

Community 201 Call:

Lessons on Messaging from the Massachusetts
Coalition for Serious Illness Care

The Conversation Project



July 17, 2019

WebEx Quick Reference

Welcome to today's session!

Please use Chat to "All Participants" for questions

For technology issues only, please Chat to "Host"

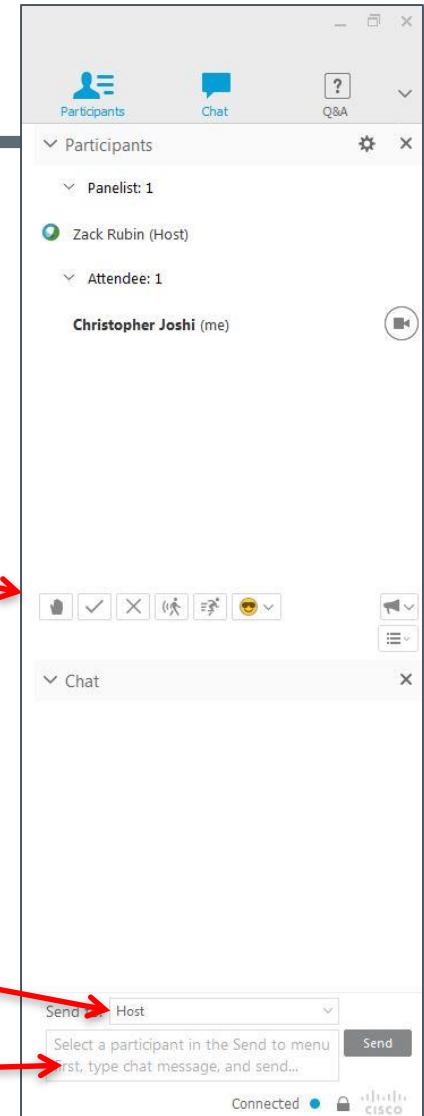
Raise your hand

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)

Select chat recipient

Enter Text



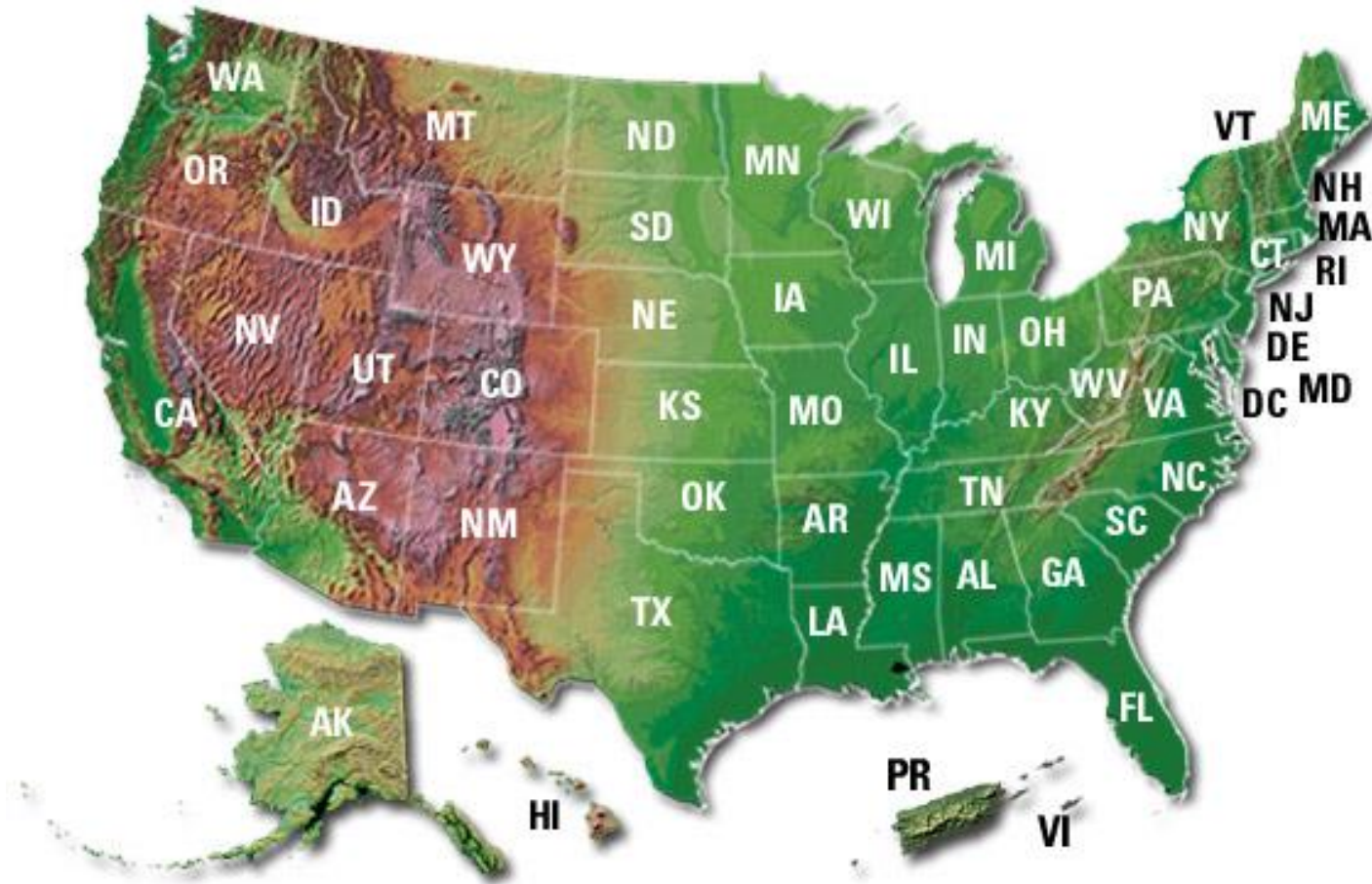
Ice Breaker Question

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?



The Conversation Project Field Team



Kate DeBartolo
Director



Christopher Joshi
Project Coordinator

Upcoming Community Calls

The next Conversation Project Community Call will take place on:

Wednesday, August 21st, 3:00-4:00 PM EDT

Date and Time	Topic
Wednesday, August 21 st , 3:00 – 4:00 pm ET	Special Interest: Planning for Conversation Sabbath
Wednesday, September 18 th , 3:00 – 4:30 pm ET	Virtual Speaker Training
Wednesday, October 16 th , 3:00 – 4:00 pm ET	Community 201: TBD

TCP Community Updates

What's New:

- Tembi Locke Blog: <https://theconversationproject.org/tcp-blog/a-conversation-with-tembi-locke-love-loss-and-fava-beans-part-1/>
- One-Pager: [Integrating End-of-life Care Conversations into Professional Services Work: Getting Started](#)
- Case study: [Fidelity's Journey and One Leader's Mission to Integrate End-of-Life Conversations into Financial Advisors' Workflow/Practice](#)
- Proxy Kit → [Health Care Agent](#) version

TCP Community REMINDER

Quarterly **Community Activity Survey** is open until
Friday, July 26th!

<https://www.surveymonkey.com/r/CYWJ7HK>

Virtual Expedition and Podcast

- Conversation Ready: Engaging Patients in Advance Care Planning
 - Becoming [Conversation Ready](#) is an effort to provide more patient-centered care by gaining an understanding of what matters most to patients when it comes to end-of-life care. This virtual training teaches the five principles of being Conversation Ready.
 - Kicked off Tuesday, July 16, 1:00-2:00 PM ET—twice a month from July to September <https://bit.ly/2KoDQHn>
- Podcast on Conversation Ready: How to Prepare for End-of-life Conversations. Part of a series on Healthcare Communication: Effective Techniques for Clinicians.
<http://bit.ly/DocComPodcast>

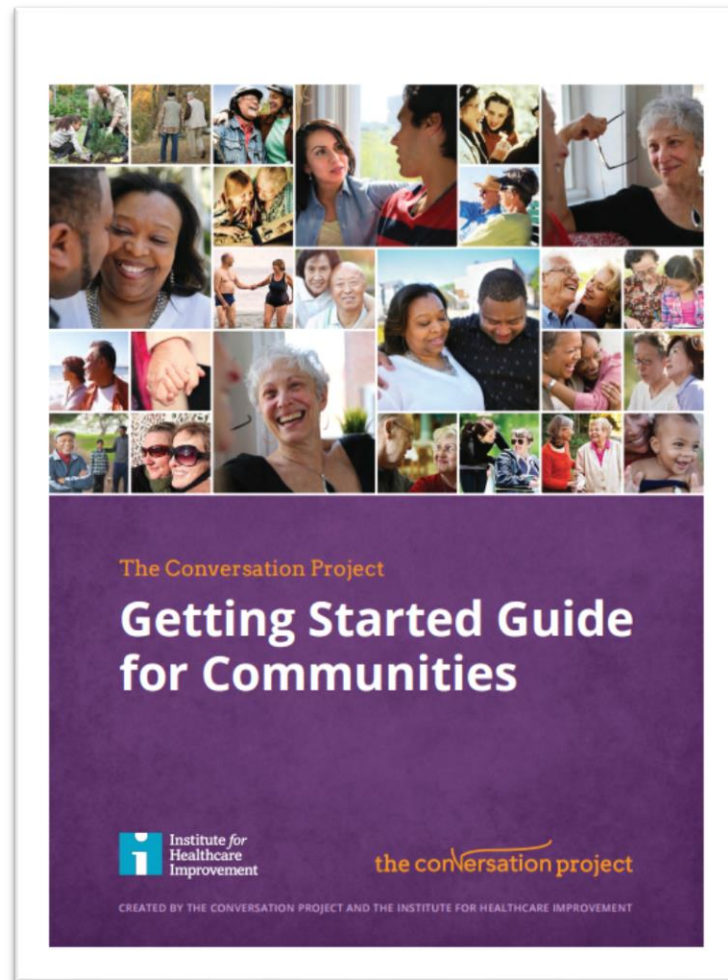


Let's get started!

- Background
- Anna Gosline from Massachusetts Serious Illness Coalition: Research Results and Learning
- Q&A and Discussion

What do you hope to learn on today's call?

Building Local Community Engagement



Getting Started Questions

- Who do you want to reach? And by when?
- What do you want to support them to accomplish?
- **How do you want to reach them?**
- What is the context of this topic for population you're trying to reach?
- Who else is already doing this work in your community? Who else could you be working with?
- Who are respected leaders or organizations that could help you advocate for the importance of this work?
- Who will be responsible for actually doing this work in your community?
- How will you measure successes and challenges?
- How do you plan to reach diverse groups of people in your community?
- What can you do by next Tuesday?

How do you want to reach them?

- What are ways you can reach your target audience where they:
 - Work
 - Live
 - Pray
- What activities might help you engage your target population? For example:
 - Writing op-eds in the local newspaper
 - Speaking at conferences or educational events
 - Creating PSA Campaign to raise awareness
- **What messaging and messenger should you consider?**



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE



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



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

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

Anna Gosline, Massachusetts Coalition for
Serious Illness Care

July 17, 2019

Research Objectives and Overview

- Through a combination of quantitative and qualitative research, 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.
- Research overview:
 - Through robust, nationally representative quantitative survey research, identify and understand key target audience segments based on their experiences and attitudes with advanced care planning and other relevant variables
 - Through structured, qualitative research with consumers representing each segment, gain in-depth understanding of what language and messages motivate all consumers to engage in advance care planning and provide additional, strategic segment-specific insights.



Segmentation

Why Segment?

- Segmenting populations into distinct groups of consumers based on their experiences, attitudes, beliefs, and personalities helps us gain a deeper understanding of the issue of advance care planning and provides an invaluable foundation for developing messaging:
 - Provides nuanced segment-specific understanding into reasons why – or why not – consumers have engaged in advance care planning
 - Helps ensure that any messaging truly works across for consumers – identifies “common ground” across all segments as well as language or concepts to avoid that may not surface if just looking at overall averages



Methodological Overview - Quantitative

Who?	Representative national sample of 2,514 adults age 18 and over. Additional Massachusetts oversample of 500 adults over 18 years of age.
When?	January 3 – January 18, 2019
How?	Online and telephone interviews. For the national sample 2,114 surveys were completed online, with 400 phone surveys conducted with people over 60. For the Massachusetts oversample 500 surveys were completed online.
Segmentation?	Segmentation cluster analysis conducted on national sample and discrete analysis on Massachusetts sample.



Five Consumer Segments



Worried Action Takers
10%



Self-Assured Action Takers
24%



Disengaged Worriers
34%



Defiant Independents
18%



Self-Reliant Skeptics
14%

Action Takers

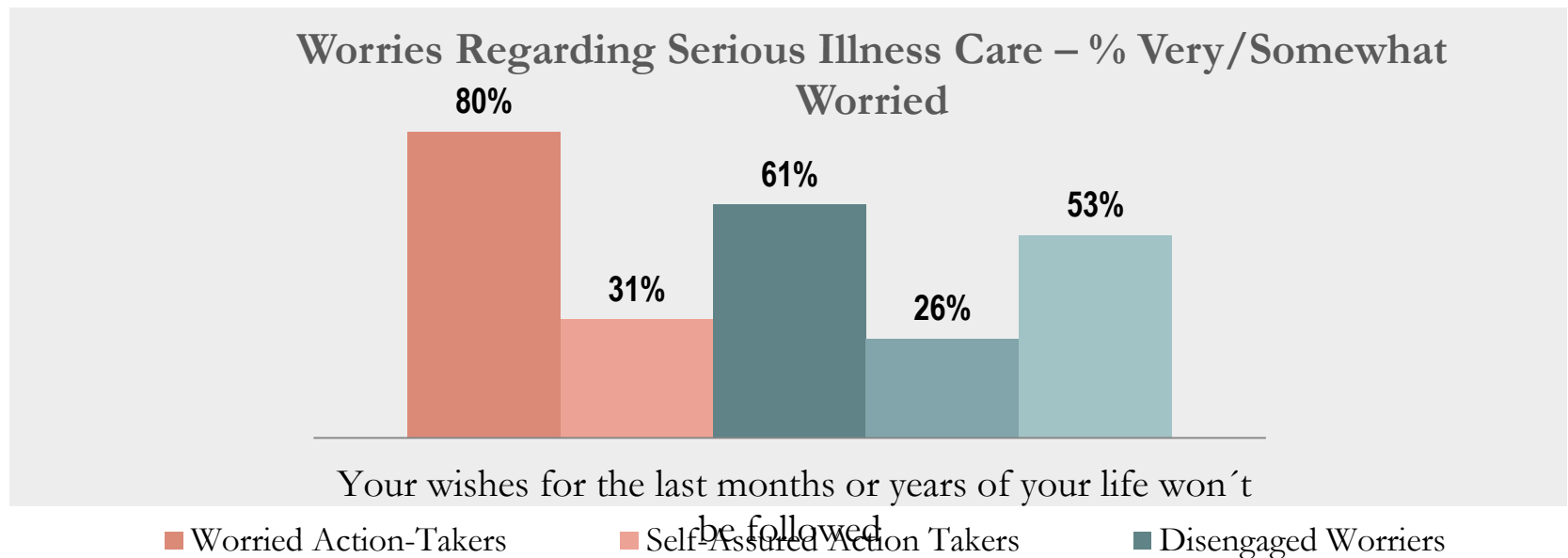
100% have both a written document naming their health care decision maker and a document that describes their wishes for care; about 90% have also spoken to loved ones about their wishes and many (50-85%) have talked to their doctors, too.

Non Action Takers

Very few have completed written documents (4 – 16%); about half have had conversations with loved ones about their wishes; few (~20%) have talked to their doctors.



Self-Assured Action Takers and Defiant Independents are considerably less worried that their wishes for serious illness care will not be followed.

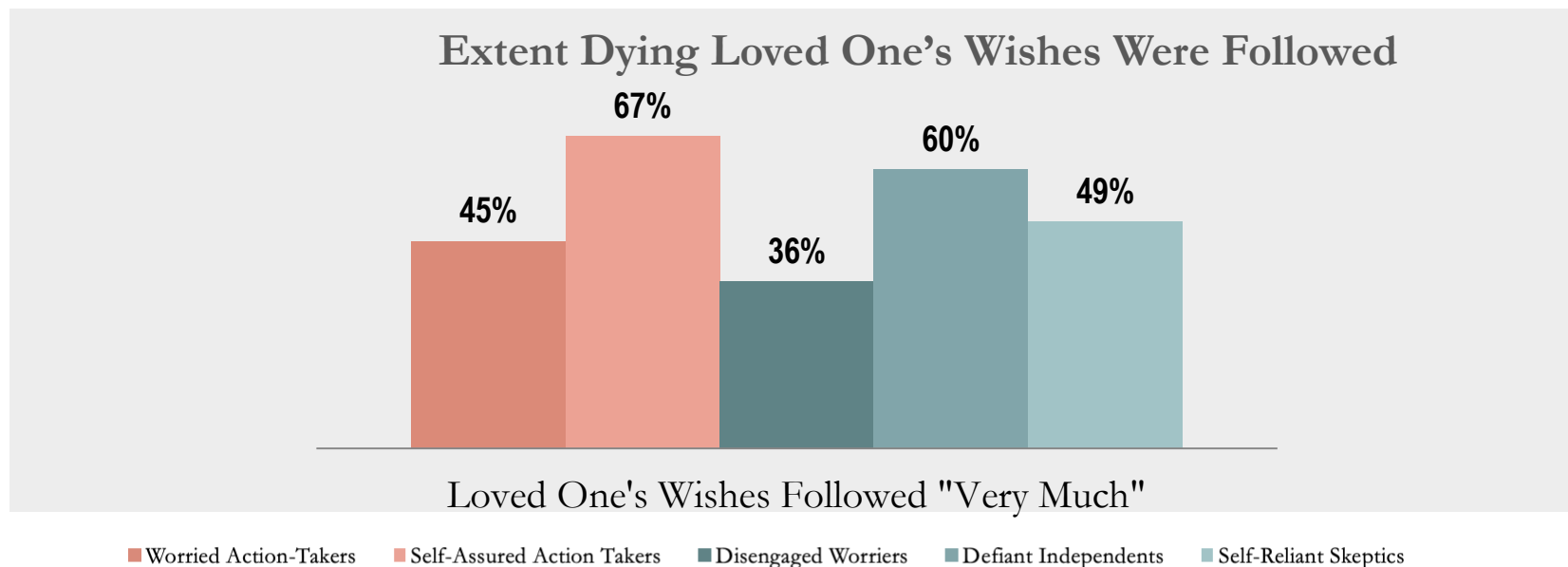


n = 258-615-850-446-345

Q10. How worried are you that if you were to become seriously ill...?



Self-Assured Action Takers and Defiant Independents are considerably more likely to say their dying loved one's wishes were followed very well, while Disengaged Worriers reflect more negatively on this experience.

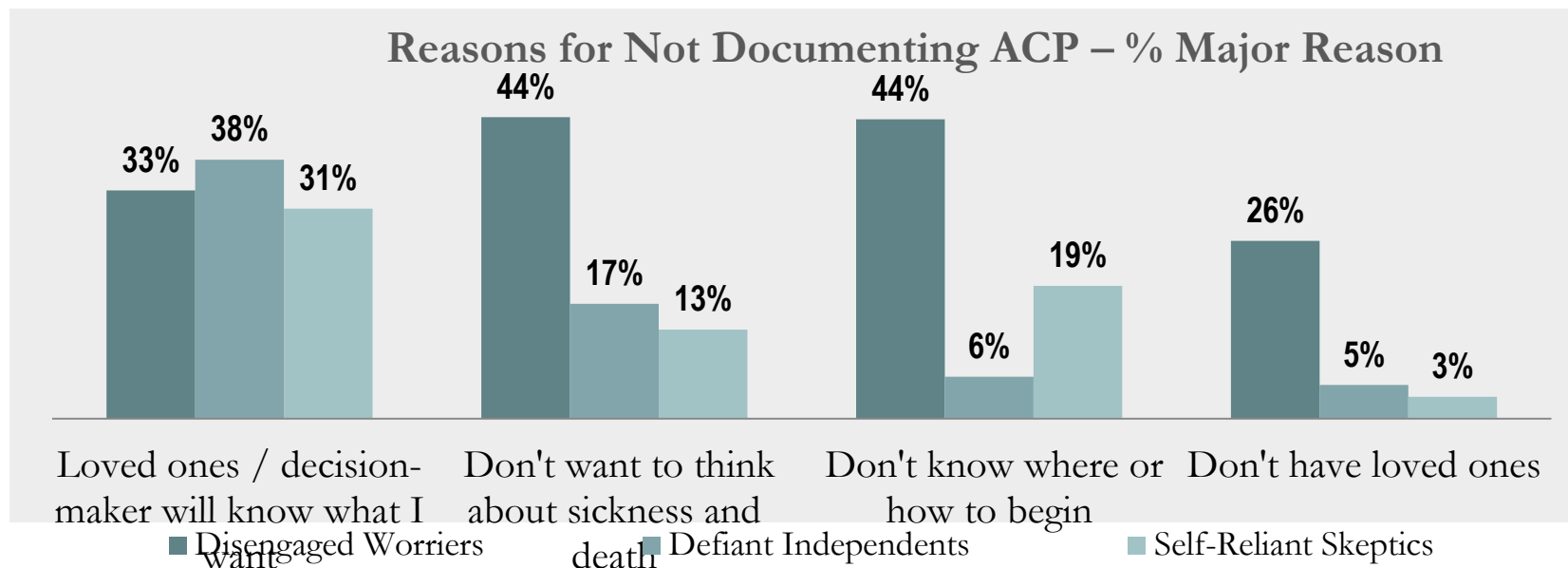


n = 199-385-488-251-219 (Lost a loved one within the past five years)

Q14. 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?



Expecting loved ones to know their wishes is a common reason for inaction across all segments. Disengaged Worriers cite many other reasons for their lack of action.



n = 850-446-345

Q11. There are different reasons why people may not [have their wishes for medical care written down and/or completed a document that names someone to make decisions about their medical care.] For each of the following, is this a major reason, a minor reason or not a reason for you?

23



Five Consumer Segments



Worried Action Takers
10%

Younger, diverse, most educated.

Highest trust and regard for the health care system. Recent caregiving for incapacitated loved one.



Self-Assured Action Takers
24%

Oldest, most likely to be white.

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.



Defiant Independents
18%

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.



Self-Reliant Skeptics
14%

Middle-aged, lower income and education.

Lowest trust of doctors and the health care system. Poor health care self-management and navigation skills.



Side note: where is X population?

- Reviewers of this work often ask where a particular population fits among the segments, especially different racial or ethnic minorities, and those with health issues, such as disabilities, behavioral health diagnoses or other serious illnesses
- Across all segments, there were more similarities than differences when it came to these kinds of demographic indicators, though some characteristics did stick out – for example, the Self-Assured Action Takers were disproportionately white and Anxious Action-Takers included a large number of those who self-identified with a disability (*also see the complementary report with the full national survey results*)
- However, those demographic characteristics generally did not **drive** the segments – when it comes to advance care planning, an African American who is in the Anxious Action Taker segment is more similar to other Anxious Action Takers than other African Americans in different segments





Messaging and Campaign Development and Testing

ACP Social Norms Marketing Pillars

Product

Behavior change/
attitude shift



Advance Care Planning

Meaningful conversations
Complete health care proxy
Document wishes

Price

Cost of adopting
behavior



Inertia

Loved ones will know
Too many things to worry about
Don't want to talk about death

Place

How to reach
target audiences



Coalition Members

Various sectors
and disciplines

Promotion

Messaging &
creative



Messaging

Umbrella
Segment-specific



Message Map

Umbrella Message

universal, aspirational value and vision

Supporting Messages

reasons/motivations

Supporting Messages

reasons/motivations

Supporting Messages

reasons/motivations

Proof Points

- 1) reinforce reasons
- 2) reinforce reasons

Proof Points

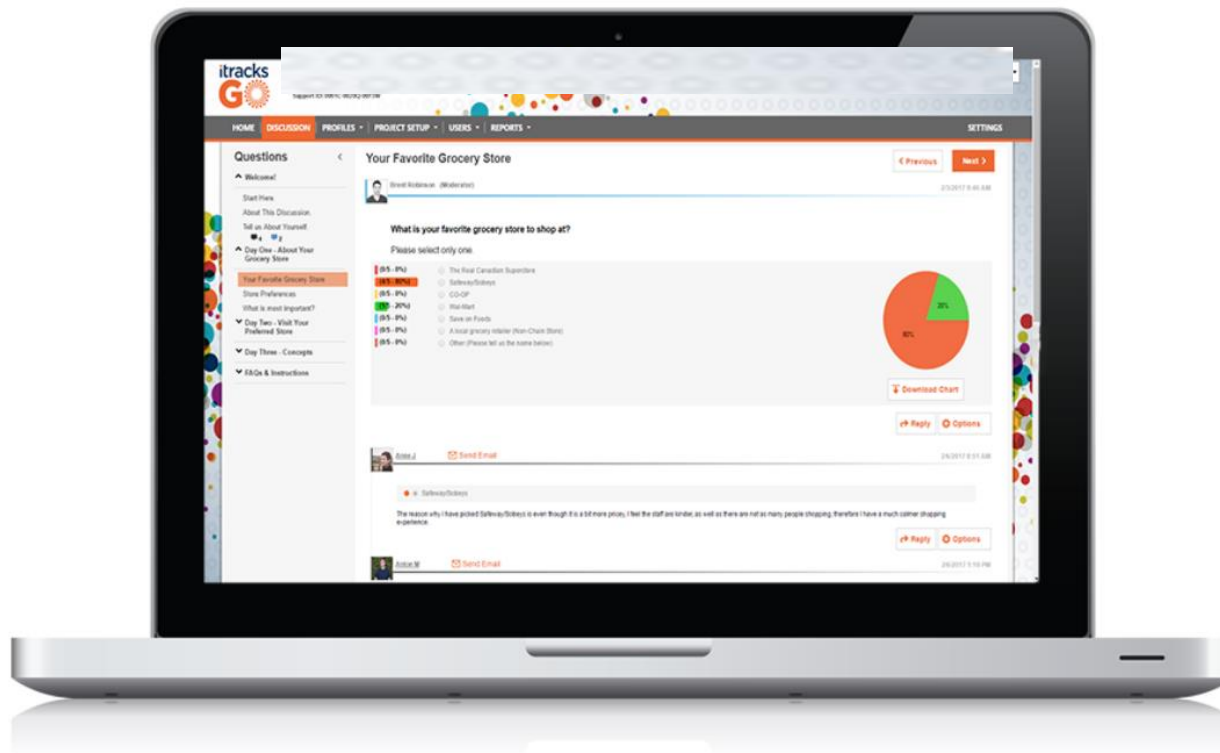
- 1) reinforce reasons
- 2) reinforce reasons

Proof Points

- 1) reinforce reasons
- 2) reinforce reasons



Two Online Communities – 150 Participants



Umbrella Campaign

Three Shared Values Were Explored

[self-determination]

“I want to have power to make my own life choices”

[quality of life]

“I want to live a good quality of life, my whole life”

[self-advocacy]

“I want care that treats me as a whole person, not just a disease”



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.



Three umbrella campaign concepts were tested.

- The umbrella campaign serves as the unifying creative and messaging, i.e. thematic glue for awareness building.
- Umbrella campaign concepts are the translation of the shared values and message research.
- Campaign concepts were developed based on what resonated with most consumers, across all segments, to encourage ACP thought and action.



Good Days Start with Good Talk.

What does your good day look like? 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, no matter what happens tomorrow. Have that good talk today.

DRAFT

Live your best life.
Start with a good talk.

Good Days Start with Good Talk.

What does your good day look like? 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, no matter what happens tomorrow. Have that good talk today.

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DRAFT

Live your best life.
Start with a good talk.

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



Ice cream

DRAFT

freedom
(even through fiction)

what's best for me

Do the people who matter know what matters to you, even if you became seriously ill? Your care is about you—and the more you talk, the better your care can be. Talking about what a good day looks like is the best way to live your best life. Stay in the equation. Say what's best for you.

My dog

DRAFT

the sun on my face

what's best for me

Do the people who matter know what matters to you, even if you became seriously ill? Your care is about you—and the more you talk, the better your care can be. Talking about what a good day looks like is the best way to live your best life. Stay in the equation. Say what's best for you.

Soft Sheets

DRAFT

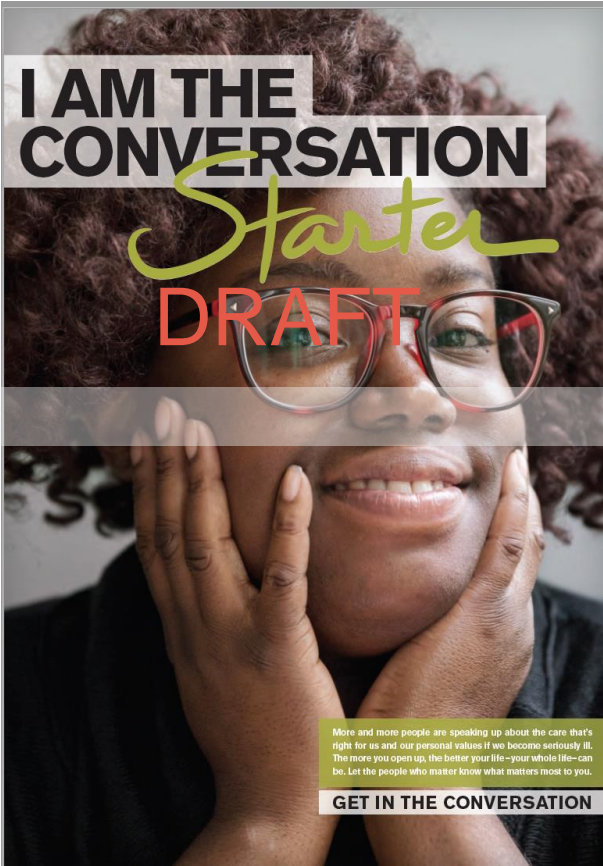
family time

what's best for me

Do the people who matter know what matters to you, even if you became seriously ill? Your care is about you—and the more you talk, the better your care can be. Talking about what a good day looks like is the best way to live your best life. Stay in the equation. Say what's best for you.

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

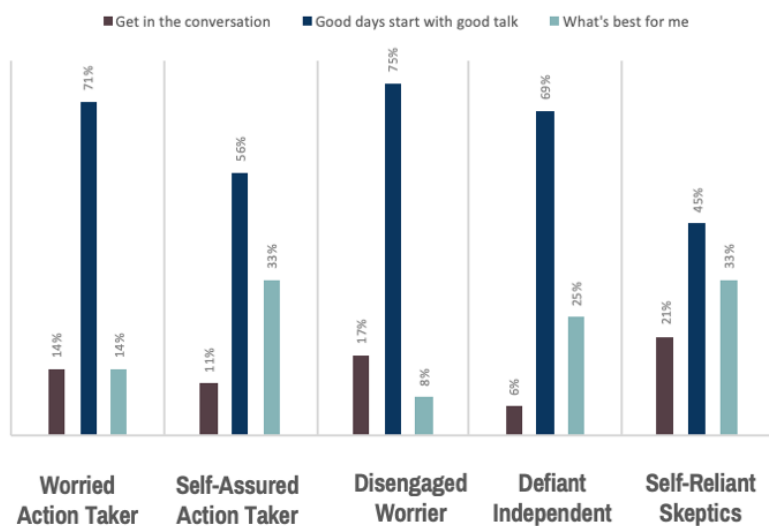
“Get in the conversation” ranked in third place



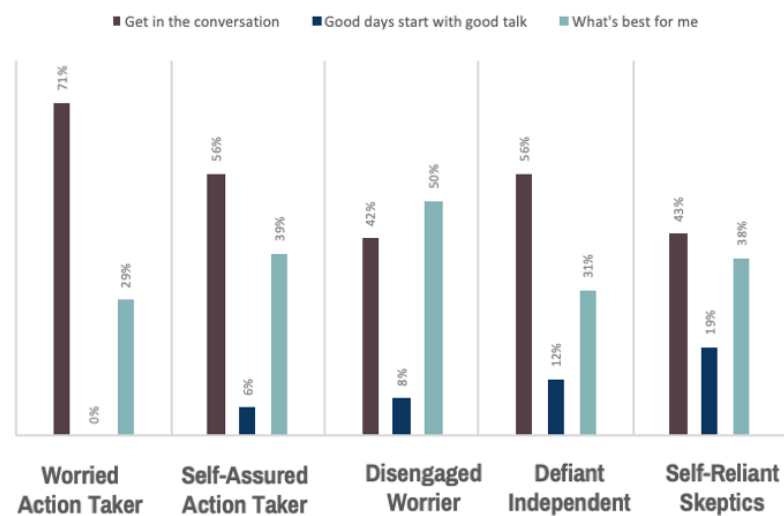
- Absence of other people in the photo
- Health care decisions shouldn't be made solo



MOST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



LEAST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



Note on Qualitative Data: Ns are small (total across both communities is 150; per segment can be as small as 30). Data observations from these communities are viewed as directional.



Messages & Language

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.

Right/Demand

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

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.



Reasons Testing

HOME DISCUSSION PROFILES

Survey

https://gosurveys.itracks.com/survey/selfserve/11c9/190321?screenname=001DT-0079L-0108S.Zamawa+A&gr...

Questions

All Groups

- Final qualification question
- Week 1
 - Activity 1
 - Activity 2
 - Activity 3
 - Activity 4
 - Activity 5
- Week 2 - Activity 6
 - Activity 7
 - Activity 8
 - Activity 9
 - Activity 10
 - Activity 11
 - Activity 12
- Week 3 - Activity 13
 - Activity 14
 - Activity 15

I want you to carefully read through the content and use a highlighting tool to share what resonates and what doesn't. You'll see the option to use GREEN to indicate words/phrases that resonate in some way, RED to indicate words/phrases that do not resonate in some way and BLUE to indicate words/phrases for which you are indifferent.

Reason #3: We can have a say in our care.

☒ Words that resonate ☐ Indifferent ☐ 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.

(Segment 3, Disability-No, 4 ...)

4/2/2019 3:28 PM



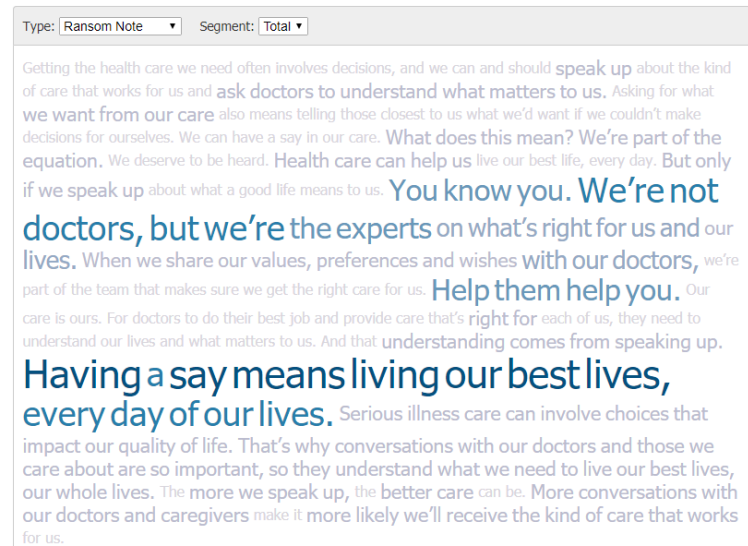
Participants read the content and did a highlighting exercise.

Example of visual output from “We can have a say in our care”

Words that resonate



Words that don't resonate



#1 People appreciate simplicity in the language

- Instances when the **language felt more conversational**, such as “you know you,” “conversations about things we can’t control can actually help to give us a sense of control,” and “if we don’t say it, they won’t know,” resonated most with participants.
- Participants were **put off by language that felt more marketing-like**: “ease the burden,” “have that good talk today,” “we’re part of the equation.”




























#2 Word choices matter

- Some reacted negatively to the word “**right**” – it puts them in a defensive mindset.
- “**Conversations**” can sound daunting, while “**a good talk**” is more approachable.
- “**Honest conversation**” can feel judgmental, while “**open conversation**” does not introduce judgment.



#3 Control and Power messages were preferred by most

	Conversations clarify	We can have a say in our care	Caring means learning about them	There is no need to wonder	Love means speaking up
Worried Action Taker					
Self-Assured Action Taker					
Disengaged Worrier					
Defiant Independent					
Self-Reliant Skeptic					



What resonated?

“Conversations clarify.”

- Information is power
- Another way to speak up
- Guiding principles speak to importance of planning and preparation

“We can have a say in our care.”

- Emphasis on self-advocacy
- Importance of speaking up
- Connection between quality of life and engaging health care team

“Caring means learning what matters to them.”

- Simple reminder
- Bring families together
- Learn something new about a loved one, no matter how hard the conversation can be



Why have ACP conversations?

UMBRELLA MESSAGE

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.

Why should we believe?

REASONS WHY

Conversations clarify.

We can have a say in our care.

Not convinced?

PROOF POINTS

➤ **Information is power.**

➤ **You know you.**

➤ **If we don't say it, they won't know.**

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



Activity #1

- How does the messaging resonate with you?
- How do you feel about the segments and personas? Do you recognize these groupings among your own constituents?
- Which segment do you personally fall into?





Search

Home

Corporate Information

Corp. Comm + Citizenship

Human Resources

Well-Being

How Do I...?

Business Areas

Culture of Well-Being

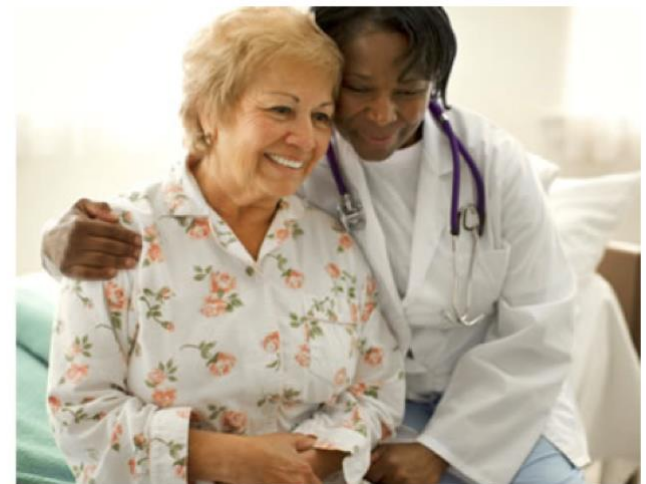
Advance Care Planning

Advance Care Planning

Ensuring your care is aligned with your values, goals and preferences at all ages and stages of life

Making sure we get the care we want, especially when facing a major injury or serious, advancing illness, starts with conversations – with loved ones, doctors, or other important people in your life. The process of reflecting on what's important to us and then documenting those preferences, values, and goals is called advance care planning. Having an advance care plan is important for all of us, because we never know when we might not be able to speak for ourselves.

Having a plan also removes the burden on our loved ones of having to guess what we would want and gives important guidance to our doctors based on our wishes. As part of our Healthy Blue program, we are pleased to offer the following trainings and resources for associates who want to start or refresh their advance care plan.

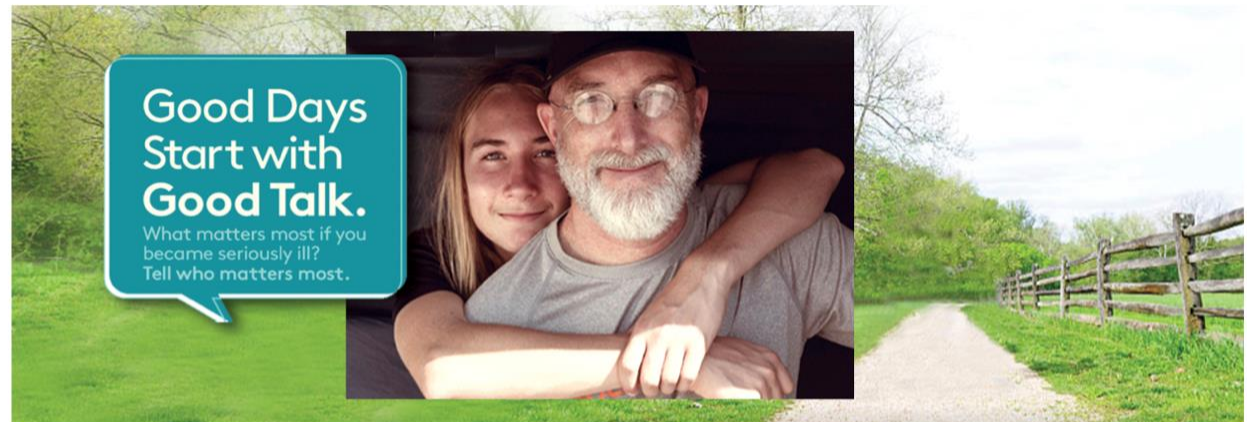


Meet the Healthy Blue Advance Care Planning Coaches!

We are excited to introduce our first class of Healthy Blue Advance Care Planning Coaches. Our coaches, who went through a 3-hour training with experts from The Conversation Project and Honoring Choices Massachusetts, are now our in-house resources on all things Advance Care Planning. Throughout the year, coaches will be offering

BEFORE

AFTER



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.

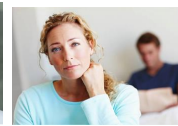
We can't plan for everything. But we can help manage life's unknowns by talking openly about what matters to us and what we'd want most if we became seriously ill. Conversations about things we can't control can actually help to give us a sense of control.



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.

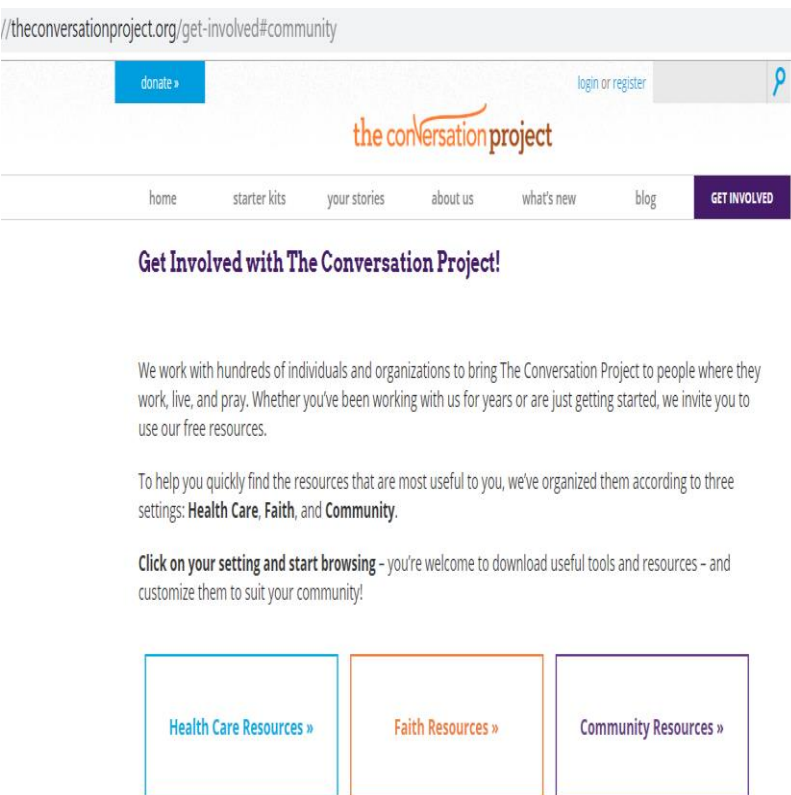
#2

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.



TCP Get Involved Page:

Community Engagement Resources



- Get started
 - Community organizing guide and resources (identifying partners and sample work plans)
 - ***Case studies***
 - Template for tracking progress, suggested metrics
- Promote your message
 - Sample promotional materials (PSAs, ads)
 - Social media toolkit
- Host an event (planning, publicizing, facilitating, evaluating)
 - Invitations and agendas for events
 - Press release and flyer templates
 - Slide deck, videos, materials to bring
 - Evaluation forms
- Bonus content
 - <https://theconversationproject.org/get-involved>

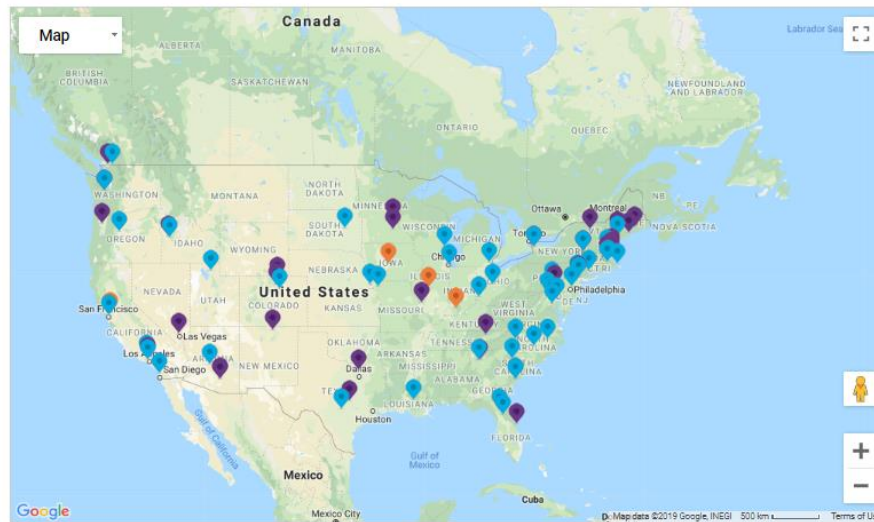
TCP Conversation Champions Map

● 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>

Write a Letter to Your Loved One

- Write a letter to your loved one(s) about what matters most to you and email your letter to conversationproject@ihi.org

“And for God’s sake, have mercy and trim my chin and upper lip hairs.”

“No heroics. Listen to your mother.”



Monthly Community Calls

Date and Time	Topic
Wednesday, August 21 st , 3:00 – 4:00 pm ET	Special Interest: Planning for Conversation Sabbath
Wednesday, September 18 th , 3:00 – 4:30 pm ET	Virtual Speaker Training
Wednesday, October 16 th , 3:00 – 4:00 pm ET	Community 201: TBD

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?

Stay Connected!

- Twitter: @convoproject
- Facebook: The Conversation Project
- Instagram: convoproject
- Newsletter:
 - General Newsletter
 - Community Engagement Newsletter



Thanks and appreciation



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