WE NEED TO TALK: HOW “CONVERSATION STARTERS” CAN IMPROVE ADVANCE CARE PLANNING

Needed: Candid conversations about serious illness and end-of-life care that occur early and often

New York, NY (December 1, 2016) – Discussions about end-of-life and serious illness care, which are now reimbursable through Medicare, make it more likely that patients will receive the kind of care they want, yet these critical conversations often fall short, start too late, or don’t happen at all. New focus group research released today by three health care foundations provides insights into practical ways to improve advance care planning (ACP).

The John A. Hartford Foundation, the California Health Care Foundation (CHCF), and Cambia Health Foundation commissioned “Conversation Starters”: six focus groups about advance care planning made up of clinicians (general practitioners, internists, oncologists, cardiologists, pulmonologists, nurse practitioners, and physician assistants). A seventh focus group, composed of 31 racially and culturally diverse adults age 40+ who have an advance care plan, was conducted online.

“The movement to increase advance care planning in health care systems across the country continues to generate powerful momentum,” said Angela Hult, executive director of Cambia Health Foundation. “This research points us towards approaches that can help providers and families get these important conversations started.”

Among the key findings:

• Providers and consumers noted important differences between “early” and “later” advance care planning conversations.
  
  o Early conversations, which can be procedural and checklist-based, provide value by raising a potentially difficult subject. Patient wishes can, however, become dated before a health crisis occurs, and further conversations are generally needed.

  o Providers may need specialized training and approaches to meet the needs of seriously ill patients and their families, the research found.

• Advance care planning (ACP) conversations frequently take place with attorneys or family members rather than healthcare providers.

• Most advance care planning (ACP) conversations among research participants took place with attorneys or family members rather than healthcare providers.

• ACP conversations take place more regularly when prompted by healthcare systems, including automated reminders within electronic medical records systems.
“Good advance care planning is really a series of conversations,” said Terry Fulmer, PhD, RN, FAAN, President of The John A. Hartford Foundation. “Only this kind of active engagement ensures that people get the care they want as they age and as they face serious illness.”

The “Conversation Starters” report, produced by PerryUndem Research/Communication, is available here.

Additional “Conversation Starters”

Focus group participants agreed on a number of strategies, such as:

- **Start advance care planning conversations early, with younger people who may not have urgent health problems.**
  Even though early conversations are only the beginning of the process, providers say they have a role to play. As a Chicago specialist who participated in the focus groups said, “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.”

- **Make advance care planning a routine topic by bringing it up during regular office visits.**
  As one Atlanta Advance Practice nurse put it, “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?’”

- **Return to the subject over time, and emphasize that wishes can change.**

- **Provide more candid explanations, and more support and guidance for patients.**
  “Explain in logical terms the possibility of accidents and disease to make it logical to not put that burden on the family,” said a 73-year old woman in Minnesota.

- **Honor the challenging, emotional, and personal nature of these conversations.**

- **Acknowledge the value of expert help from social workers and palliative care teams, opportunities to learn from other clinicians, and communications workshops.**
  As one specialist said, “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.”

- **Increase awareness of racial, ethnic, and cultural concerns to improve care.**
  “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,” said an Advance Practice nurse from Atlanta.

“Good advance care planning is really about deepening your relationship with your patients,” said Dr. Sandra R. Hernández, president and CEO of the California Health Care Foundation. “Only this kind of honest engagement ensures that patients can make informed decisions about the care they want as they face serious illness.”
New Medicare benefit still under-utilized
The impact of the effect of Medicare reimbursement for these conversations, which went into effect in January 2016, is still unclear. The benefit was expected to be a driver of better care, but an earlier survey by the same foundations found only a small fraction of physicians had used the reimbursement code in the first two months it was available. In the “Conversation Starters” focus groups, providers described feeling burned out by paperwork as one reason why.

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About the “Conversation Starters” Focus Groups
The research included six focus groups with health care clinicians conducted June 7-29, 2016. Those groups were composed of:

- 8 Family/General Practice Physicians and Internists, Atlanta, GA
- 9 Advance Nurse Practitioners and Physician Assistants, Atlanta, GA
- 7 Specialists (Oncologists, Cardiologists, and Pulmonologists), Chicago, IL
- 8 Advance Nurse Practitioners and Physician Assistants, Chicago, IL
- 11 Family/General Practice Physicians and Internists, Los Angeles, CA
- 5 Specialists (Oncologists and Pulmonologists), Los Angeles, CA

The research also included one online focus group with 31 adults ages 40+ who have an advance care plan and have talked with clinicians about their wishes within the last five years. Participants included a mix of race/ethnicity, gender, education, income, and region of the country. The discussion was conducted September 8, 2016.

About PerryUndem
PerryUndem Research/Communication, a nonpartisan research firm, conducts public policy research for nonprofit organizations, foundations, and government agencies. PerryUndem works on a number of health related policy issues, including health reform implementation, delivery system reform, health IT, costs, and quality. PerryUndem has briefed numerous state and federal policymakers on their work, including members of Congress, White House staff, Secretary Sebelius, and CMS leadership. For more information, visit http://perryundem.com.

About The John A. Hartford Foundation
Founded in 1929 by John and George Hartford of the Great Atlantic & Pacific Tea Company (A & P), The John A. Hartford Foundation, based in New York City, is a private, nonpartisan philanthropy dedicated to improving the care of older adults. Every eight seconds, someone in America turns 65. The largest-ever generation of older adults is living and working longer, redefining later life, and enriching our communities and society. Comprehensive, coordinated, and continuous care that keeps older adults as healthy as possible is essential to sustaining these valuable contributions. The John A. Hartford Foundation believes that its investments in aging experts and innovations can transform how care is delivered, lowering costs and dramatically improving the health of older adults. Additional information about the Foundation and its programs is available at www.johnahartford.org.

About the California Health Care Foundation
CHCF is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and those
whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system. Learn more at www.chcf.org.

About Cambia Health Foundation
Based in Portland, Oregon, Cambia Health Foundation is the corporate foundation of Cambia Health Solutions, a total health solutions company dedicated to transforming the way people experience health care. Cambia Health Foundation strategically invests and partners with organizations regionally and nationally to advance national palliative care quality, access and understanding; improve the behavioral and mental health of underserved children; and transform health care to a more person-focused, equitable and economically sustainable system. Learn more at www.cambiahealthfoundation.org.

Media contact:
Elliott Walker
ewalker@aboutscp.com
917.846.6334