

# Conversation Starters:

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



Webinar – December 1, 2016

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# Speakers



**Introduction:**  
Terry Fulmer, PhD, RN,  
FAAN, President,  
The John A. Hartford  
Foundation



**Respondent:**  
Ellen Goodman,  
Co-Founder, Co-Director,  
The Conversation  
Project



**Findings:**  
Marcus Escobedo, MPA,  
Senior Program Officer,  
The John A. Hartford  
Foundation



**Respondent:**  
Susan Block, MD,  
Director, Serious Illness  
Care Program,  
Ariadne Labs



**Moderator:**  
Sandra Hernández, MD,  
President and CEO,  
California Health Care  
Foundation



**Closing Remarks:**  
Angela Hult,  
Executive Director,  
Cambia Health  
Foundation



# “Conversation Starters” Focus Groups



**Terry Fulmer, PhD, RN, FAAN**  
**President**  
**The John A. Hartford Foundation**



# “Conversation Starters” Focus Groups



Marcus Escobedo, MPA  
Senior Program Officer  
The John A. Hartford Foundation



# “Conversation Starters” Focus Groups

## Goal:

Explore experiences and ideas from both clinicians and patients about starting and having quality conversations about advance care planning and serious illness and end-of-life care.



# “Conversation Starters” Focus Groups

## Background:

Follows 2016 survey: “Conversation Stopper: What’s Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?” & launch of new Medicare payment for ACP conversations.

- **Nearly half (46%)** of physicians report they frequently or sometimes feel unsure of what to say.
- **Less than one-third (29%)** report having had any formal training or systems in place to help.



# “Conversation Starters” Research Methods

Six focus groups with health care clinicians conducted  
June 7 to 29, 2016

## Los Angeles, CA:

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

## Chicago, IL:

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

## Atlanta, GA:

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

# “Conversation Starters” Research Methods

One online focus group with patients conducted  
Sept. 8, 2016

- 31 adults over age 40.
- Have an advance care plan and have talked with clinicians about their wishes within the last five years.
- Reflect a mix of race/ethnicity, gender, education level, income, and regions of the country.



# “Conversation Starters” Findings

Focus group participants noted an important distinction between “early” and “later” advance care planning discussions.

## Early advance care planning

- Brief, transactional and relatively easy for clinicians and generally healthy patients.
- Clinicians and patients agree conversations should start early, in 20’s and 30’s.

# “Conversation Starters” Findings

Focus group participants noted an important distinction between “early” and “later” advance care planning discussions.

## Early advance care planning

- Brief and transactional for clinicians and relatively healthy patients.
- Clinicians and patients agree conversations should start early, in 20’s and 30’s.

## Later advance care planning

- After a serious illness diagnosis or near the end of life.
- More difficult to navigate: emotionally difficult time, info overload for patients.
- Having an “early” conversation makes the “later” one easier.

# “Conversation Starters” Findings

Focus group participants noted an important distinction between “early” and “later” advance care planning discussions.

*“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 doesn’t have a good prognosis.”*

# “Conversation Starters” Findings

Early Advance Care Planning conversations frequently take place outside of health care context.

- About half have talked to attorneys about their wishes.
- Virtually all married participants say their spouses helped plan out their wishes. Those who are divorced or widowed turned to children.
- While having early conversations can be easy for clinicians, patients say it is not very helpful for actual planning and decision-making.

# “Conversation Starters” Findings

Early Advance Care Planning conversations frequently take place outside of health care context.

*“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.”*

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

# “Conversation Starters” Findings

ACP conversations take place more regularly when clinicians are prompted by healthcare systems.

## Clinicians’ ideas for prompting conversations:

- Formalize questions or prompts for a discussion in the Medicare Annual Wellness Visit EHR “checklist.”
- Implement an alert system in EHRs for follow-up reminders with patients.
- Be careful that new measures do not overly burden clinicians.

# “Conversation Starters” Findings

ACP conversations take place more regularly when clinicians are prompted by healthcare systems.

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

*“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.”*

# “Conversation Starters” Findings

Patients recommend integrating ACP conversations into routine care, want providers to be direct yet sensitive and offer practical assistance.



# “Conversation Starters” Findings

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## Patient ideas for prompting conversations:

- Have advance care plan forms to give patients and staff ready to help fill out paper work.
- Tell patients they should not to be offended by the conversation because everyone should have a plan.
- Be straightforward about reasonable expectations.



# “Conversation Starters” Findings

Patients recommend integrating ACP conversations into routine care, want providers to be direct yet sensitive and offer practical assistance.

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

*“Why make an appointment just to talk about death?...This can be done at a regular appointment.”*

# “Conversation Starters” Findings

Clinicians acknowledged the value of other health care team members and palliative care, learning from each other, and communications training.



# “Conversation Starters” Findings

Clinicians acknowledged the value of other health care team members and palliative care, learning from each other, and communications training.

- Most say they learned through trial and error or personal experiences with their own family members.
- Clinicians suggest holding workshops or trainings to learn more about having quality conversations.
- Also suggest health systems provide opportunities for clinicians to share and learn from each other.

# “Conversation Starters” Findings

Clinicians acknowledged the value of other health care team members and palliative care, learning from each other, and communications training.

*“I think it would be great if every single one of us could get a lesson in end-of-life care...”*

*“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.”*

# “Conversation Starters” Findings

Clinician ideas for improving discussions with diverse patients.

- Have some background knowledge about the racial/ethnic/cultural community; this helps open the door.
- Speak the same language, or find someone who does. This helps build trust and captures important nuances within conversations.
- Talk to patients about their lives, not just about their health.
- Increase awareness among clinicians about unconscious bias.
- Clinicians would like more opportunities for training and talking with colleagues.

# “Conversation Starters” Findings

Clinician ideas for improving discussions with diverse patients.

*"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."*

# “Conversation Starters” Findings

| 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.  |
| Integrate end-of-life wishes during a visit that covers other issues.  | Treat advance care planning as routine and not singled out as about death.                                |
| Check in with patients occasionally about their wishes.  | Know that end-of-life conversations are an iterative, ongoing process rather than a one-time event.       |
| 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.  |
| 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.   | Use palliative care teams to help facilitate conversations and care.                                      |
| Have staff that can help fill out paper work.  | 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. |

# “Conversation Starters” Focus Groups

## Implications & Questions:

- How do we make ACP conversations a routine part of care for younger, healthier patients?
- How do we connect early ACP conversations with later ones to make the process more clinically and personally meaningful?
- How do we integrate the ACP conversations that are happening in other settings into the health care system?
- How do we improve later ACP conversations (at time of serious illness or later in life) to make them easier and more effective for patients and clinicians?



# “Conversation Starters” Focus Groups



**Sandra Hernández, MD**  
**President and CEO**  
**California Health Care Foundation**



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**Ellen Goodman**  
**Co-Founder, Co-Director**  
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# Discussion and Q&A

To ask a question,  
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**Angela Hult**  
**Executive Director**  
**Cambia Health Foundation**



# Learn More

Please visit  
[bit.ly/ACPresearch](https://bit.ly/ACPresearch)

to download the full report, PPT slides, press release,  
and webinar recording.

Or contact:  
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# Thank you!

