



**MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE**

#MASeriousCareSummit

We are grateful for the generous support of our sponsors.



MASSACHUSETTS
MEDICAL SOCIETY



Hebrew
SeniorLife



CAPE COD HEALTHCARE



Methodological Overview

- 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%

They've taken action because they're worried.



Self-Assured Action Takers
24%

They've taken action so they're not worried (if they ever were).



Disengaged Worriers
34%

Despite many worries, they don't want to deal with ACP, and wouldn't know where to start if they did.



Defiant Independents
18%

They confidently think they don't need ACP – their loved ones will know what they want.



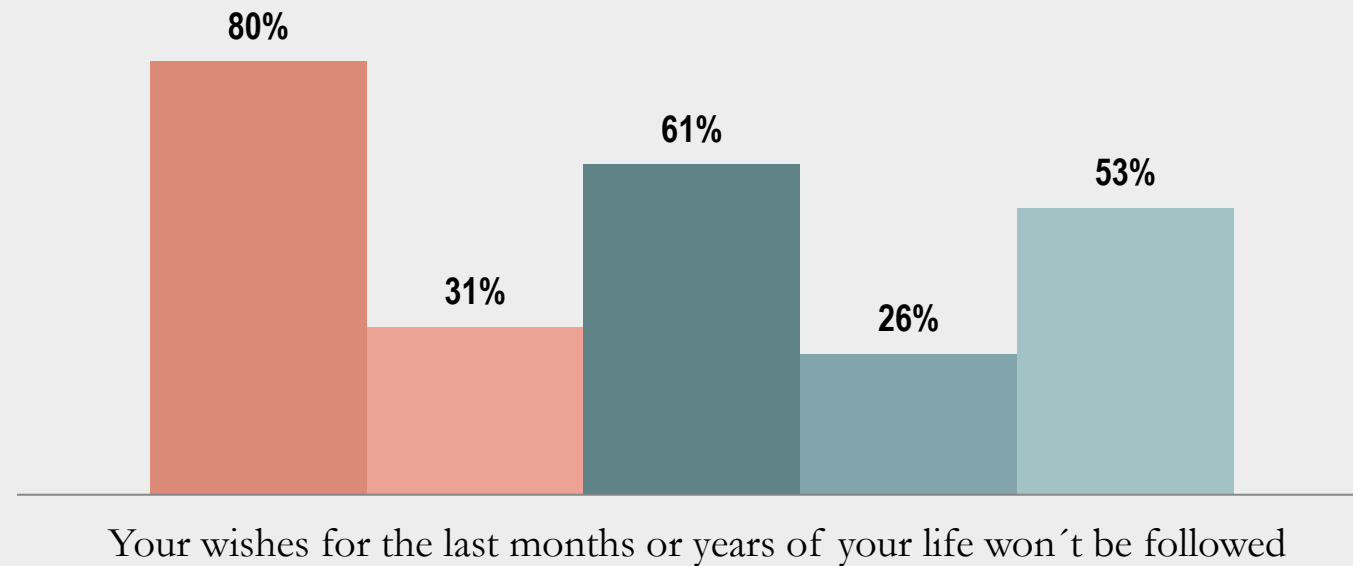
Self-Reliant Skeptics
14%

They hope their loved ones knowing their wishes will be enough, but may have their doubts.



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

Worries Regarding Serious Illness Care – % Very/Somewhat Worried



■ Worried Action-Takers ■ Self-Assured Action Takers ■ Disengaged Worriers ■ Defiant Independents ■ Self-Reliant Skeptics

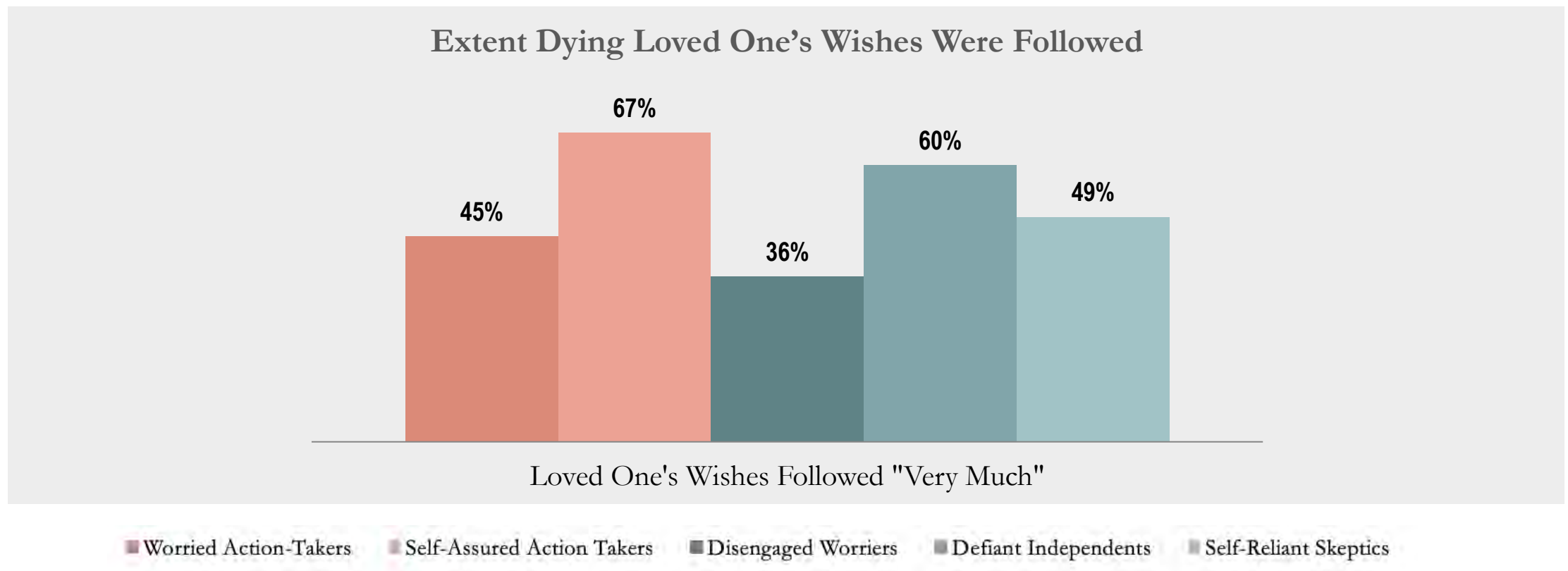


n = 258-615-850-446-345

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

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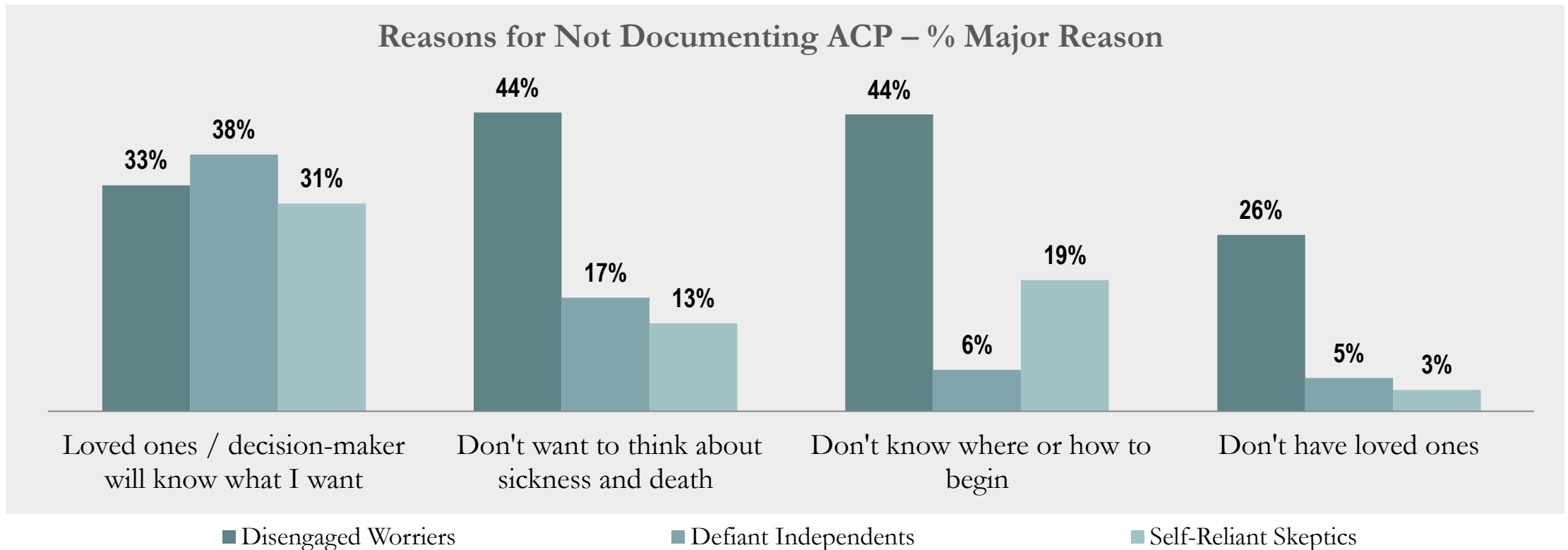
Self-Assured Action Takers and Defiant Independents are considerably more likely to say their dying loved one's wishes were followed very well, while Disengaged Worriers reflect more negatively on this experience.



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?

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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.



Messaging

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

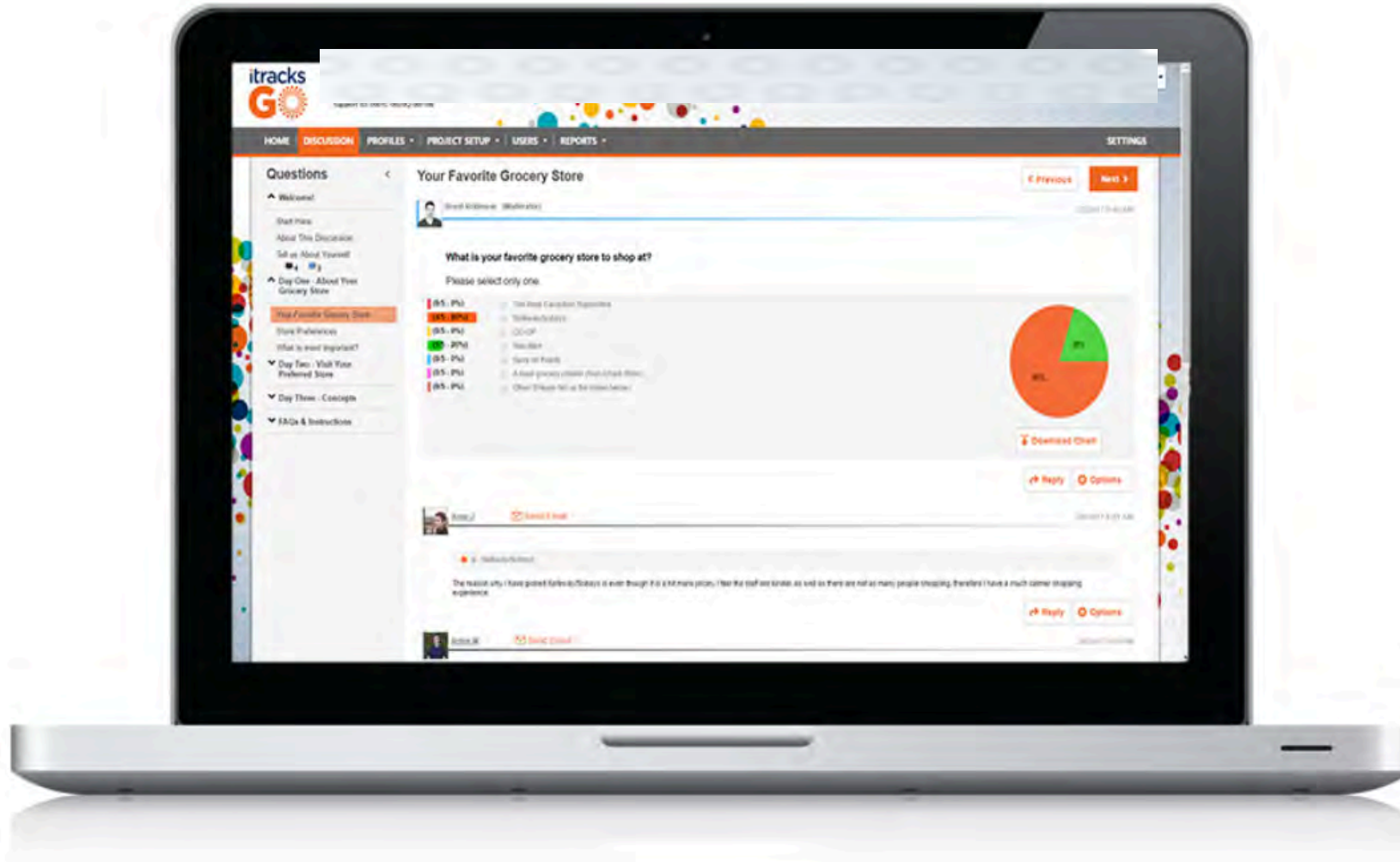
Proof Points

- 1) reinforce reasons
- 2) reinforce reasons

Online Communities

March 18 – April 12

Two Online Communities – 150 Participants



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”

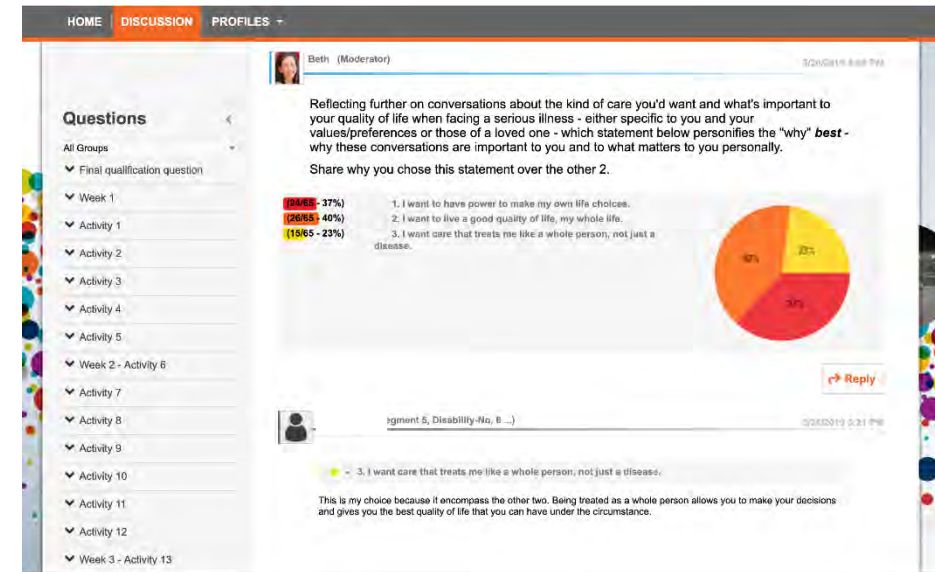
[self-advocacy]

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



People see value in “Live a good quality of life, your whole life.”

- While “**quality of life**” resonated most, having “**control**” and “**power**” over decision-making also struck a chord.
- Participants viewed **all three** as being **critically important** and **interrelated**.

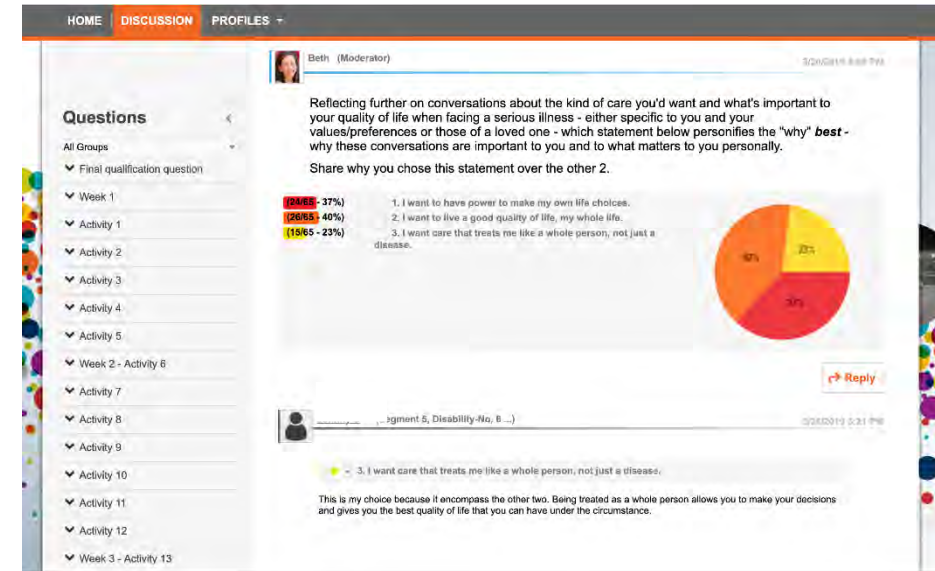


Note: Image is of one of the online communities testing exercises. It is shown here for illustrative purposes, it reflects partial data only.



A noticeable contingent don't have family or are estranged from their family.

- The “**power**” shared value rang true for most.
- Some found it hard to engage in dialogue about “**loved ones**” – associate language with family.



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.



Umbrella Campaign Messaging and Creative

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.



Strategic Decisions

- 1) **Re-state** “quality of life” into concepts that create a mental image.
- 2) **Normalize** what it means to have the “conversation.”
- 3) **Be inclusive** and sensitive to consumers without family/loved ones.
- 4) **Recognize** people want to have a sense of “control” and “power.”
- 5) **Tie message** to current life circumstances.
- 6) **Be aspirational** to draw consumers in.



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.

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

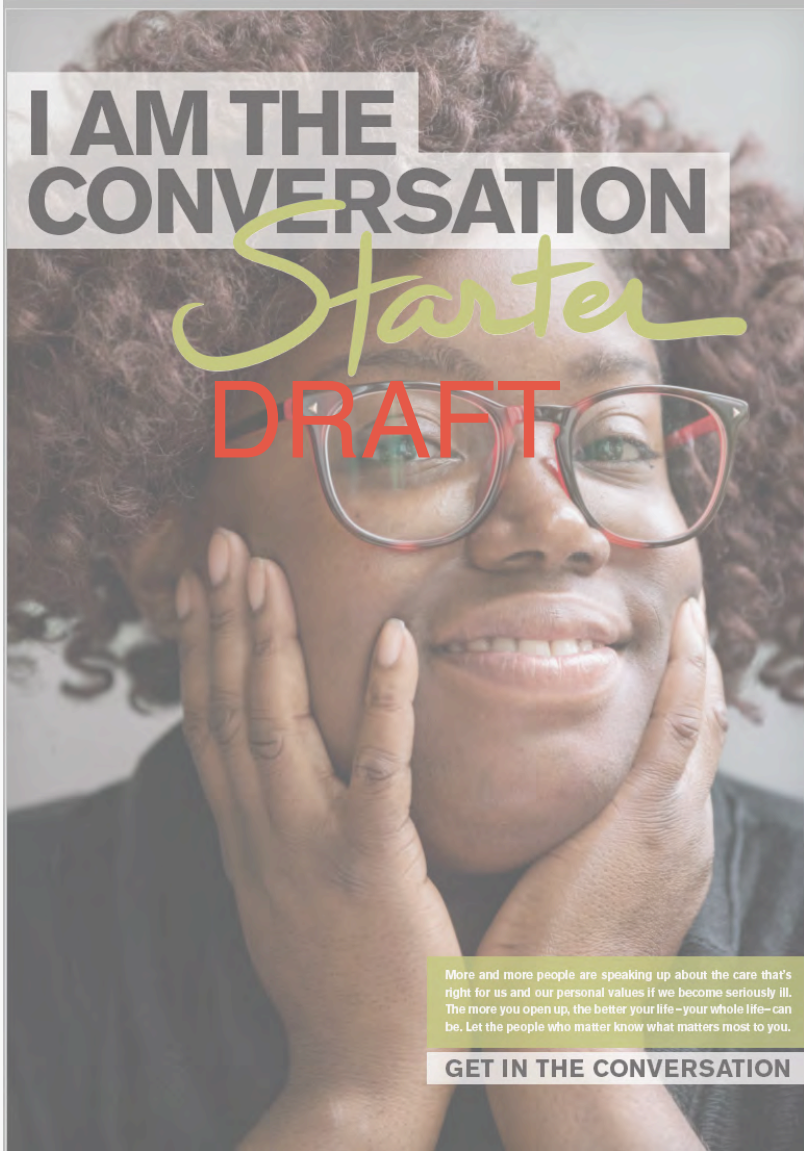
family time

=

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.

What does your good day look like? If you have a good day, it's not just about what happens, it's about how you feel. From the way you wake up to the way you feel at the end of the day, it's all about the balance between what happens and how you feel.

DRAFT

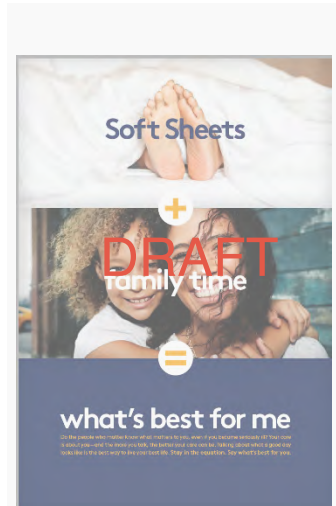
Live your best life.
Start with a good talk.

“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

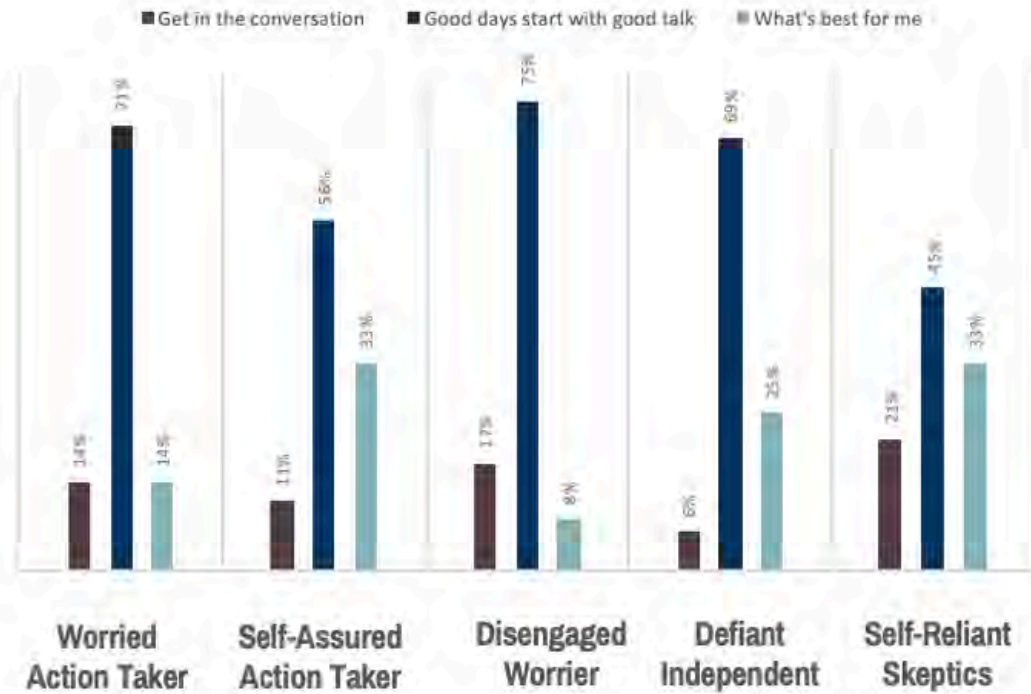
“Get in the conversation” ranked in third place



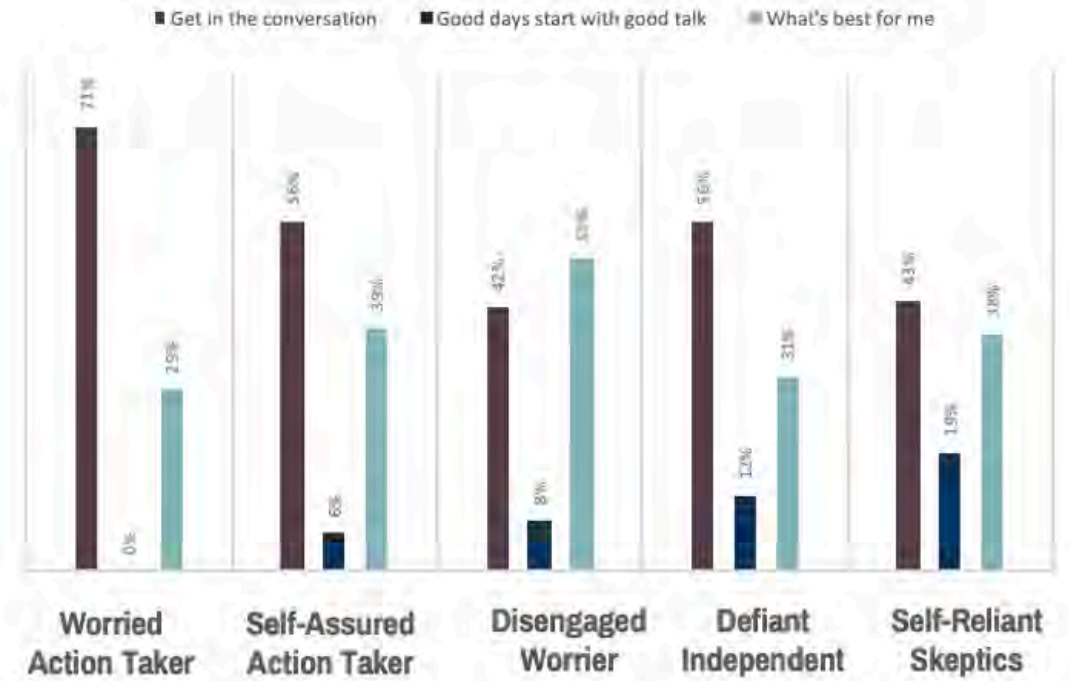
- Absence of other people in the photo
- Health care decisions shouldn't be made solo



MOST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



LEAST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



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.

Reply 3:00 PM

Reply 3:15 PM

Reply

(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

Type: Ransom Note Segment: Total

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.

Legend:  **Least Selected** **Most Selected**

Words that don't resonate

Type: Ransom Note Segment: Total

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.

Legend:  **Least Selected** **Most Selected**



#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.
- For some, “**Conversations**” (associated with serious illness) 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.**

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

➤ **You know you.**

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



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

Messaging Research Workshop

 #MASeriousCareSummit

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.



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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.



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



Messaging Summary: 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.**
- **If we don't say it, they won't know.**

- **You know you.**
- **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?



Activity #2

- What are the types of people you currently communicate with (patients, employees, community leaders, etc.)?
- How do you currently communicate with them?
- How might the messaging be useful in your communications?
- What do you see as the biggest challenges in augmenting your communications with the messaging?



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

#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					

*Why should we 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?*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.

Not convinced?

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.

SUPPORTING MESSAGE/REASON

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.

PROOF POINTS

#1

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.

#2

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.



SUPPORTING MESSAGE/REASON

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 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

#1

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.

#2

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.



SUPPORTING MESSAGE/REASON

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.



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.



SUPPORTING MESSAGE/REASON

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.

PROOF POINTS

#1

Talking reveals truth. Everyone knows that serious illness is a possibility. Acknowledging it with conversations about the kind of care that's right for us provides a sense of confidence and comfort. The more thinking and talking we do now, the better prepared we'll be down the road—whatever the future may hold.

#2

More talking leads to more answers. Open, regular conversations as our needs evolve mean fewer questions, more answers and a clearer path forward if the people who matter to us need to make decisions on our behalf.



Consumers were asked to indicate what steps they would imagine taking, and to choose from the following options.

- **Pick your person.** Talk to a friend, a family member or another trusted person about becoming your decision-maker in case you became seriously ill.
- **Think about it.** The conversation starts with thoughts, not words. Things to think about:
 - What do you need for a good day? Watching your favorite sport? Reading a great book? Enjoying your favorite food? Time with family and/or friends?
 - How could a serious illness interfere with your good day?
 - Who in your life would you want to make decisions for you if you weren't able to express them yourself?
- **Make it official.** Have your doctor add your proxy form, and any other documents describing your care preferences and values, to your medical record.
- **Talk about it.** Start a good talk with the person you've named. What do you need them to know about you—what you'd want if you became seriously ill—in order to speak up for you?
- **Write it down.** Use one of the many online tools and resources that provide guidance on talking with loved ones, health professionals and others; put pen to paper and spell out your thoughts on quality of life, values and care preferences.
- **Talk with your doctor.** Talk with your doctor about your quality of life, values and care preferences.
- **Document your proxy.** After you've picked your health care proxy, complete your state-specific proxy form (often found online) and (if necessary) have someone officially witness you signing your form.
- **Talk again.** A good talk takes time. The more conversations we have, the better prepared we'll be to speak up for ourselves or each other if we need to.
- **Talk with a loved one or friend about their care.** Is there someone in your life for whom you can imagine needing to help make decisions? Talk with them about their quality of life values and preferences, and the care that's right for them.



Bringing the segments to life through “consumer personas”

- Based on our research findings and the understanding we developed of each of the five audience segments, we created consumer personas—composite sketches of our audience segments. These are intended to be illustrative.
- Consumer personas bring to life the key characteristics of each segment—behaviors, attitudes, beliefs and motivations—through a representative archetype consumer.
- Quotes associated with each persona are from participants in the Online Communities.
- Each persona includes
 - A *Bio Sketch* synthesizing insights from the quantitative and qualitative research.
 - *Additional Motivating Messages* featuring the language that resonated with that particular segment, in addition to the Umbrella Message and two Supporting Messages (see page 3) that resonated with most consumers.
 - *Next Steps* indicating which next step(s) (see page 14) they imagine taking based on where they are in the ACP process.



Worried Action Taker



DEMOGRAPHIC SKEWS

- Skews younger, toward age 25-44
- More likely to be male
- Higher proportion of Blacks and Hispanics than other segments
- Consider religion very important
- More likely to identify with a disability/impairment

ACP ACTIVITY & EXPERIENCES

- Has documented both wishes for medical care and health care proxy.
- Vast majority have had ACP-related conversations with both loved ones and medical professionals.
- Had recent experience with an ailing or dying loved one, which in many cases did not go according to loved one's wishes.
- Far more likely to have recently cared for an incapacitated loved one than other segments.

Worried Action Taker



VALUES

- Strong desire to live healthy/good quality of life but would consider extending care over quality of life.

HEALTH CARE ATTITUDE

- Very trusting of doctors.
- Favorable opinion of the health care system.
- Actively involved in taking care of his health.

WORRIES

- Wishes not being followed.
- Affording medical care.
- Being a burden.

SOCIAL/EMOTIONAL DYNAMICS

- Death was discussed occasionally with family while growing up.
- Seeks reassurance that everything will be ok.

Meet Oscar, the Worried Action Taker



Bio Sketch

Oscar grew up in a close, traditional family who believe in hard work and faith—they attend mass together every Sunday. A worrier by nature, Oscar has typically harnessed his stress as motivation to achieve, though he’s struggled with severe anxiety from time to time. With his family’s support, he steadily worked his way through college and graduate school, and now works as a business consultant, comfortably supporting his wife, Carla, and son, Orlando.

Recently, Oscar lost his beloved grandfather after supporting him through a serious illness—a pivotal life event that has him reevaluating his health choices. He’s always been up-to-date on preventive care, regularly scheduling physicals and asking the right questions at appointments. But he watched as his grandfather suffered at the end of his life, so he recently asked his doctor to help him plan for a time when he might become ill in the future. And he named Carla as his proxy. That way, he and his family won’t have to worry about having the same experience that his grandfather had down the road.

“I want to feel good about myself and have people around me that care about me and love me as a whole.”

Age	39
Status	Married
Children	One young child
Education	Graduate degree
Parents	Living
Religion	Very Important

Meet Oscar, the Worried Action Taker



Next Steps

Make it official. Have doctor add proxy and other documentation to his medical record.

Talk with doctor. Talk about quality of life, values and preferences.

Additional Motivating Message

MOTIVATION

In addition to the umbrella message and two supporting messages that resonated with most consumers featured on page 3, the “activate the conversation in others” message also resonated with Oscar.

Given that Oscar has documented his wishes for medical care and health care proxy and has had ACP-related conversations, he is also motivated to engage loved ones and/or friends in ACP conversations.

MESSAGE

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.

Self-Assured Action Taker



DEMOGRAPHIC SKEWS

- Skews significantly older, nearly half are 65+
- More likely to be white
- Religion is important

ACP ACTIVITY & EXPERIENCES

- Has documented both wishes for medical care and health care proxy.
- Vast majority have had ACP-related conversations with both loved ones/friends, less likely with medical professionals.
- Many with a recent experience say their loved one's wishes were followed very well (they had conversations and/or documented wishes beforehand).

Self-Assured Action Taker



VALUES

- Being the decision maker when determining how best to live a good quality of life.

HEALTH CARE ATTITUDE

- Takes charge of her health.
- Would consider it helpful for a doctor to initiate a conversation about ACP.

WORRIES

- Not particularly worried about affording medical care or wishes not being followed.

SOCIAL/EMOTIONAL DYNAMICS

- Usually the first one to initiate conversations with family.
- Doesn't let stress and worry get in the way.

Meet Mary, the Self-Assured Action Taker



Bio Sketch

Mary has always been a high achiever: top of her class through graduate school, a strong 45-year marriage and three well-adjusted children. She loves to cross off a to-do list, and her health is no exception. She considers herself a bit of a health nut, taking recommended supplements and keeping up with lifestyle research.

Mary's an optimist who always believes things will work out for the best—an attitude that helped see her through a breast cancer scare two years ago. She and her husband, David, completed ACP as part of their estate plan a while back and she named David as her proxy. Having checked that box, she hasn't seen a need to revisit it by having another conversation.

“I’m very independent and I want a good life where I can be in control. Quality, not quantity, is what matters in life.”

Age	70
Status	Married
Children	Three adult children
Education	Graduate degree
Parents	Deceased
Religion	Important

Meet Mary, the Self-Assured Action Taker



Next Steps

Make it official. Have doctor add proxy and other documentation to her medical record.

Additional Motivating Message

MOTIVATION

In addition to the umbrella message and two supporting messages that resonated with most consumers featured on page 3, the “activate the conversation in others” message also resonated with Mary.

Given that Mary has documented her wishes for medical care and health care proxy and has had ACP-related conversations, she is also motivated to engage loved ones and/or friends in ACP conversations.

MESSAGE

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.

Disengaged Worrier



DEMOGRAPHIC SKEWS

- Younger, skewing more toward the 18-34 range
- More likely to be single
- Less likely to be white than other segments
- Religion is not very important

ACP ACTIVITY & EXPERIENCES

- Most have not documented either wishes for medical care or health care proxy.
- About half have had ACP-related conversations with loved ones/friends; about one-quarter with medical professionals.
- Many say their loved one's wishes were not followed very well.
- They have many reasons for not taking ACP action: don't want to think about it, too many things to worry about, don't know where to begin.

Disengaged Worrier



VALUES

- Having control and being independent.

WORRIES

- Very worried about affording medical care.

HEALTH CARE ATTITUDE

- Not actively involved in taking care of her health.
- Not confident navigating the health care system.

SOCIAL/EMOTIONAL DYNAMICS

- Death was rarely discussed while growing up.

Meet Alex, the Disengaged Worrier



Bio Sketch

Alex has a lot on her plate. Between paying the rent, dating and socializing with friends, she mostly lives her life fully in the present. After all, she's still young—plenty of time down the road to think about something big and scary like serious illness. In fact, Alex's outward confidence belies her natural tendency to worry—and at times, her daily worries have overwhelmed her and triggered periods of depression. But living with a healthy dose of denial has worked so far (and why tamper with a good thing?).

Alex has mild asthma but isn't great about remembering her maintenance medication. She only goes to the doctor when she's sick, but doesn't see preventive care as a top priority since she's only 27 and basically healthy. Alex had a falling out with her parents last year, so the idea of talking with them about serious illness is not something she's comfortable with. She has a few close friends, but ACP conversations aren't on their radar—and Alex believes she's the best person to make her own choices, anyway. So, for now she's putting off ACP, like many serious life decisions. Still, she's not opposed to having a direct conversation with her doctor and friends in the future, when serious illness is more of a concern.

“I'm not really a glass half-full person, but I'm trying to live my life to the fullest.”

Age	27
Status	Single
Children	None
Education	Associate degree
Parents	Living
Religion	Not Important

Meet Alex, the Disengaged Worrier



Next Steps

Think about it. What would she need for a good day, and how a serious illness could interfere with her good day.

Talk about it. Who in her life would she want to make decisions for her if she weren't able to do so herself.

Additional Motivating Message

MOTIVATION

Alex is used to being independent and in control, and does not like asking for help and burdening other people unless it comes to a certain point. And while she's not very confident navigating the health care system, she thinks it's crucial to have a voice in her own care.

Alex recognizes she'll have to have ACP conversations eventually, and could be prompted to think about it and talk about it.

MESSAGE

Unlike other segments who had varying degrees of receptivity to each message, Alex was only motivated by the control and power supporting messages: ***Conversations clarify*** and ***We can have a say in our care.***

Defiant Independent



DEMOGRAPHIC SKEWS

- Skews moderately older, 45-65
- Religion is very important
- Less likely to identify with a disability/impairment

ACP ACTIVITY & EXPERIENCES

- Most have not documented either medical wishes or health care proxy.
- About half have had ACP-related conversations with loved ones/friends, and about one-quarter with medical professionals.
- Less experience with dying/ailing loved ones.

Defiant Independent



VALUES

- Independence and driving health care decision making.

WORRIES

- Not worried about affording medical care.
- Unconcerned about wishes not being followed.

HEALTH CARE ATTITUDE

- Takes charge of his health.
- Confident navigating the health care system.

SOCIAL/EMOTIONAL DYNAMICS

- Death was never discussed with family while growing up.

Meet Craig, the Defiant Independent



Bio Sketch

Craig's got this. From a young age, he was taught to steer his own ship, and he likes to be in control at all times. He deals with issues as they arise, and doesn't let future worries get in the way of a good day today. He and his wife, Erin, are all in on this next phase of life now that their son, George, is on his own. They've got big plans to travel, and they're working closely with a financial advisor to make sure all their affairs are in order.

When it comes to ACP, Craig has had a few brief conversations with Erin so she'd know what to do if he became ill. After all, he knows what's best for himself, and he still wants to be in charge—even if he becomes really sick. He trusts Erin completely and thinks she can make the right calls for him even though he has not named her as his proxy. So, he's checked ACP off his list for now.

“It's important to me to be as independent as possible for as long as possible. I just want to make the most of every day.”

Age	56
Status	Married
Children	One young adult
Education	College degree
Parents	Father deceased
Religion	Important

Meet Craig, the Defiant Independent



Next Steps

Think about it. What would he need for a good day, and how a serious illness could interfere with his good day.

Talk about it. What would the person he picked need to know in order to speak up for him.

Write it down. Use one of the many online tools and resources to document proxy and/or wishes.

Additional Motivating Message

MOTIVATION

In addition to the umbrella message and two supporting messages that resonated with most consumers featured on page 3, the “love means speaking up” message also resonated with Craig.

Craig wants to be driving all decisions related to his health care, but he has yet to document his health care proxy and name his wife Erin as his agent. He thinks she will know what he wants. Craig could be prompted to take concrete ACP next steps.

MESSAGE

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.

Self-Reliant Skeptic



DEMOGRAPHIC SKEWS

- Tends toward 45-54 age range
- More likely to be female
- Religion is not very important
- More likely to identify with depression/anxiety

ACP ACTIVITY & EXPERIENCES

- Most have not documented either wishes for medical care or health care proxy.
- Over half have had ACP-related conversations with loved ones/friends; and about one-fifth with medical professionals.

Self-Reliant Skeptic



VALUES

- Strong desire to be in control.

WORRIES

- Very worried about being a burden.
- Fairly worried about affording medical care.

HEALTH CARE ATTITUDE

- Skeptical of doctors.
- Negative perception of the health care system.

SOCIAL/EMOTIONAL DYNAMICS

- Death was rarely discussed with family while growing up.

Meet Joanne, the Self-Reliant Skeptic



Bio Sketch

Joanne’s been thinking about her health more and more since she turned 40. Her kids are in high school, and she wants to make sure she can stay healthy as the girls head off to college and she starts a new phase of life. But she felt rushed and dismissed the last time she went to her primary care doctor for a physical, so she’s been putting it off this year. That last encounter confirmed her suspicions that her voice probably wouldn’t be heard if she became seriously ill and had to make tough decisions about her care.

That sense of distrust goes for her family, too. Her parents passed away a few years back, and she doesn’t get along with her sister at all. She and her husband, Mark, have had their ups and downs as well, so she’s not even sure she could trust him to make the right decisions for her in the case of serious illness. One time after they watched a movie about a dying spouse, she told Mark she wants to make her own decisions for as long as possible. Since she’s the only one who really knows what’s best for her, that’s the extent of ACP she’s comfortable with—at least for now.

“I would feel very stressed and upset if I didn’t have power to make my own choices. I want to be in control of my own life.”

Age	45
Status	Married
Children	Two teenagers
Education	High School
Parents	Living
Religion	Not very important

Meet Joanne, the Self-Reliant Skeptic



Next Steps

Pick a person. Talk with a family member or trusted person about becoming her decision-maker.

Think about it. What would she need for a good day, and how a serious illness could interfere with her good day.

Talk about it. What would the person she picked need to know in order to speak up for her.

Additional Motivating Message

MOTIVATION

In addition to the umbrella message and two supporting messages that resonated with most consumers featured on page 3, the “love means speaking up” message also resonated with Joanne.

Joanne has spent time thinking about quality of life values and preferences and what she’d want if she were to become seriously ill and unable to make decisions for herself. She is motivated to pick a person.

MESSAGE

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.