial/ethnic/cultural community; this helps open the door.
- ▶ Speak the same language. This helps build trust and captures important nuances within conversations.

“Something that you could say is: ‘Here are five things that our practice thinks are really important you know: getting your flu vaccine; making sure you’re coming to your visits on a timely basis, and understanding advanced care directives and end-of-life kind of care.’ So it’s sandwiched in with some other things. That might not be so much like, ‘Let’s talk about death, shall we?’”

“I leave it like you always have a choice. Even if you make this decision, you can always change your mind.”

“I always start the conversation off by telling them a hundred years from now none of us will be here.”

- ▶ Practice non-verbal communication such as: being at the same eye level, staying close to the bed, using touch, smiling, and maintaining eye contact.
- ▶ Talk to patients about their lives, not just about their health.
- ▶ Ask the same questions of everyone, regardless of background, to avoid bias.
- ▶ Treat patients consistently. Do not make assumptions because of racial or ethnic background.
- ▶ Increase awareness among clinicians about unconscious bias.
- ▶ If possible, have a family member present during these conversations. Increased presence of family members helps patients feel more comfortable.

“You need to be touching that person and almost up close to them, at least with [some cultures]. You’ve got to be with the family hugging them and looking at everybody before you can actually speak to them.”

Fear of talking about death emerges as a challenge throughout discussions – more public awareness and education may be helpful. Some clinicians feel patients are becoming more aware of living wills. However, there are still many patients who are uncomfortable with the topic. Increasing public awareness and education can help lessen some of the stigma and fear around death.

To be successful, measures created to increase the number and quality of patient-clinician conversations should be careful not to overburden physicians. Most physicians feel overwhelmed and frustrated with their jobs. They say practicing medicine has become increasingly challenging over the years as a result of more documentation requirements, increased need for prior authorizations, and EHR demands.

“I think it would be great if every single one of us could get a lesson in end-of-life care, but there are no such lessons that exist. And unfortunately a lot of people are getting their information from Grey’s Anatomy.”

Early Advance Care Planning Discussions: Prior to an Illness

The #1 conversation starter: a routine and fairly easy set of questions integrated into a formal assessment system. The survey shows that physicians who report having a formal system for assessing end-of-life wishes are more likely to have those discussions. We see this in the qualitative research as well. Several of the advanced nurse practitioners and physician assistants say they routinely initiate advance care planning conversations as part of the Medicare annual wellness visit. Their EHR prompts them to ask about living wills and advance care plans during these annual visits – this is part of the “checklist.” Another participant who works at a pharmacy retail clinic says the EHR prompts them to ask every older patient they see – regardless of the reason for the visit – whether he or she has a living will.

“We bring [up living wills] with all patients. It is in our charting system. So it’s a bullet that we have to click on and have to chart. Whether they have a living will or whether they want one.”

“I generally try to encourage them to have a family member with them in going through [the form]. Then I let them know, ‘if you want to think about it, have any questions, come back with somebody if you want.’”

Physicians and specialists connected with palliative care teams or who have had similar training also initiate planning conversations. These clinicians may provide a POLST form to every new patient at the first visit, provide forms for all patients once they turn 65, and begin discussing the issue with all patients at age 18.

For others, advance care planning conversations start arbitrarily or do not happen at all. Some primary care physicians and specialists are hesitant to initiate a conversation about advance care planning. They worry about upsetting the patient or say that more trust needs to be established before having the discussion. A few say patients have raised the issue with them, instead of the other way around.

Many early advance care planning conversations – prior to a diagnosis – seem brief and transactional. Clinicians say they first ask patients whether they have an advance care plan (many use the term “living will”). If a patient does not know what an advance care plan or living will is, the clinician explains. Several providers say they also offer the patient information about the topic to take home. A few clinicians say they use materials such as Five Wishes or POLST forms. Others cannot remember where the materials come from, possibly a state or federal agency. None of the clinicians report having in-depth conversations at this stage in the advance care planning process.

Even though there is now a new Medicare benefit for advance care planning conversations, nearly all clinicians say they are folding these conversations into routine visits – not separate visits billed to Medicare. Clinicians in the focus group cite documentation requirements as the main reason they are not billing Medicare for advance care conversations. Many feel the reimbursement for the time involved in having an advance care planning discussion is not worth the hassle of the

paperwork. Several physicians also say that the reimbursement request may get refused by Medicare or a third party if they inadvertently do something incorrectly. Several also mention that the process may put them at risk for being audited later. Overall, physicians feel that the time, process, and uncertain outcome make filling out the reimbursement paperwork “not worth it.” However, 75 percent of physicians in the national survey say the new benefit makes them “much more” (35 percent) or “somewhat more” (40 percent) likely to talk with patients about advance care planning.

Some clinicians say patients do not follow through with creating an advance care plan. Clinicians say many patients forget about the issue and tend not to have the paperwork or plan filled out when they come to their next appointment. There seems to be little engagement by these clinicians in learning why patients have not filled out plans or how to engage and motivate patients to do so.

“I may get five in 50 [patients who] say give me the information [about advance care planning.] But they never bring [the living will or plan] back because they’re just getting the information to shut me up. And they figure that’s it. But they never bring it back.”

Many feel patients should complete an advance care plan when they are young and healthy. Clinicians want patients to plan for end-of-life wishes and care when they are fully cognizant and at a stable mental and emotional place. While wishes and care needs may change, clinicians feel the earlier and healthier the patient, the easier the conversation. Some suggest beginning as early as 18 if a trusting relationship has been established.

“The documentation defeats the purpose of the reimbursement... Yes, you have to have the conversation, but you have to jump through about 50 other hoops and document about 60 other things.”

“As a society we’re playing catch up. It’d be wonderful to have [this conversation] in the 40s and 50s, but we have all these 90-year-olds that still haven’t done it, so we’re trying to catch them up.”

Advance Care Planning Discussions After a Diagnosis

Conversations after a serious illness diagnosis or near the end of life are more difficult than earlier planning discussions. The conversation at the time of diagnosis is emotionally difficult for the patient – and as a result, can be the same for the clinician. Clinicians say patients can feel overloaded with information at the time of diagnosis, making it difficult for patients to absorb and process information about advance care planning. Additionally, conversations with the family are complex and difficult at this stage.

“In the ICU, people come in who should’ve had the conversations in the offices with their doctors. But they come in when they’re 90 years of age... And now they’re on dialysis and it’s very, very difficult to explain to the family this patient really doesn’t have a good prognosis.”

“[A patient is] now at the end-of-life stage and no one has any form of discussion and no one in the family knows what they really want...It’s just so much more difficult. You’ve got a difficult situation, complicated by the lack of ignorance of what’s going on.”

A variety of clinicians play important roles. Clinicians say nurses, nurse practitioners, social workers, palliative care team members, and psychiatrists play important roles. The most commonly mentioned roles are interpreters for any confusion about what the physician says as well as for those with lower education levels or diverse populations; educators to help answer questions that arise after a conversation with a physician; and an advocate

on the patient’s behalf. These team members can also help physicians better understand the patient’s needs and desires. Additionally, clinicians agree that whomever has the highest degree of trust with the patient should start the later stage advance planning conversation with that patient.

Many clinicians say end-of-life conversations are an iterative, ongoing process rather than a one-time event. Beginning at the advance care planning stage through the end of life, clinicians say conversations are part of an ongoing process. Several specialists in oncology and pulmonology say that conversations start with a formal assessment at or close to the time of a diagnosis. After the initial conversation and follow-up, clinicians cite many events throughout a patient’s experience that may require additional conversations: a change in prognosis, when a patient becomes intolerant to treatment, a hospital admission, and if family members disagree about the patient’s end-of-life plan.

A #1 conversation starter near the end of life: having an advance care plan or “living will” already in place. Clinicians say that having an advance care plan in place makes conversations much easier near the end of a patient’s life. They say that family disagreements are one of the biggest challenges. Having wishes documented makes the clinician’s job of navigating disagreements or uncertainties much easier.

“I had an elderly patient who had a living will and a medical power of attorney when he was healthy. And [then he] ended up getting diagnosed with pancreatic cancer. As [his illness progressed], it was very easy for me to say: ‘This is what your father wanted. That’s not a point of contention. We’re doing exactly what he wanted.’ As hard and as painful as it was for the family, it was an ideal situation.”

“[With a living will in the medical record,] you can always fall back on that and say: ‘Well this is what your mother said.’”

Several mention using palliative care teams to help facilitate conversations and care. Clinicians who are able to engage or refer patients to palliative care teams greatly value this resource. The ability to pull in a social worker, a chaplain, or case manager to help facilitate questions that may come up during conversations is helpful in having a comprehensive discussion with patients beyond a diagnosis.

Many clinicians learn from their own experiences, not formal training. Several say they learned through trial and error and gaining experience as they aged along with their patient population. Many also cite difficult personal experiences with their own family members at the end of life as a powerful learning experience. A few say they have learned from discussions with colleagues.

Conclusion

Clinicians and patients who participated in this research agree that advance care planning conversations are important and should happen when people are healthy and relatively young. While raising the topic is fairly easy for clinicians who have a formal system in place, patients in the research say this initial conversation is not very helpful when it comes to the actual planning and decisionmaking process. These patients were much more likely to turn to family members and attorneys to plan their decisions. As a result, these patients have not had the opportunity to weigh all of the probable scenarios, treatments, and options for care with their provider.

When it comes to conversations at diagnosis or near the end of life, patients want clinicians to be direct, honest, and sensitive. Clinicians say having an advance care plan in place facilitates this type of conversation. Many also have ideas to help clinicians navigate difficult conversations, such as increasing opportunities to talk with colleagues about the issue and getting training.

Successful measures to increase conversations might begin with integrating conversation starters into formal systems to assess whether patients have an advance care plan. This can happen in a routine wellness visit or another type of visit.

Measures might also include creating opportunities to have more in-depth planning discussions. Medicare now reimburses for these visits, although clinicians may need persuading to bill for these visits. Documentation requirements and overall physician burnout weigh heavy on their minds.

Clinicians may also need education and training on their role and what patients need from them around planning. Many clinicians in this research project feel it is their responsibility to raise the idea of advance care planning, but many do not seem to participate in the decisionmaking process.

Finally, both clinicians and patients feel these discussions can be uncomfortable, unpleasant, and easy to avoid. They say more public discussion on end-of-life care could reduce anxieties, increase awareness, and ultimately, facilitate action around documenting wishes for care.