



## Webinar Transcript

# **ENGAGING COMMUNITIES, PATIENTS, AND PROVIDERS IN ADVANCE CARE PLANNING**

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Kate DeBartolo  
Amy Tucci  
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## ENGAGING COMMUNITIES, PATIENTS AND PROVIDERS IN ADVANCE CARE PLANNING

**JOANNE EASON:** Hello, and thank you all for joining us today. I'm so excited to have everyone for our 15th Five Wishes Practice Community Webinar. We must have hit on a nerve this time, because registration is the largest that we've ever had. So, welcome to everybody! And I know this topic is important because over the last two weeks I've been to two organizational meetings — an ACO summit and the American Case Managers Association meeting — and the number one topic that everyone wanted to talk about was engagement.

So, our panelists and their organizations have done an excellent job in creating awareness around ACP. Now that we have the interest of all these communities, how can we now start to engage them? I'm looking forward to learning more from our industry's experts. But first, I'm pleased to introduce Kathleen Taylor, Five Wishes Healthcare Program Director. She will be moderating today's session. Kathleen has decades of experience in managing ACP program development and increasing engagement along the continuum. Kathleen?

**KATHLEEN TAYLOR:** Thanks, Joanne. And good afternoon or morning everyone, depending on where you are, and thank you for joining us for our Five Wishes Practice Community webinar today: *Engaging Communities, Patients, and Providers in Advance Care Planning*.

For anyone new, the Five Wishes Practice Community is for any and all healthcare professionals who use any component of the

Five Wishes Program. A lot of you are using the documents, some of you are using our training resources, some of you are using custom solutions that we're building for you, or outreach components. No matter which component of the Five Wishes Program that you're using, the Practice Community is for you.

Our primary goal with having a Practice Community is to help gather you together and share best practices, insights, learnings about how to elevate your practice and advance care planning so that all of us can do a better job. Advance care planning is one of those things that you never perfect. We're all always continuing to grow our skills and make sure that this is accessible and relevant and compassionate for patients and families and human beings that need what it is that we're doing. So, we're glad you're here and we hope that you find today's webinar useful.

As Joanne was saying, one of the most challenging aspects of advance care planning, as all of you know who are engaged in this work, is engaging our patients, providers, and community members in having discussions about a thing they don't necessarily want to talk about.

Today we're going to explore the topic of engaging people in advance care planning, and we're going to hear about some really successful initiatives from some of the best thought leaders and experts in the field. So it's my pleasure to introduce them to you today, and just in alphabetical order...

**Kate DeBartolo**

Kate is the Senior Director at the Institute for Healthcare Improvement and The Conversation Project — their Public Engagement Initiative, to help everyone talk about their wishes for care through the end of life so that those wishes can be understood and respected. Additionally, Kate manages and cultivates relationships with national and state level organizations that help engage the general public in advance care planning.

Since joining IHI in 2007, she has been involved in the 5 Million Lives campaign, Improvement Map, Project JOINTS, and many of IHI's other large scale programs.

To learn more about Kate or The Conversation Project, visit [TheConversationProject.org](http://TheConversationProject.org).

**Amy Tucci**

Amy is the President and CEO of Hospice Foundation of America. It's a charitable organization that educates professionals and the public about care at the end of life. In her nearly 20 years with HFA, she has produced numerous educational programs on advanced illness care and grief, edited many books on topics involving end of life, and directed several successful grant projects involving public engagement.

Prior to joining HFA, Amy began her career as a newspaper journalist, served as a press secretary on Capitol Hill, and worked in marketing and communications for a hospice and nursing home in Washington, D.C.

To learn more about Amy and HFA, visit [HospiceFoundation.org](http://HospiceFoundation.org).

**Jessica Zan**

Jessica currently serves as the director of IT Clinical Applications Ambulatory for Integris Health in Oklahoma City. She designed and built their advance care planning program that has been highlighted in multiple recent journal articles for successfully scaling compassionate advance care planning conversations all the way across the health system. Jessica has received several awards in recognition of her professional dedication and her personal grit, including the Daisy Foundation Award for Extraordinary Nurses. She also privately consults with health systems and providers, helping them to achieve high quality advance care planning outcomes.

To learn more about Jessica and Integris, visit [IntegrisOK.com](http://IntegrisOK.com). To learn more about the project that she's going to talk about, we'll give you a link to that in the followup.

**Joanne Eason, MA**

Joanne is the President of *Five Wishes*. Since 2014, she has strategically focused the Five Wishes program on creating unique new tools and resources, and building scalable programs to meet unique and specific advance care planning needs within organizations and communities. With more than 30 years of experience in healthcare and insurance communications, marketing, and relationship development, Joanne leads the program with a special emphasis on partner relations and collaboration, as well as insight into organizational decision-making.

**Kathleen Taylor, MA, LMHC**

Kathleen serves as the Five Wishes Healthcare Programs Director. She has nearly 30 years of healthcare experience with specific focus in advance care planning, palliative care, and end-of-life care. In her roles as a hospice clinician, program director, clinical

trainer, and community engagement professional, she has fostered clear communication within families, care teams, and communities. Kathleen is a Florida Licensed Mental Health Counselor and Qualified Clinical Supervisor, and a Certified EQ-i 2 Emotional Intelligence coach.

**KATHLEEN TAYLOR:** Just a reminder to everyone — this is a frequently asked question on all of our webinars. — we are recording. We will send out a link to the recording after the completion of the webinar; and we will send out any links to resources that are mentioned, so stay tuned for that.

And with everyone introduced, again thank you, welcome, and I'd like to get us started today with defining what it is we mean by engagement. So, when we're talking about engaging communities, engaging providers, engaging patients and families in advance care planning, what are we talking about them doing? What is it that we would like for them to do?

And I'll just frame that with a couple of data points. We have lots and lots of research that is replicated every couple of years pretty much that's telling us that about 90-95% of Americans say it's important and that they would be willing to discuss their end-of-life wishes. But only about a third — and this is pretty much every time we measure it — have actually documented their wishes. So we have a gap between what people are saying matters to them and saying what they would be willing to do, and actually taking action to do something about it. That's the engagement piece, is turning this into action.

So, in my understanding, to give us a frame around defining this, engagement involves *awareness* first of all; *activation* — so I am aware of this, I become active, then I take action; and at some point, *adoption* of this problem or issue or solution by this individual or community or system or enterprise — it gets taken and owned.

With that said, I wonder if — and anyone who would like to begin, please do — if we can talk first about the community level.

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What is it we want to see from communities in regard to community engagement?

**AMY TUCCI:** Kathleen, I’ll jump in here and talk about community engagement since it’s what we’ve been doing for years now. I think what we’re talking about as engagement includes education. So engagement is, for so many people, we have found that nobody has even asked them what they want to do at end of life, or if there is a serious health emergency, nobody has even asked them that question. So it involves education — engagement through education, asking people to think about what they’d like, and then encouraging people to take that next step — either having a conversation with family and friends, or ideally, completing and advance directive.

**KATE DEBARTOLO:** I’d love to...

**KATHLEEN TAYLOR:** Oh good, you’re already talking. I was just going to ask you, The Conversation Project is all — that’s what The Conversation Project is, is kind of moving people from: we want to create your awareness of this topic, into doing something about it and engaging in the conversation. So, how do you see this dilemma between the data about people want[ing] to have these things, these conversations, they think they are important,

but we are not seeing the same numbers in terms of completed advance directives?

**KATE DEBARTOLO:** I think that’s one of the pieces of... Sometimes it’s hard when you’ve introduced the concept, to know whether or not a conversation was had, or if it’s only about capturing advance directives completed, that may not... It’s a hard thing to measure, this activation is kind of a hard thing to measure.

I know for us with building awareness, it’s like any kind of marketing, where we’re trying to reach people eight times, eight different ways. For us, it may be about reaching people where they already are and where they’re spending time, and not expecting somebody to come to us, but where are they spending time in the community or on social media... You know, they’re already scrolling through Instagram, how do you start to weave the message in there?

And I think it’s helping people realize that they can do this, and it doesn’t always take a really expensive legal process or waiting for a doctor to bring it up. It’s not just a medical experience, that this is something anybody over 18 can do, and really trying to normalize that. Shifting away from, “I don’t have to do that because nothing’s wrong with me right now,” or “What’s the matter with you?” versus “What matters to you?” So

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*“What’s the matter with you?” versus “What matters to you?”  
...it’s a lot about **normalizing it**, helping people realize it applies to them, and then giving really easy bite-size pieces to tackle...”*

for us it’s a lot about normalizing it, helping people realize it applies to them, and then giving really easy bite-size pieces to tackle — sample icebreaker questions that they could ask, or — people are literally looking for words like “What is the sentence I could open with to bring this up with my mom?” And those are the kinds of tools that we’re trying to help people feel like they can have something to kind of guide them through.

**KATHLEEN TAYLOR:** I like that you mention normalizing as a word. I think that’s a huge piece of engaging really all of the audiences that we talked about, and moving this from something that is — an old marketing term was “an unsought service”, it’s a thing people don’t really want to think about — into something that seems like it is beneficial, and this is relevant. And Jessica, I want to ask you about engagement, kind of within the frame of normalizing, but in the clinical definition of that. We had a webinar a few webinars ago, where Diane Meier talked about the importance of normalizing and routinizing advance care planning conversations and questions. Like, we ask this the same way we ask about having a flu shot or wearing a seat belt. And I want to just ask you about defining engagement for systems and practitioners, because if we’re not engaged then we’re not going to get the patients engaged.

**JESSICA ZAN:** Yeah, it’s all a big bundle of social responsibility. And so we have, the government has interest in helping these conversations become — I say normalized and standardized, I also like routinized. We’ve got that pressure that should be building around the community, and that pressure should be communicated to the health care systems that are embedded in the community.

So, I’m in the largest healthcare complex within Oklahoma, and moving the needle in that organization is changing the conversation for the community. So if I can help my organization come to the point where it accepts that advance care planning conversations are just grownup conversations. They’re not dying conversations, they’re not sick conversations, they’re an expression of who a person is and what they’re willing to tolerate happening to their body. If we can normalize that within the healthcare system, and then that healthcare system partners even further within the community to the community organizations and the groups and the individuals and the local media to share that information that: we ask you what your name is, we ask you who your insurance

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provider is, and oh by the way, if you can't make medical decisions for yourself, who do you want making them for you? We wrap it in to an everyday, every healthcare encounter kind of experience. While at that junction you're primarily meeting the sick, as you spread that notion out you push it into healthier and healthier spaces, and eventually you can even remove it from the clinical setting at all — although the clinical setting has utility — but pushing it out and engaging with the community organizations around you.

**KATE DEBARTOLO:** Can I add one thing to that? I love the point of kind of bringing this earlier and earlier, and not having it be something like, "Oh Doc, what are you telling me, is this bad news?" But nope, this is just something we do with everybody at their first Medicare visit, or everybody on their 50th birthday, or whatever, continuing to move it upstream.

And then I think there's also a piece about exemplifying this ourselves. I remember talking to somebody in Memphis who said, "We've got 10,000 hospital employees in this city. If each of us could have these conversations with somebody important to us, we could be this snowball who helps

*"And then I think there's also a piece about exemplifying this ourselves. I remember talking to somebody in Memphis who said, 'We've got 10,000 hospital employees in this city. If each of us could have these conversations with somebody important to us, we could be this snowball who helps normalize it.'"*

normalize it." And how within health systems and even hospice facilities — we see this day in and day out — how many people still haven't done it themselves? That can be a really helpful way of normalizing it in the community and walking the walk. So if you're bringing it up with a patient you can say, "I know this is kind of hard, because when I did it...x-y-z." But it gives us a lot more credibility.

**KATHLEEN TAYLOR:** Yeah, I think that's — in some of the examples that we're about to review with you all, we will see that. And one of the things we all know is true is that the best way to create champions and advocates for advance care planning is to have them — again, we're going to use the word engagement — have them engage in the process themselves. When people have their own stories and their own experience, they start to understand the benefit of this in a different way, and they can articulate that, I think, to people in a way that makes it easier to understand. So that's great that you're talking about this.

And I hope what is clear in the conversation so far is that it really does require all of these links. Advance care planning is a systemic issue, or process, and it really requires for us — to move the needle as you said, Jessica — it really requires the community, community organizations, systems, health care systems, the practitioners within those systems, the individuals who come in to those systems to [*clipped audio*: engage in these conversations before they are] at the end of their life. Most people are, whether we like it or not, most people are dying in a healthcare facility. They're not — even though we have great hospice care in this country, you could argue — most people are not dying at home anyway. So it's more and more important I think to have these conversations and to

have all of these links in place, so I'm glad we started off this way.

And since you've all done such incredible work, I want to get in to reviewing some of your initiatives. And maybe we can start kind of at the broad community level. And Kate, I wonder if you can give us some highlights about what The Conversation Project has learned about community engagement, and what The Conversation Project is, for people on the webinar who may not be familiar? I can't imagine that anyone's not, but there might be some people, so if you can review that and give us some highlights, that would be great.

**KATE DEBARTOLO:** Sure. So, The Conversation Project is a public engagement initiative trying to help people have conversations about their wishes for care, with no preference for what those wishes might be. We offer a lot of free conversation guides that are available in English, Spanish, Chinese... They have a Creative Commons license on them so you can adapt them for your setting. So for example, there's a guide of How Do You Choose a Health Care Proxy, or How Do I Be a Health Care Proxy, and if [in] your state that's called a Health Care Agent, you can swap it out, or you want other languages, you can change that.

But when we first started to create these tools, with again, the idea of trying to normalize these conversations, helping people realize they could do this around the kitchen table and not in the ICU — because a crisis is a really hard time to learn — a lot of community groups started to say, "Can I bring this to Boulder, Colorado... Can we do this in Barrington, Illinois?" It could be everything from Nancy Nurse, retired ICU nurse who saw this day in and day out and just has kind of an encore career as part of

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retirement to individually bring this to the community, or more formal structures within health systems, hospital associations, those kinds of groups.

And so, this idea of bringing it to where people live, work, pray, and learn has been really helpful, especially trying to think of where is there the most trust within a community. There are some people who might not be ready to hear this from a healthcare provider because it makes them too nervous that there's bad news coming, or "what are you telling me?" But if a congregation is the one who's incorporated this into their preaching, or pastoral care, or the programming, that can really help somebody feel more comfortable with the introduction of the concept.

We help, we facilitate National Health Care Decisions Day, which I know a lot groups



help do as well, which is nice to give that punctuation point once a year, to try to give people the excuse to make sure you're updating what your resources are, that this isn't... For us it's not a one-and-done type thing. We hope that this is never a document that gets filled out and lives in a filing cabinet and nobody ever talks about it, or families aren't in agreement. And I think that's one of the key things for us in the normalizing, is certainly we are trying to keep the person at the center whose end of life we might be discussing. But I am much more drawn to this also for the survivors of that loss. How can you grieve the loss of somebody without the complexity or complications of family members not getting along, or being in disagreement, or second guessing that you made the right choice?

And so that's what we're trying to build more muscle around, or give people language so they can go there and talk about it. But it's been really neat to see high school students, college students, in addition to health professions schools as well, introducing this — all different denominations, groups that clearly are not clinical or legal, who are helping normalize it within that context for people.

And we love when the conversation starter guides are used with *Five Wishes*, that often goes really well to say, "Here's something you can fill out. Think about it, how do you want to talk about it? And now you can keep these documents really easily," has been a great pairing.

**KATHLEEN TAYLOR:** It is a great pairing. And for those of you on the webinar, if you haven't gone to The Conversation Project [web]site, I would recommend that you do that after this webinar. There are so many

really wonderful resources that are free, available to anyone now, and they really help with — the question we get all the time is, "Well, how do I start this?" Literally, there is a thing called The Conversation Starter Guide. So I would recommend that you visit that. There are great resources for how to bring this up in a community setting and also in a family setting, but I think it's wonderful to have trusted entities in the community kind of leading this. Faith communities have been a wonderful spot for this... Go ahead, Kate.

**KATE DEBARTOLO:** I think that for each organization, the same way an individual will say, "Well, how do I get started?" community groups will say, "This is really important, how do I get started?" And it really depends on what the target is within your community. Do you want advance directives completed among people with a serious illness? That kind of community programming looks very different from, you want 18-year olds who are moving away

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from their households to realize they should choose a proxy.

So depending on the audience you want to reach, what action you want them to take, the programming might look a little bit different, but we try to help people answer some internal questions for themselves of what success would look like in the end. And then based on that we might recommend different programming.

**KATHLEEN TAYLOR:** I love that, thanks for that. Again, visit The Conversation Project and look at those resources. And Amy, I want to move to you if we can, and talk about some — there have been so many projects that Hospice Foundation of America has been part of, a lot of grant programs that have involved engaging health systems and hospice providers in engaging their communities. So, it's been you're getting the organizations to participate, engaging them in doing outreach to their own communities about advance care planning. And I don't know which one you want to start with. There's Project Talk that's going on right now, and you have a poster behind you from the Being Mortal project that was done a couple years ago. Maybe you can talk about both of those and just what they were, what happened, and what the outcomes were.

**AMY TUCCI:** So, Project Talk is going on as we speak, and that is a five-year randomized control trial, and it involves The Conversation Project actually, and also another advance care planning tool called the Hello Game. And we have a control that we're using, there's a game called Table Topics, which is similar to [the] Hello Game but without an end-of-life focus.

So, I hope that some of you who are on this webinar today will go to [ProjectTalkTrial.org](https://ProjectTalkTrial.org) and apply to be a site. We're doing 75

locations throughout the United States. So far we've done about 30 — no, a little bit fewer than that, we're about a third of the way through — and we are targeting specifically underserved populations. So, we have 15 Spanish language sites. We have, we're looking at rural White, rural Black, Hispanic, urban White, and urban Black. And so those are sort of our groups of demarcation in terms of underserved. Of course, meeting all the other underserved criteria as well.

So, people can apply to be part of this project. The host fills out an application where we're looking to determine your connection, involvement with your community, whether you've done previous events. What we're finding is — I can't really talk about what we're finding in terms of the data so far — but what we're doing is, a host will host the — whatever part of the trial they're assigned to, so let's say somebody has the Hello Game. What they will do is hold this community event. We give the participants up to \$90 in gift cards, depending on how much of the process, the protocol they complete. So they don't get paid to complete an advance directive, but they get paid to complete the interviews associated with the follow-up phone calls.

So of course what we want to find out is if the people who are attending these events and participating in these events are completing an advance directive or what kind of action they're taking after they've participated in this very community-focused event. We have people, up to 45 or so people will be participating at one location, and depending on the tool that's being used, [the] intervention being used, it's about a two- to, can go to three-hour event.

So, that's the really exciting thing we're doing right now and we're really happy to have The Conversation Project be part of that. Because as Kate referenced earlier, you know it's really hard to tell if these interventions have positive outcomes. I mean, you can go talk about advance care planning, but do you know if anyone's actually taking any steps after you've talked about it?

That was part of the challenge with Being Mortal. So, Being Mortal was incredibly successful. It was not a research project but an outreach project, and we were able to screen this documentary, beautiful documentary that Frontline produced, in more than 1,200 communities around the United States. As I said, it wasn't a research project, but we did our own survey research after that, and what we found was that most people who were engaging in this activity had some awareness, or they had already completed an advance directive. So in a way we were kind of singing to the choir here. Even though people absolutely loved it, they also, what we found was that we were attracting the demographic that we all know is most likely to complete an advance

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directive — white, female, over 55 — those were the people who were attending the events.

With Project Talk we are really going to the population that [has] not completed advance directives for one reason or another. And as I said at the very beginning, often I think that it's not because there is such a reluctance, but more that they have never been engaged properly, they haven't been engaged at all. They have never had this type of experience. So, we're excited about both of those things.

**KATHLEEN TAYLOR:** I want to take a couple things you said and pull them up and highlight them if I can. I love that this project is aiming for reaching underserved populations. And I want to talk just a little about underserved populations with advance care planning and what that is, and why that is. We know from research over the last 30 years that I've been doing this, **there have historically been certain populations and certain cultures that do not engage in advance care planning** at the higher rates that other groups — nobody is really doing it at a high rate, but there are some populations that are engaged in this even less, so...

But I think that what we used to do was, you know, educate *on* them, thinking that that would turn the tide, and what we've really learned over time is that some of the reasons for that, for less engagement, have to do with the fact that **in these populations legal documentation is not highly valued** like it is for people who will readily complete a legal document called an advance directive. It's just not in their value system, and that's o.k.

It's also that **some populations have an earned distrust of the medical system.**

They've had less access to it, they have not been treated as well within it, or had their pain controlled or had their issues addressed as well. So they have earned that distrust of the medical system, and engaging in something that says, "there's an option for me to decline care" is not a message that resonates with them.

And then I think the last piece of that with underserved populations and advance care planning is that the **messengers about the value of advance care planning have not been from these communities traditionally**. We have not looked like them, we have not used the same language.

So those are some of the reasons that — I'm only bringing that out because I think those are of particular importance when we're talking about engaging people. All of those things are necessary to recognize, and also to recognize that — the next webinar we do is going to be on measurement, so we'll talk about that then — but completed advance directives are not always the only or the best way to look at whether we're engaging communities. What we're trying to do is prepare people to make end-of-life decisions for themselves and their loved ones when the time comes. And hopefully they'll document that, and Kate you [audio out].

**KATE DEBARTOLO:** Yeah, I love that we're talking about this. We're part of some research that was done with the Massachusetts Coalition for Serious Illness Care that did some national research around this topic, and found just what you were describing, of people who take action around advance care planning and people who don't, and why they don't, and sometimes it has to do as you were saying with kind of lack of trust or a poor experience before, caring for somebody.

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*...And because of that, different messages really resonated better or worse around advance care planning. And the two that they found resonated across all different demographics was this idea that conversations clarify.*

*...And then the second one was around power or control, and... that you can have a say in your care, that your providers want to know what matters to you."*

Who has the belief that the healthcare system's going to care what I have to say, and who expects their wishes to be honored...

And because of that, different messages really resonated better or worse around advance care planning. And the two that they found resonated across all different demographics was this idea that conversations clarify. Some people don't take action because they think, "Well my kids will know what I want, I don't need to bother them with that now, I don't want to upset them." So that idea that conversations clarify and this is a chance to be sure...you know, you've made every other major life choice of your own, why would you leave this one up to [chance]?

And then the second one was around power or control, and that when things are so out of control, this is a chance to have some conditional control, that you can have a say in your care, that your providers want to know what matters to you. People will say, “What would you do if this was your mom, Doc?” and it’s like, well, “Tell me what your mom likes to do, or what matters most to her, and I can make recommendations.”

But I think sometimes there’s a deference either to, “My family will know what I want”, or, “The doctors know best, why should I have an opinion on this?” This is again for us why it’s so important to talk about your values in general and not only hypothetical medical scenarios that could play out, but what’s helpful for somebody to know about what matters most to you.

And I think your point of how we could engage somebody now, and hopefully we’re doing a better job of getting further upstream, we’re years away from when somebody’s wishes may need to be honored. Our goal is to kind of practice using those muscles, so that when the time comes and you really do have to have a hard conversation, it’s not your very first time doing it and stumbling over language, but it’s a chance to say, “O.k. we’ve done this a few times, I know how I can bring it up, I know how my mom’s going to react.” So I love the comments that you made around that.

**KATHLEEN TAYLOR:** Yeah, and that’s the best predictor of whether people will engage in advance care planning conversations is if they’ve had the conversations before. The more conversations you have, the more conversations you have.

And Jessica, I want to, I really want to spend some time with you talking about the project that you did for Integris Health, because everything that we just talked about — having language, messaging, people being able to speak in their own words about what’s important to them — that was really at the center of the initiative that you led there. So can you tell us what that was, what you did, what happened? And we’ll talk about lessons learned from all of these later, but I really want to hear about this from you.

**JESSICA ZAN:** Yeah, thank you. I’d love to talk about it. We started our advance care planning program — actually it started as an idea, kind of a thought bubble in my head. I’ve been engaging in nursing and palliative care for a long time, so I’ve seen a lot of suffering, and have always been motivated to, in the midst of suffering, re-center the person who’s in the suffering. So I come at this from a “sick” aspect. I come from the hospital, I see the worst, and it’s motivated me to push the conversation further and further and further out from that most traumatized moment that our patients often end up in, where we’re talking through wires and tubes to say, “We did it, did you want it?” you know — “and now what do we do?”

So I went to the leadership at our hospital system and described this notion I had. It was actually my director — became my director shortly after my vice president, shortly after — [and] described this notion that I had of how we could normalize and standardize bringing the patient’s voice into care, how we could infuse that into our healthcare system and how we could turn the heads of providers and nurses in moments that happen along the traditional healthcare journey from ambulatory settings



to the acute setting, and start folding in moments of advance care planning and bringing those to our patients before the moment got too hot or irretrievable.

And we initially started a pilot in our first big Oklahoma wave of Covid, which was December of 2020 going into January of '21. I started our first pilot there in our largest ER, going to see patients who had elevated mortality risk and a positive Covid score — positive Covid test — and just presenting at their bedside and letting them know I'm a person who's interested in learning about you, I'm a nurse who wants to hear about you, and I want to know what's important to you. Who would you want making decisions for you if you couldn't communicate? You know, if you have Covid these are some of the things that sometimes happen, what do you want us to do if these are the things that come up?

And we had, in the first ten days I was in that space, I saw 28 patients. Of those 28 patients, 14 decided to be DNR; and of those 14, 6 stayed in the hospital — were admitted; 8 discharged from the ER straight to hospice. It was just — it was such a compelling evidence to the notion that when we actively engage with our patients, when we transparently share our expertise — which stops at the medicine, right — we know what happens physiologically to bodies and we can share what's happening physiologically to yours — that's the end of my expertise — I invite you to be the expert in this space and share with me who you are and what you want me to do with your body in this condition.

And we found our patients had very adamant feelings about those things. And absent this intervention, those patients would have *all* admitted to the ICU. And

many of them would have died. We ended up having somewhere around a 45% mortality rate amongst the folks that we were seeing.

So, that's where we started the pilot. As I was invited in to design this program, we started building that conversation, based on my experiences, based on my training, my education, with Respecting Choices and other really well-respected organizations that have these conversations around the country. And I designed a conversation guide that would be malleable to an ambulatory setting or a full sit-down advance care planning visit: that's what we're here for and we're going to have that conversation from beginning to end and if you want to sign documents you can.

But the conversation tool was also built into our electronic records, so if the patient was in the hospital, we would have access to any conversation that happened out in the community, that was documented in our electronic record, and we could update it. Or if the person hadn't had those conversations yet while they're alert and oriented, let's find out, who do they want as their decision maker? And let's ask them, the conversation goes all the way through to code-status questions, which of course become really pertinent if the patient makes it from the community into the hospital.

And to me, this speaks back to what we were just talking about with marginalized communities. We did find, particularly at one of our hospitals that serves more underserved populations, folks were less likely to complete the document, but we still had documented their words, their answers to their questions about quality of life, about where they stop — about where life is no longer defined as living for them and where

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it's just mere existence — and then at that point, what they wanted us to do with that. And we were able, within the two years that the program was in it's position the way that I initially designed it, to see thousands of patients, and we got thousands of documents. And sometimes we didn't get documents, but we still had decisions or indications from our patients documented in the medical record of how to handle their devastation and their illness when it went the way that nobody wanted it to go.

That tying the conversation in to the medical record became a really big part of how we were able to measure that we were making a difference for folks, even if they weren't willing to go as far as creating a legal document that felt binding to them, that felt impersonal to them.

**KATHLEEN TAYLOR:** Just a data point. You took your over-65 conversations from about 30% up 20 points to 50%, is that right?

**JESSICA ZAN:** Yeah, so... Yeah, we saw our advance directive rate — which is a measure,

it's not a meaningless measure, although I hear all of this kind of being a little bit trepidatious with saying we don't want that to be the only measure, right? But we did see that value go up.

One of the other measures that we — that personally I found very telling was that we did see a change in the metrics on our code statuses. So, we saw a higher rate of DNR-related code statuses across our organization, and I saw that as a giant success. Not because we want people to die. DNR is about what we do when you're dead, it's not how we get you to dead. How do we treat you while you're alive, and what do we do if and when you die? And to see that with engagement, our patients were more often setting their foot down and saying, "Listen, treat me. Do everything you can, except when I die. I can accept that I'm dead." And that was a metric that we did see also shift. That landscape shifted as we saw the program get engaged.

And you know, one of the things that we never really got our heads wrapped well around, we were working on building and reporting the metrics for, is as we infuse this in the standard practice for case managers in the ambulatory setting, what were we going to see over time? Were we going to be able to see that that return led to fewer hospitalizations or readmissions or higher palliative care referrals or earlier hospice referrals? That was the long term target, but it's two years in, those numbers don't exist for us just yet.

**KATHLEEN TAYLOR:** You talked about a couple of things, and again, I'm going to try to pull these out because I think they're really important: standardizing and normalizing. And I think with looking at — specifically with health systems —

completed advance directives is a measure, it is an important measure. It can be truly indicative of what is happening, and you can see those measures shift when processes are standardized — improved and standardized — and when the conversations are normalized, and when they are skilled.

There was a — The Hartford Foundation (I was blanking on The Hartford Foundation) — and California Coalition did a — this was some years ago, but they did a survey with providers called Conversation Stoppers and Conversation Starters — maybe in 2016. And they found, you know I think what we've all experienced to be true, that most clinicians have had no formal training in having end-of-life conversations. And about half of them said, "I'm not really sure what to say." And we've even had a question come up in the Q&A today about, "What is the sentence? How do I start this?"

And what that speaks to, to me, is sometimes the barrier to engagement is the discomfort of the person who feels it is their role to start the conversation with a patient or family, or the discomfort of the family member about starting that conversation in their family, or the discomfort of the community leader. You know, it's that "How do I get started?" piece.

So, I just want to say — and Kate's going to echo this I hope — training and resources to help people feel comfortable is a huge part of tackling this problem. And go ahead Kate...

**KATE DEBARTOLO:** Yeah, I feel training and resources, and also, it might be controversial to say it, but not everybody is going to be super comfortable with this, and that's o.k., and to figure out... I remember hearing from one facility where there was an MA who loved these conversations and

was really good at them, and was more comfortable having them than others on the team, so she went for it. Or a practice where they offered group patient visits, and so any provider could say, "I think this might be something you'd be interested in, can I suggest you do this group visit?" and that was facilitated by somebody who was really comfortable with it.

My favorite was a health system in Rhode Island who found that a lot of their palliative care consults were really to help families have conversations, and that wasn't keeping everybody operating at the top of their license. They brought in a hospice nurse who was really skilled in these conversations to

*"...a lot of their palliative care consults were really to help families have conversations, and that wasn't keeping everybody operating at the top of their license. They brought in a hospice nurse who was really skilled in these conversations to do it, and nobody would talk to her, and they realized it's because her nametag said Hospice Nurse, and when they changed the nametag to Conversation Nurse, they hired three more and a conversation social worker.*

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do it, and nobody would talk to her, and they realized it's because her nametag said Hospice Nurse, and when they changed the nametag to Conversation Nurse, they hired three more and a conversation social worker.

And so finding there's different ways of staffing this or looking into, how can we get somebody who's very skilled to be the one who really focuses on this, so it doesn't always have to feel like you have to... For some people who just really aren't comfortable with it, maybe don't start there.

**KATHLEEN TAYLOR:** Those are great tips! And I wanted us to move to lessons learned and tips next, and you're totally taking us there, so thank you.

You just talked about two things. Language and messaging is hugely important. That nametag, that's a great example of making sure that the language we're using around this is not scary to people. Part of the reason that people don't want to engage in the conversations is when it's just introduced as, "Do you have an advance directive?" That's — first of all, does the person even know what you're talking about? Do you know what you're talking about? Is it *available* — meaning accessible, present in ways that people can pay attention to it when they're not in the middle of a crisis necessarily, and not frightening? Is it *understandable* — is it in language that makes sense, could the person explain it back to you? Is it *relevant* — does this person see how this matters to them right now, like this is relevant in your life right now? And is it *meaningful* — does the person feel that taking action will make a difference for someone, for them or for someone in their family?

So I think those things are where we want to try to get, and I would love to hear your lessons learned, and just your takeaway tips,

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after all this experience about how to make things available, understandable, relevant, meaningful for all the populations we talked about.

**AMY TUCCI:** Well, one thing you could... One other project that we have under way that is I think meaningful for a lot of communities is Six Plays, that we lease on behalf of a playwright, an award-winning playwright, and these are all about advance care decision making. There are three ten-minute plays and three longer theatre production-type length plays. And Kathleen, I think you've been able to see one of those ten-minute plays in Florida recently. They are great conversation starters for communities, both within the clinician — for clinicians, because there's one play that is just for clinicians, and then there are two other plays that are community focused.

So, those are great, and so just into the tips part of it, I think, you know, the earlier we start talking about these things always, advance care planning or what you would want at the end of life, [is] always better, earlier is better. And also, that there needs to be somebody who connects with that community who's there.

That's why with Project Talk, the project —the NIH thing with Penn State — we are selecting people really who have close ties to their communities, or who can partner with somebody with close ties. And I think obviously the tool that's being used is very important too. There are so many great tools out there, but... The Hello Game for example is a very fun and unthreatening way to start a conversation around advance care planning or your wishes at the end of life.

The Conversation Project is very helpful in starting those conversations and really provides a guide, a little bit more structured, and you know, just on and on... And of course *Five Wishes* is a great tool to be able to use in either a clinical setting or at home with family.

So, I think having that person that identifies with the community, having an unthreatening environment, not having these conversations at the very last minute if you can avoid that, and really getting people starting to think about them are the best things.

Venue is important if it's a community event, right? You don't want to invite people to a place that they're not familiar with or is hard to get to, I mean really simple community planning things. In African-American communities churches are very very important, so having one of these tied to the faith community is really great. We've

done many of those, and senior centers, senior housing places, also great venues for these events.

**KATHLEEN TAYLOR:** Yeah. What I love about many of the HFA projects involving advance care planning is that they take place in communities, for communities, run by people who live and serve and work and are cared for in those communities. And having attended a few of them, I just want to mention that the dialogue that happens in those rooms is very much kind of "of the people" of the particular community that's engaged in that initiative. Kate, you got something?

**KATE DEBARTOLO:** There's some messaging work that we've been a part of nationally that has like five little takeaways that I hope would be helpful for this group:

Of really talking up **benefits** of how these services or care can improve somebody's life, and not leading with dying. There's a lot of people who that's a hard stop for them, so open up with the benefits.

Making sure that there's **choices** at every step. I hope nobody ever hears, "Mrs. Jones, there's nothing more we can do for you," but there are, at any stage of illness there are choices available.

Using **stories** tends to resonate more with people than statistics, so having those kind of positive stories... It's not always that everybody's healed perfectly and cured, but more kind of aspirational stories, instead of the doom and gloom "here's what can go wrong if you don't do it."

And really just trying to **create and invite dialogue**. This isn't a one-time thing, this isn't your only chance to state what your wishes are. Your wishes can totally change



for very valid reasons later and we can change the entire process.

And really just trying to kind of **invoke a new team**. That this isn't just the clinicians, but we want patients, caregivers, other people who know what matters most to be there.

And the messaging that has resonated the best, either as an opening or a closing or even if you haven't come to full resolution is just, "We'll figure this out together. You are not alone in having to sort through this, but

*"...talking up **benefits** of how these services or care can improve somebody's life, and not leading with dying.*

*...Making sure that there's **choices** at every step...at any stage of illness there are choices available.*

*Using **stories** tends to resonate more with people than statistics, so having those kind of positive stories...*

*...**create and invite dialogue**. This isn't a one-time thing, this isn't your only chance to state what you wishes are. Your wishes can totally change for very valid reasons later and we can change the entire process.*

*...**invoke a new team**...this isn't just the clinicians, but we want patients, caregivers, other people who know what matters most to be there."*

we'll do it together." Those have all worked really well with groups that we've worked with.

**KATHLEEN TAYLOR:** I love those recommendations, that's great. And I think we'll probably pull those out and highlight them when we send something out to people who have been on the webinar today. Especially don't open with dying, that's great. Yeah, Jessica...

**JESSICA ZAN:** I think for us part of — like if I boil down what we did that allowed our patients — because most often we were seeing patients — we did community endeavors but that was a "side hustle" more or less — what helped us to have some success is never asking a patient to come to a decision before asking them to walk on a journey of self awareness. And so, you know, the best conversations allow an individual to reflect on things that probably society hasn't asked them before about their experiences, about their values, about their traditions, and about walking them closer and closer to the edge of their imagination for how those things impact what they might want for health care and from health care.

And then, once we had really figured out what felt like a good rhythm with that piece of the conversation, we also did everything that we could to bring down the complexity of the documents that we're often requiring people to fill out, because we very limited choices in Oklahoma about our documents, we brought that complexity and just washed it, washed it, washed it until we had gotten it down to a single page offering to a patient, almost like an imagination multiple choice quiz. "If this and this, then what?" you know?

And allowing that — because at some point you gotta get into the boring stuff, you

know? It's not just about how do we get them in, it's also, "O.k. now they're here, how do they know where they are *in here?*" so those are the things that we really focused on for the patient experience, the consumer experience, to be not only navigable but meaningful for them.

**KATHLEEN TAYLOR:** Thank you for that. Thank you all. This has been a really rich

conversation. And as I mentioned at the beginning, we have recorded this conversation. We will send something out to everyone who registered, including a link to the recording and to any resources that we mentioned that might be of interest.

And thank you all for you wisdom. I could talk about this for another hour but we are at our time.

**END**

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This Five Wishes Practice Community Webinar was recorded live on April 24, 2023. To learn more about the Five Wishes Program for Healthcare or to participate in future live Webinars, please visit us at [FiveWishes.org/Healthcare](https://FiveWishes.org/Healthcare).