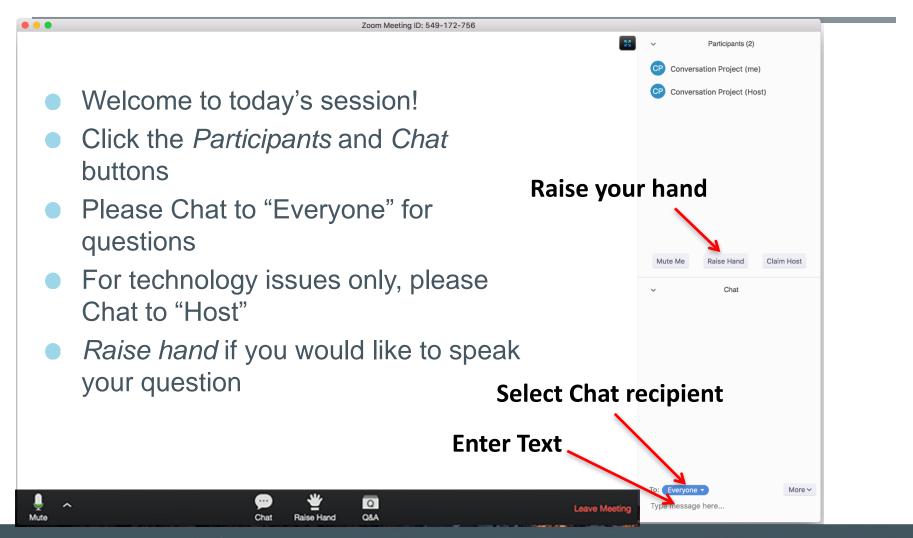


# The Conversation Project National Healthcare Decisions Day

February 19, 2020

Kate DeBartolo Katie Nerney

## Zoom Quick Reference





# The Conversation Project Field Team



Kate DeBartolo
Director



Katie Nerney Project Assistant



# Ice Breaker Question

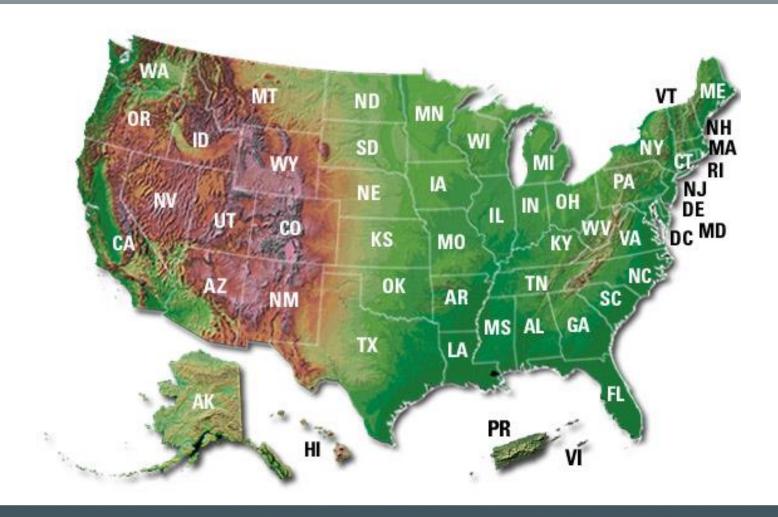
Type into the chat box your response to the following question:

How did you learn about this call?

Make sure you send your message to "All Participants."



## Where are you located on the map?





# Agenda

- History of National Healthcare Decisions Day (NHDD)
- Massachusetts Coalition for Serious Illness Care
- Sharing your plans for NHDD, questions, feedback



A public engagement campaign dedicated to assure that everyone's wishes for end-of-life care are expressed and respected.

the conversation project



# the conversation project







Nathan A. Kottkamp
Founder
National Healthcare Decision Day
<a href="https://theconversationproject.org/nhdd/">https://theconversationproject.org/nhdd/</a>



# The Origins and Future of National Healthcare Decisions Day

Nathan A. Kottkamp, JD, MA (Bioethics)

National Healthcare Decisions Day, Founder & Chair Waller, Partner



- April 16
- Founded by Nathan Kottkamp out of years of experience on ethics committees dealing with situations when failed to make their healthcare wishes known.
- All across the country, health care facilities, health care professionals, chaplains, the legal community and others will be participating in a collective effort to highlight the importance of making advance health care decisions and to provide tools for making these decisions.
- www.nhdd.org

## Reported Results from the First 10 Years

- Participation by at least 110 national organizations
- Participation by at least 1,600 state/local organizations
- Participation at US military at bases throughout the world
- Over 4.7 million facility/organization staff members received NHDD/advance directive information or training
- At least 3.9 million members of the general public participated in NHDD events and/or were known to have received advance directive information
- Over 15 million people were exposed to NHDD via various social media outlets: Facebook, Twitter, and LinkedIn, and #NHDD "trended" on Twitter (2015)
- Over 37,000 advance directives were completed on the ten NHDDs alone

#### **Solutions**



- Lead by example Do your own
  - For the benefit of your loved ones
  - To understand what patients go through when completing their advance directives
- Talk with others
- Volunteer to speak
- Collaborate in the community
- Share the resources

## The Future...

- Psychiatric advance directives
- Better integration with POLST initiatives
- Development of a national form

### **Spread the Word**



- NHDD is about you professionally
- NHDD is about you personally
- April 16 or anytime
- Free resources year round at: https://theconversationproject.org/nhdd/

## Questions?

Nathan A. Kottkamp Waller 804.301.8568

nathan.kottkamp@wallerlaw.com

https://theconversationproject.org/nhdd



Anna Gosline
Senior Director of Health Policy and
Strategic Initiatives
Blue Cross Blue Shield of Massachusetts





# Advancing the language of advance care planning: a messaging research project

Anna Gosline, Massachusetts Coalition for Serious Illness Care

#### The Massachusetts Coalition for Serious Illness Care



#### Launched in 2016

- Co-founded by Ariadne Labs, BCBSMA,
   The Conversation Project
- Atul Gawande and Maureen Bisognano, cochairs
- BCBSMA is the primary funder and administrative home

#### The Massachusetts Coalition for Serious Illness Care: 110+ diverse members



- Medical care organizations
- Hospice, home health and extended care organizations
- Trade associations/professional societies
- Serious illness communications/advance care planning-focused organizations
- Consumer advocacy
- Government agencies
- Medical and nursing schools
- Faith-based and other community organizations

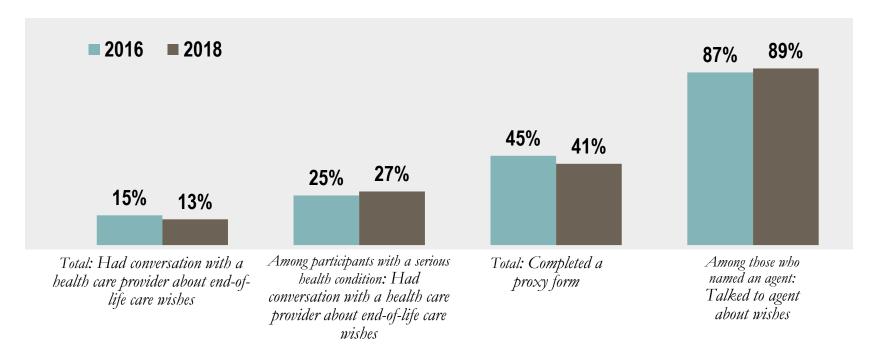


#### Previous Massachusetts Coalition Consumer Research

- 2016 baseline survey (representative statewide survey; n=1800): advance care planning related actions; experience of care for loved ones who recently died in Massachusetts
- 2017 'hybrid' follow-up survey with many open-ended questions
- 2018 follow-up survey (representative statewide survey; n=1500), including additional questions comparing to national statistics (from Nov 2017 Kaiser Family Foundation survey)

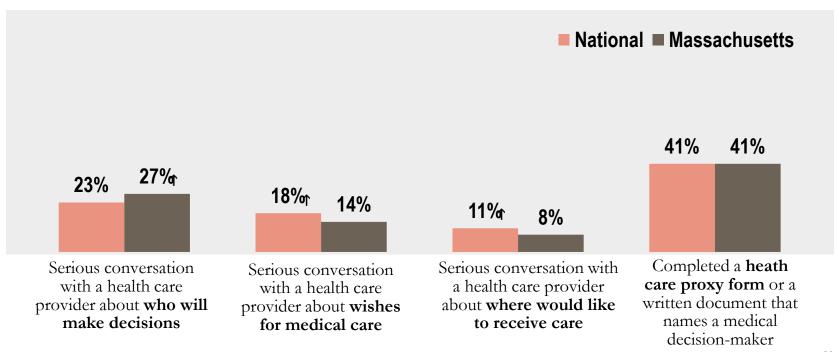


There was no change in the percentage of participants who talked to doctors, completed a proxy or talked to their agent about their wishes for care.



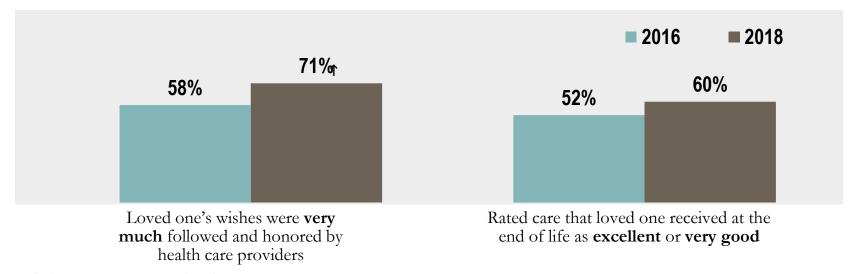


## Compared to national rates, Massachusetts residents are largely comparable in their engagement in advance care planning activities.





But...there was a significant increase in the percentage of participants who said their loved one's wishes were honored at the end of life. Participants' assessment of care quality also improved, but not significantly.



<sup>↑</sup> Significantly higher than comparison group at 95% confidence level.



Q: To what extent would you say that your loved one's wishes were followed and honored by health care providers at the end of their life? Base: Death of a loved one

Q: Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one

#### What did we learn?

- The public strongly equates advance care planning with DNRs and life-sustaining treatment choices
- Despite significant attention, energy and activity, Massachusetts is similar to the rest of the nation with respect to advance care planning activities
- Changes in outcomes experience of care near the end of life can improve despite no population-level changes in traditional advance care planning activities



# Messaging Research Project

### Research Objectives and Overview

- Develop unifying set of messages that motivate consumers to have meaningful conversations about their preferences, values, and goals at all stages of life and health
- Shift conceptual focus away from life-sustaining treatments and care at the very end of life to quality of life, serious illness care, and shared decision making.
- Deploy methodologically rigorous quantitative and qualitative research designs to understand key 'segments' of the population to identify language and concepts that resonate universally, as well as a more detailed understanding of what works by segment



# Quantitative Research

## Nationally representative survey (n=2500)

- **Demographics**: age, marital status, race, income, education
- Experiences with advance care planning (including reasons for not engaging)
- Experiences as a caregiver or with the death of a loved one
- Worries about a future serious illness
- Trust and regard for health system/doctors
- **Confidence**/ability to manage their health or navigate the health system
- Personality traits
- Importance of **religion**
- Health status/diagnoses/disability

Cluster analysis

Consumer Segments

Nondemographic variables\*\*



Population segments that are most alike in terms of how they view ACP, their experiences with health care, caregiving, other relevant beliefs, attitudes, experiences and worries

\*\*though we know many these have strong correlations to race, age, and income etc.



2

## **Five Consumer Segments**







Disengaged Worriers 34%



Confident Independents 18%



Self-Reliant Skeptics 14%

#### **Action Takers**

100% have both a written document naming their health care decision maker and a document that describes their wishes for care; about 90% have also spoken to loved ones about their wishes and many (50-85%) have talked to their doctors, too.

#### **Non Action**

Very few have appleted written documents (4 - 16%); about half have had conversations with loved ones about their wishes; few  $(\sim 20\%)$  have talked to their doctors.



### **Five Consumer Segments**



Worried Action Takers 10%

Younger, diverse, most educated. Nearly half identified as having a disability.

Highest trust and regard for the health care system. ~80% have been a caregiver for an incapacitated loved one.



Self-Assured Action Takers 24%

Oldest by far; most likely to be white and least likely to be lowincome.

Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.



Disengaged Worriers 34%

Youngest, most diverse, lowest education and income; poorest health and health care navigation and management skills.

Seen loved one's wishes not honored. Many worries about their health and future serious illness.



Confident Independents 18%



Middle-aged, lower

14%

Older (mostly 45+), average education and racial composition.

Fewer experiences with dying loved ones.

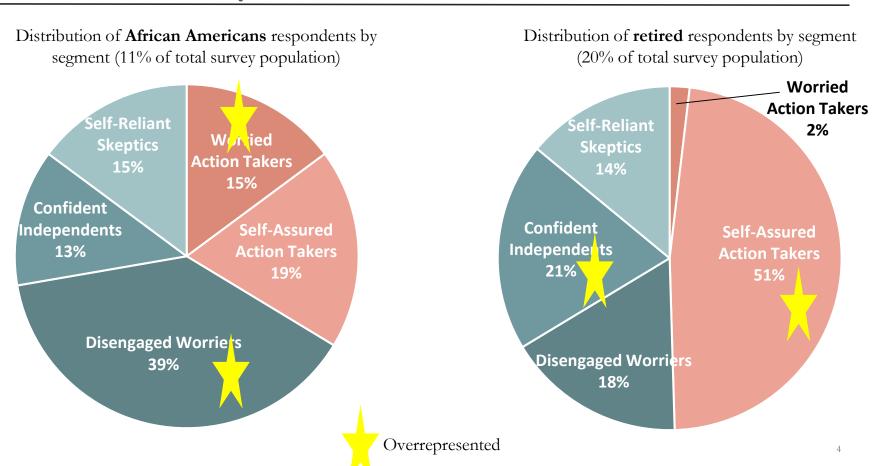
Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

Middle-aged, lower income and education.

Lowest trust of doctors and regard for the health care system. Poorer health care selfmanagement and navigation skills.



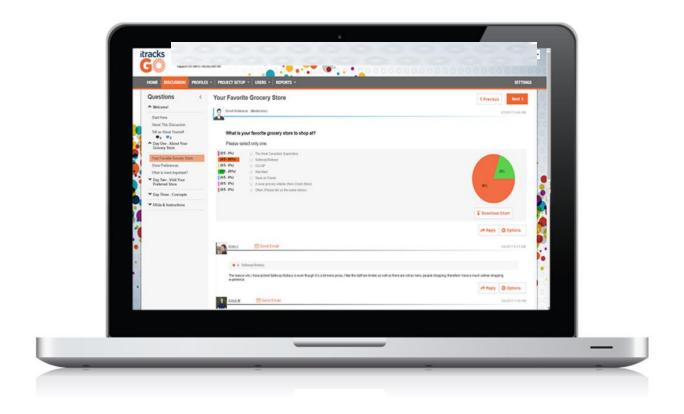
# Examples: where is the African American community? Where is the retired community?





# Messaging and Campaign Development and Testing

## Two Online Communities – 150 Participants



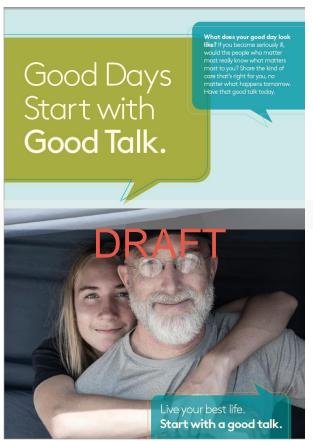


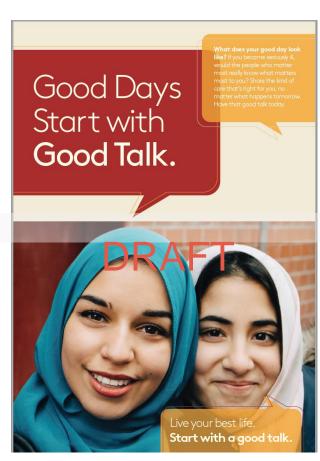
### Three Key Insights

- 1) While "quality of life" resonated most, having "control" and "power" over decisions impacting one's life and care is the way to attain and preserve the quality of life they envision.
- 2) People reacted positively to talking about "what matters to them" and what having a "good day" meant, shifting focus away from treatment options, DNRs, etc.
- 3) The idea of **family and loved ones** can be a loaded topic for some and an excuse for others some didn't have 'loved ones' and felt excluded from ACP (including many Disengaged Worriers); others felt their loved ones 'would know' and therefore didn't need ACP (notably, the Confident Independents)



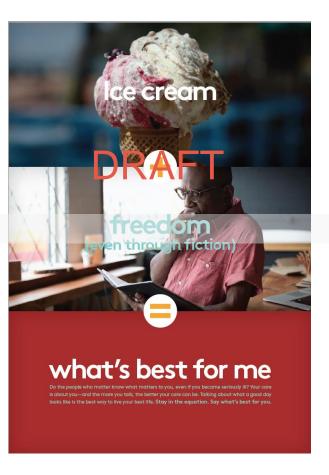


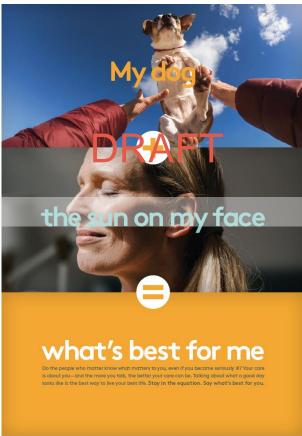




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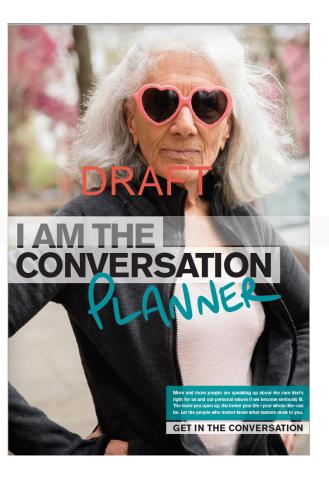


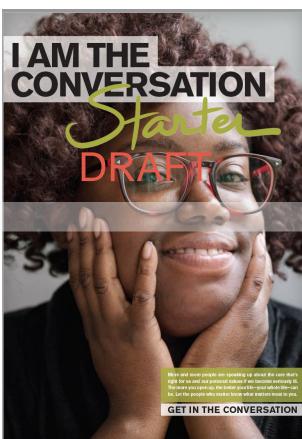


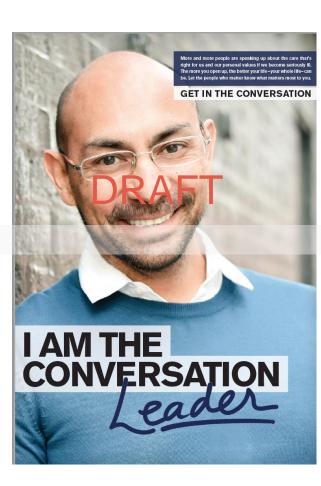


Posters shown here for illustrative purposes only and reflect work in progress.









Posters shown here for illustrative purposes only and reflect work in progress.





# "Good Days Start with Good Talk" was the most preferred across all segments

- Warm, cheerful
- Conveys togetherness
- Relatable
- Easy to understand, clear, simple
- Easy-to-remember tagline
- Straightforward
- For a few it felt "pushy"



# "What's best for me" ranked in second place



- Vague
- Disconnect between images and text

# "Get in the conversation" ranked in third place



- Absence of other people in the photo
- Health care decisions shouldn't be made solo



### Five Supporting Messages/"Reasons" Were Tested

#### Love/Gift

Love means speaking up.

If any of us became seriously ill, those closest to us may have to make important decisions about our care. Asking and sharing what would matter most to each other in that event is an act of love and kindness that can make future decisions easier—a gift we can give to those who matter most.

#### Peace of mind

There's no need to wonder.

The future is full of unknowns. But open conversations can pave the way to clarity, no matter what happens with our health. Having conversations about serious illness and the kind of care that's right for us gives us a shared understanding that fosters peace of mind.

## Demand the right care

We can have a say in our care.

Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we'd want if we couldn't make decisions for ourselves.

## Control (via decision-maker)

Conversations clarify.

We can't plan for everything. But we can help manage life's unknowns by talking openly about what matters to us and what we'd want most if we became seriously ill. Conversations about things we can't control can actually help to give us a sense of control.

## Honor loved ones' wishes

Caring means learning what matters to them.

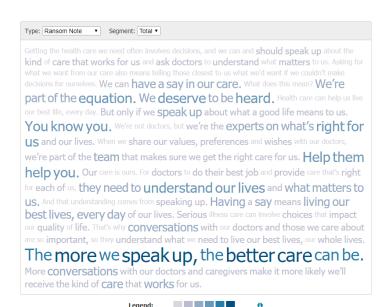
There may be a time when we have to help the people closest to us—our friends, our spouses, our parents or grandparents—get the care that's right for them. Delivering on the promise means understanding what is most important to them in the face of serious illness.



### Participants read the content and did a highlighting exercise.

#### Example of visual output from "We can have a say in our care"

#### Words that resonate



Least Selected Most Selected

#### Words that don't resonate

Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us and ask doctors to understand what matters to us. Asking for what we want from our care also means telling those closest to us what we'd want if we couldn't make decisions for ourselves. We can have a say in our care. What does this mean? We're part of the equation. We deserve to be heard. Health care can help us live our best life, every day. But only if we speak up about what a good life means to us. You know you. We're not doctors, but we're the experts on what's right for us and our lives. When we share our values, preferences and wishes with our doctors, we're part of the team that makes sure we get the right care for us. Help them help you. Our care is ours. For doctors to do their best job and provide care that's right for each of us, they need to understand our lives and what matters to us. And that understanding comes from speaking up. Having a say means living our best lives, every day of our lives. Serious illness care can involve choices that

impact our quality of life. That's why conversations with our doctors and those we care about are so important, so they understand what we need to live our best lives, our whole lives. The more we speak up, the better care can be. More conversations with our doctors and caregivers make it more likely we'll receive the kind of care that works for us.





### Control and Self-Advocacy "reasons" were preferred by most

	To gain control  Conversations clarify	To demand shared decision-making We can have a say in our care	for others	To get peace of mind There is no need to wonder	To give a gift to loved ones Love means speaking up
Worried Action Taker					
Self-Assured Action Taker				•	
Disengaged Worrier				•	
Defiant Independent			•	•	
Self-Reliant Skeptic					



#### **Lessons:** Word choices matter

- Some reacted negatively to the word "**right**" it puts them in a defensive mindset.
- For some, "Conversations" can sound daunting (when associated with serious illness as part of umbrella messaging) while "a good talk" is more approachable.
- "Honest conversation" can feel judgmental, while "open conversation" does not introduce judgment.



### Lessons: Certain concepts used in ACP did not resonate

- The concept of "**Peace of mind**" and that doing ACP provides a sense of relief did not resonate across all consumer segments. For some consumers it felt overpromising and possibly exclusionary to those in lower income households (can't carry through wishes of a loved one given financial situation).
- The concept of "Lessen/ease the burden" was viewed negatively because some consumers felt that it should not be a burden to care for a loved one, while others thought that having the conversation doesn't really ease the burden of having loved ones seriously ill.
- Comparing ACP (i.e., having meaningful conversations) to "wellness" and an "annual check-up" was viewed negatively and implausible.



### Different conceptual paradigms behind the top reasons..

"Conversations clarify."

"Caring means learning what matters to them."

- Emphasis is on selecting surrogate decision maker in the case of incapacity
- More traditional approach to advance care planning marketing
- Closer conceptual connection to life sustaining treatment choices

"We can have a say in our care."

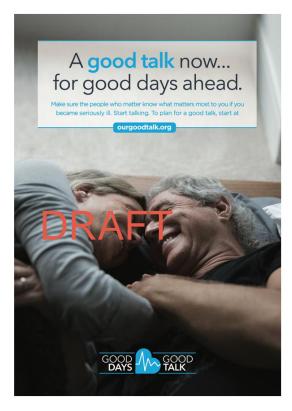
- Emphasis on expectation/demand for shared decision making by the patient as part of clinical process
- Less traditional approach
- Not exclusive to serious illness relevant for active treatment of any condition/stage of illness or health status

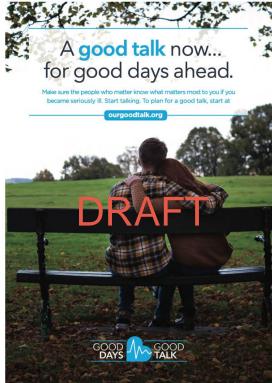


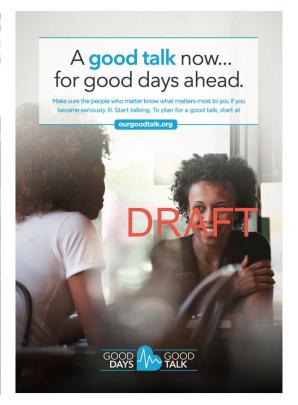
## Updated campaign testing

Additional campaign testing with 120 participants in August 2019

### Campaign A - Direct

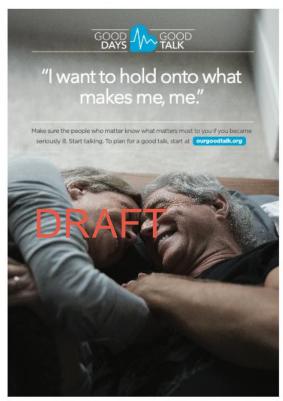


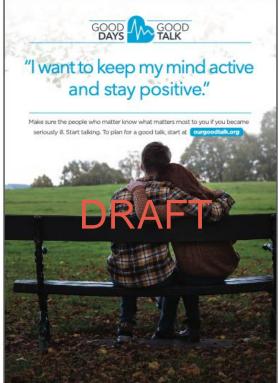


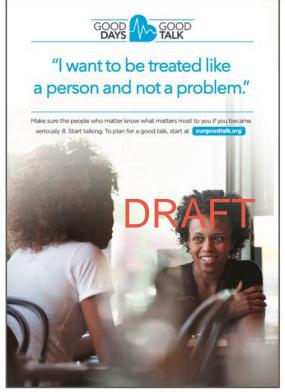




### Campaign B - Quotes

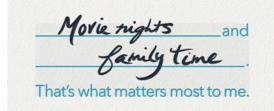


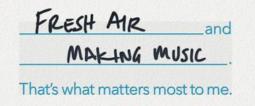


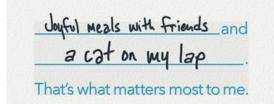


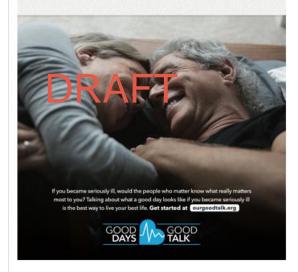


### Campaign C - "Madlibs"















### Campaign A was preferred overall and by most segments and groups

- Campaign A slightly edged out the others due to it's simple, direct language and positivity
  - Preferred (or about tied with C)
     by most segments
- It was the most preferred by those with a serious illness or who were a caregiver of a person with a serious illness

"I feel like a lot of people (myself included) don't really think about these things and this ad does a good job of bringing the point of consideration at hand very well and again tastefully. I genuinely like it. I also appreciate that the text is straightforward, but not in a pretentious sense either and that the good days good talk is easy to remember." MEREILLE 25-34



### Campaign B was more hit or miss

- Some consumers relate to the more concrete language/examples from the quotes in Campaign B (the emphasis on "what I want"),
  - Those who could identify with the exact quotes tended to like the campaign
  - It was the most preferred by our Self-Assured Action Takers
  - It was also tied with Campaign A with those identifying as having a disability
- But it was the **least preferred overall** and by a pretty notable amount in most segments
- Assumption is that the focus is on end of life care



### Campaign C was a close second to Campaign A

- Campaign C was deemed the most personal of the three:
  - Consumers relate to the handwriting font and fill in the blank examples
  - Many commented that it prompted them to think of what their examples would be
- A few shared that the primary message is not as intuitive as Campaigns A and B that it takes a few reads to fully understand "what's being sold."



### Value in all three campaign versions

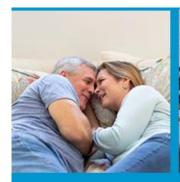
 Lead with Campaign A as the umbrella awareness building campaign



 Use Campaign C as a secondary educational and engagement tool















## THE GOOD TALK TOOLKIT

Advancing the language of advance care planning







## Social media graphics

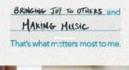




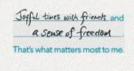


#### **Handouts**

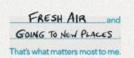


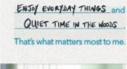






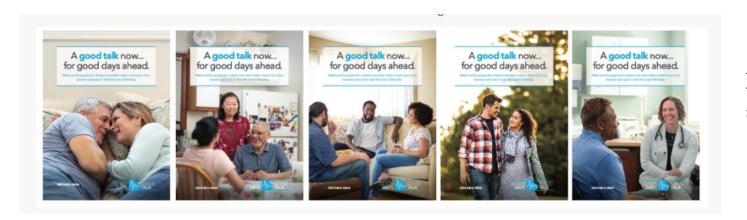












## Editable posters - add your logo



Powerpoint resources



### More coming soon!

- Spanish translations
- Fill-in-the-blank "What Matters Most to Me" handouts
- Brief guide for medical care providers so they are prepared for the 'Good Talk' should a patient ask for one
- Consumer website: triage to more detailed references

What else would you want?



# Appendix: Detailed Language

#### UMBRELLA MESSAGE

### RESONATES WITH ALL CONSUMER SEGMENTS











A good day tomorrow starts with a good talk today. If you became seriously ill, would the people who matter most really know what matters most to you? Share the kind of care that's right for you, and what your good days look like—no matter what happens tomorrow.

#### SUPPORTING MESSAGES/ REASONS WHY

Conversations clarify. We can't plan for everything. But we can help manage life's unknowns by talking openly about what matters to us and what we'd want most if we became seriously ill. Conversations about things we can't control can actually help to give us a sense of control.

We can have a say in our care. Getting the health care we need often involves decisions, and we can and should speak up about the kind of care that works for us, and ask doctors to recognize what matters to us. Asking for what we want from our care also means telling those closest to us what we'd want if we couldn't make decisions for ourselves.

#### **PROOF POINTS**

Information is power. We can help answer tomorrow's questions today by sharing our values and preferences with the people who matter most. We may not be able to predict every choice we'll have to make, but we can give those we love the guiding principles to confidently make decisions for us.

If we don't say it, they won't know. Our caregivers may need to make decisions for us, whether we've told them what we want or not. We can't simply assume they know.

You know you. We're not doctors, but we're the experts on what's right for us and our lives. When we share our values, preferences and wishes with our doctors, we're part of the team that helps us get the right care for us.

Having a say means getting the most out of every day.

Serious illness care can involve choices that impact our quality of life. The more we speak up, the better care can be, and the more we'll have the chance to receive the kind of care that works for us.



#### SECONDARY MESSAGING

### RESONATES MOSTLY WITH THESE THREE CONSUMER SEGMENTS







HONOR LOVED ONE'S WISHES/ ACTIVATE CONVERSATION IN OTHERS Caring means learning what matters to them. There may be a time when we have to help the people closest to us—our friends, our spouses, our parents or grandparents—get the care that's right for them. Delivering on the promise means understanding what is most important to them in the face of serious illness.

#### **PROOF POINTS**

#1

It's worth it. To ensure our loved ones get the care that's right for them, we have to understand their values, preferences and needs by making conversations a priority. The more we talk about the kind of care our loved ones want and expect, the more comfortable it becomes for all of us.

#### #2

Talking can strengthen relationships. The trust involved in conversations about care, and what matters most, can serve to bring us closer. Asking those closest to us about what they would want in the face of a serious illness is a way to show them we care. And it helps prepare us to be the best support we can be.



### SECONDARY MESSAGING

### RESONATES MOSTLY WITH THESE TWO CONSUMER SEGMENTS





**LOVE** 

Love means speaking up. If any of us became seriously ill, those closest to us may have to make important decisions about our care. Asking and sharing what would matter most to each other in that event is an act of love and kindness that can make future decisions easier—a gift we can give to those who matter most.

#### **PROOF POINTS**

#### #1

Conversations guide us. Planning for a day when we might become seriously ill or unable to make health decisions for ourselves is a kindness to loved ones who may need to make those decisions for us. An expression of our values and preferences will make the decision-making process easier for those we care about.

#### #2

#### Conversations align us toward a common goal.

Sharing what matters provides a sense of confidence—that we will be prepared to cope with a serious illness and honor each other's wishes together, whether we are a patient or a caregiver.



## Questions?





What are your plans for NHDD 2020?





## Continue to Share your NHDD plans

We want to highlight what you are planning for NHDD in our newsletter/social media

- Tweet us, tag us on social media
  - Twitter: @convoproject
  - □ Facebook: The Conversation Project
  - Instagram: convoproject







 Email us plans, blogs and/or other content <u>ConversationProject@ihi.org</u>



### NHDD resources

- NHDD Media Tool Kit
- Additional resources on <u>www.NHDD.org</u>: communications materials, events and presentation materials, promotional and media outreach materials and more!
- Blogs on <u>www.conversationproject.org:</u>
  - Ideas and Resources for National Healthcare Decisions Day: Join the Movement!
  - National Healthcare Decisions Day: Get Inspired and Get Involved
- MASIC: The Good Talk Toolkit



## **Upcoming: TCP Community Connections**

Date and Time	Topic
Thursday, March 26 <sup>th</sup> 3:30-4:30 EST	Twitter chat: Alzheimer's or other forms of dementia
Wednesday, April 22 <sup>nd</sup> 3:00-4:00 EST	Community Call: Getting Started with TCP



## New TCP resource

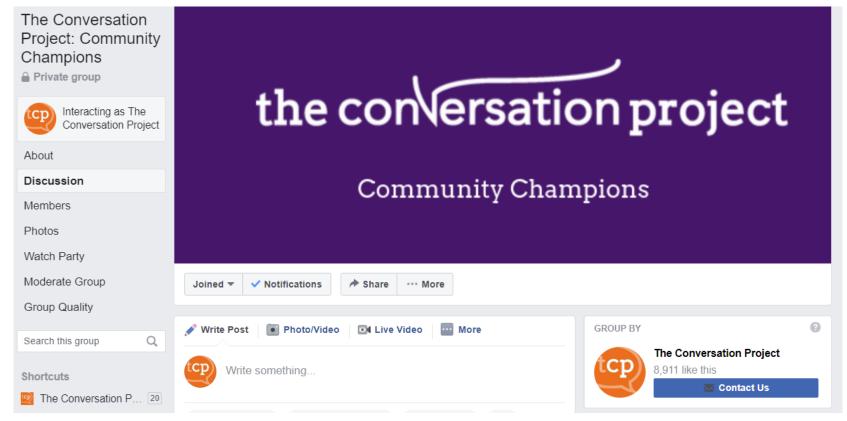
Video: Ellen Goodman talks Alzheimer's Disease

and Dementia





## Facebook Group: TCP Community Champions



https://bit.ly/2ukc7B0



## Other ways to Engage with TCP's network

- Sign up and share: Monthly <u>Newsletters</u>
  - General Newsletter
  - Community Engagement Newsletter
  - NHDD

https://theconversationproject.org/get-involved





## Ways to Engage with TCP's network

Search, connect/network and learn together

#### Conversation Champions Map

- · Connect with others doing similar work in your area.
  - You can search by location, organization, name, and filter by setting: faith, health care, or community. Feel free to reach out directly to members on the map via their listed contact information.
- . Apply here to be listed on the map if you are actively sharing TCP resources and/or messaging.

The Conversation Project (TCP) relies on the Conversation Champions, like the ones listed on the map below, to help spread the importance of end-of-life care conversations in their communities. These groups plan their own programming using TCP resources or messaging (in addition to their own). As a reminder, TCP has no preference for what someone's wishes for end-of-life care should be – we just want folks to start talking about it. Please read more about our principles HERE.





https://theconversationproject.org/get-involved



## We want your feedback!

 After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today's topic, what would you like to learn more about?
- Any other comments on today's session?
- What are your plans for NHDD 2020?



## Thanks and appreciation



## The John A. Hartford Foundation

Dedicated to Improving the Care of Older Adults



