



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

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

November 2019

We are grateful for the generous support of our sponsors.



ADVANCING CARE.
ENHANCING LIVES.



MASSACHUSETTS
MEDICAL SOCIETY



Hebrew
SeniorLife



CAPE COD HEALTHCARE



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)

Cluster analysis

Consumer Segments

- **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

Non-demographic 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.



Five Consumer Segments



Worried Action Takers
10%



Self-Assured Action Takers
24%



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 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.



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 low-income.

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%

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.



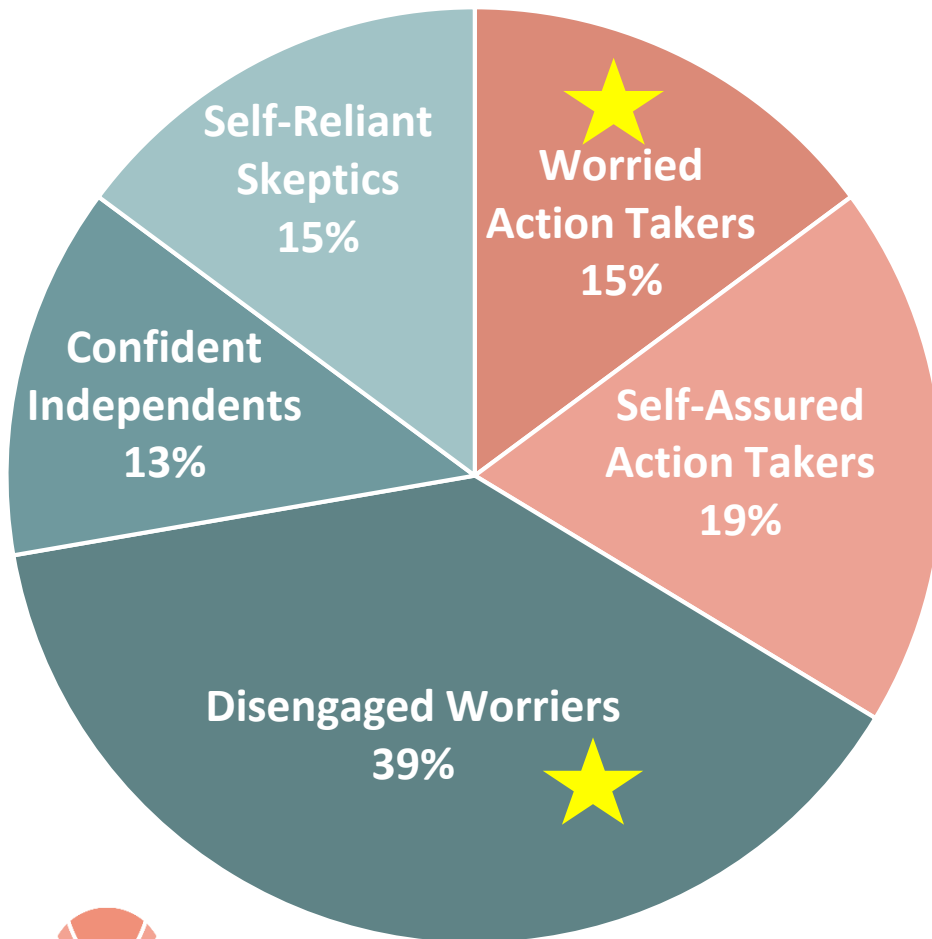
Self-Reliant Skeptics
14%

Middle-aged, lower income and education.

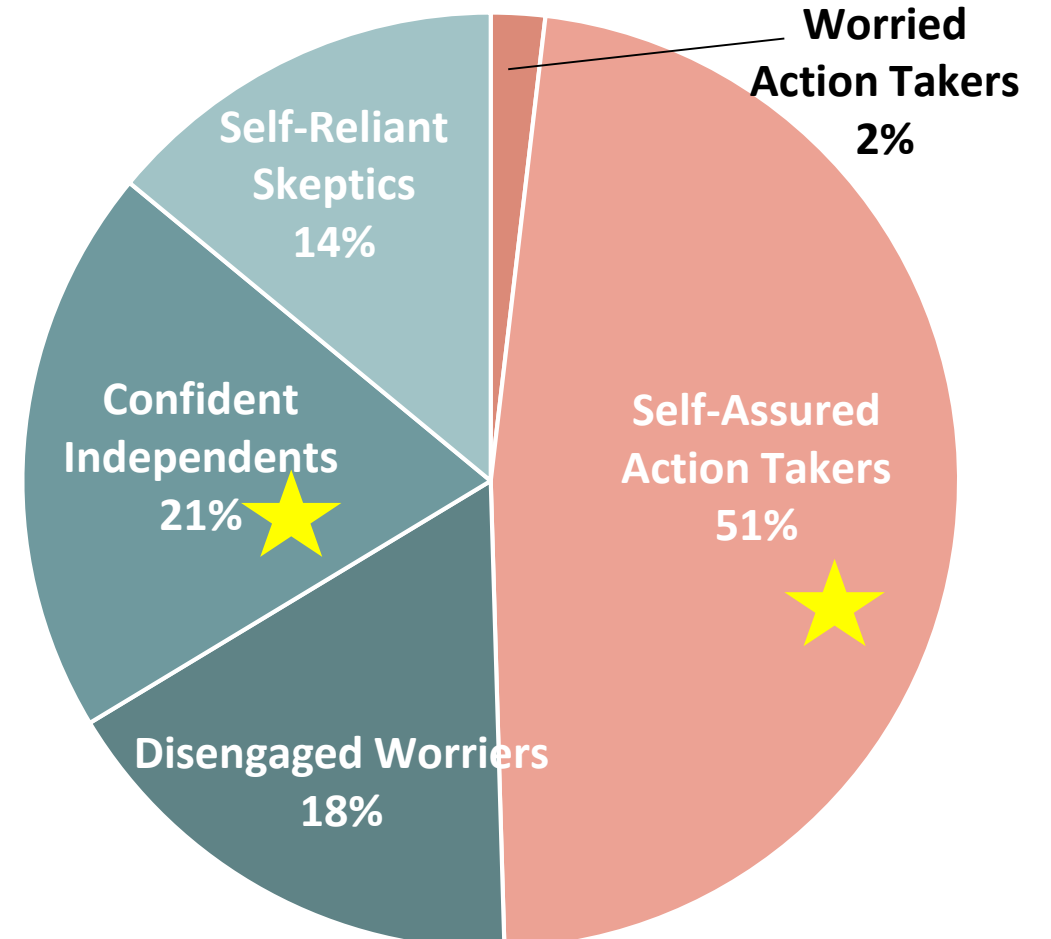
Lowest trust of doctors and regard for the health care system. Poorer health care self-management and navigation skills.

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

Distribution of **African Americans** respondents by segment (11% of total survey population)



Distribution of **retired** respondents by segment (20% of total survey population)



 Overrepresented

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

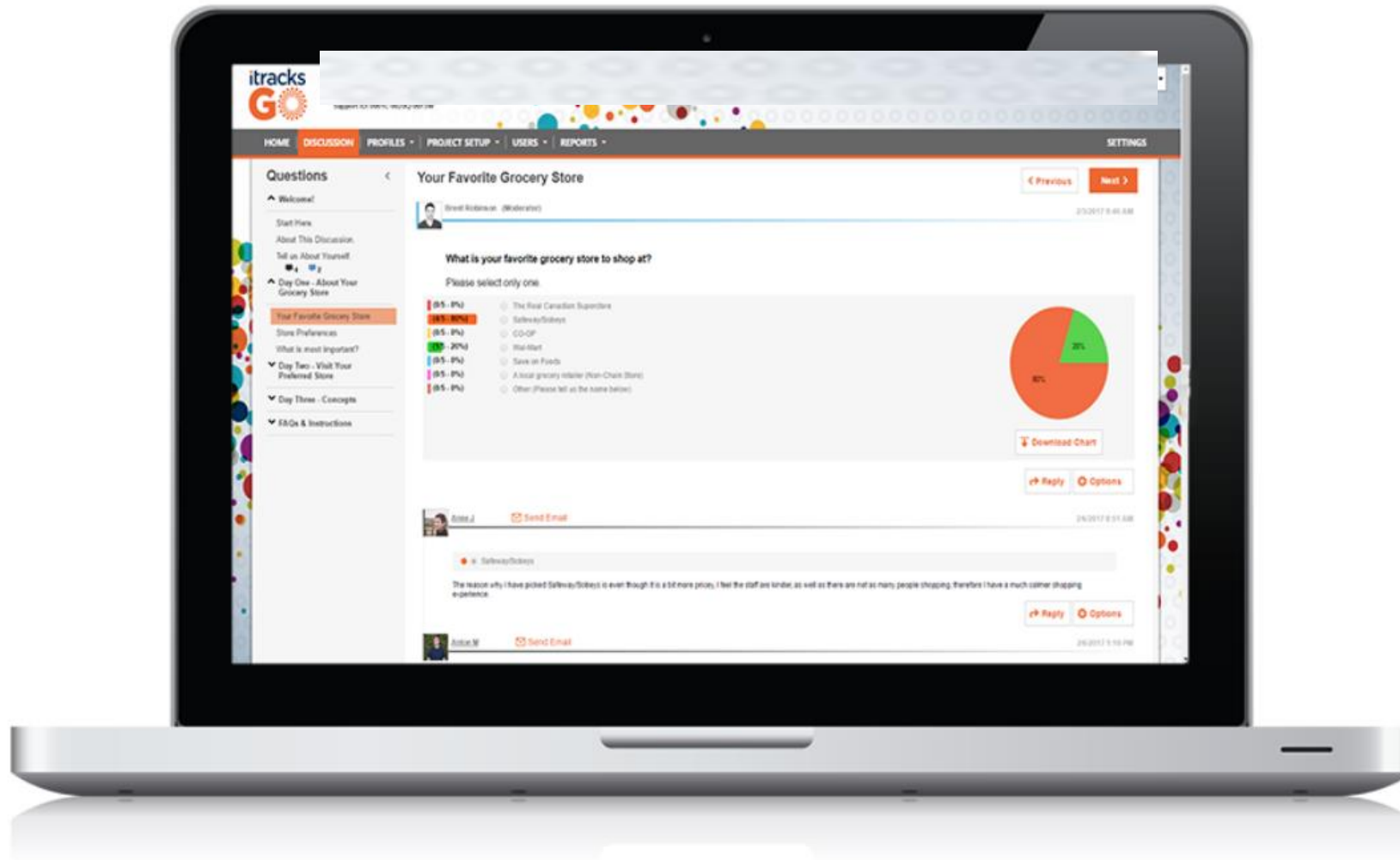
Proof Points

- 1) reinforce reasons
- 2) reinforce reasons

Proof Points

- 1) reinforce reasons
- 2) reinforce reasons

Two Online Communities – 150 Participants



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”

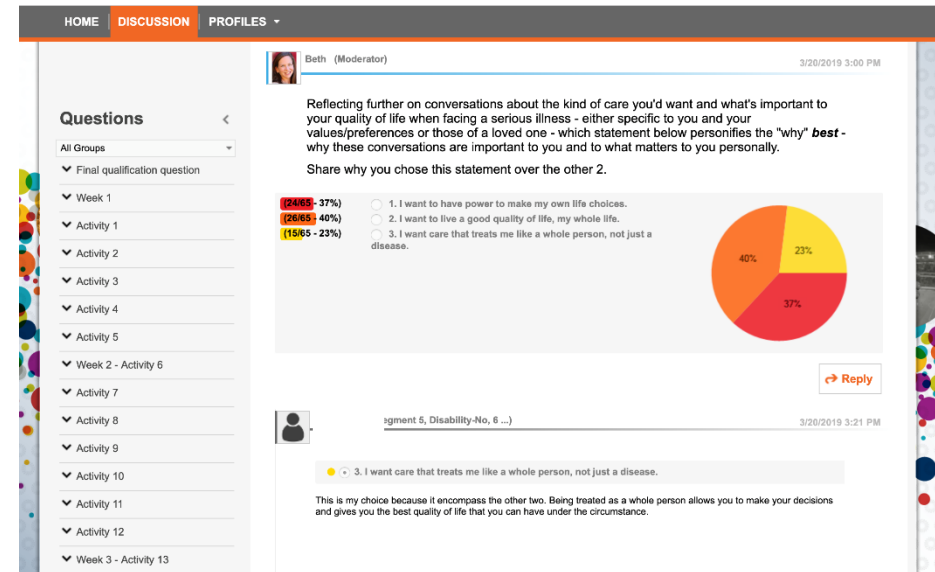
[self-advocacy]

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



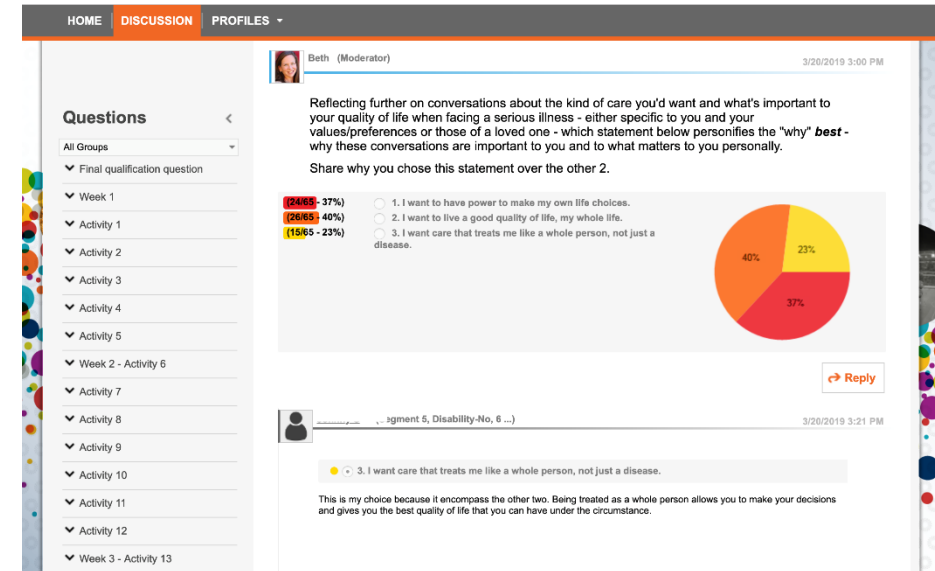
People see value in “Live a good quality of life, your whole life.”

- 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**.



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 – 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)



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.



Umbrella Campaign Messaging and Creative

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.

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.

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

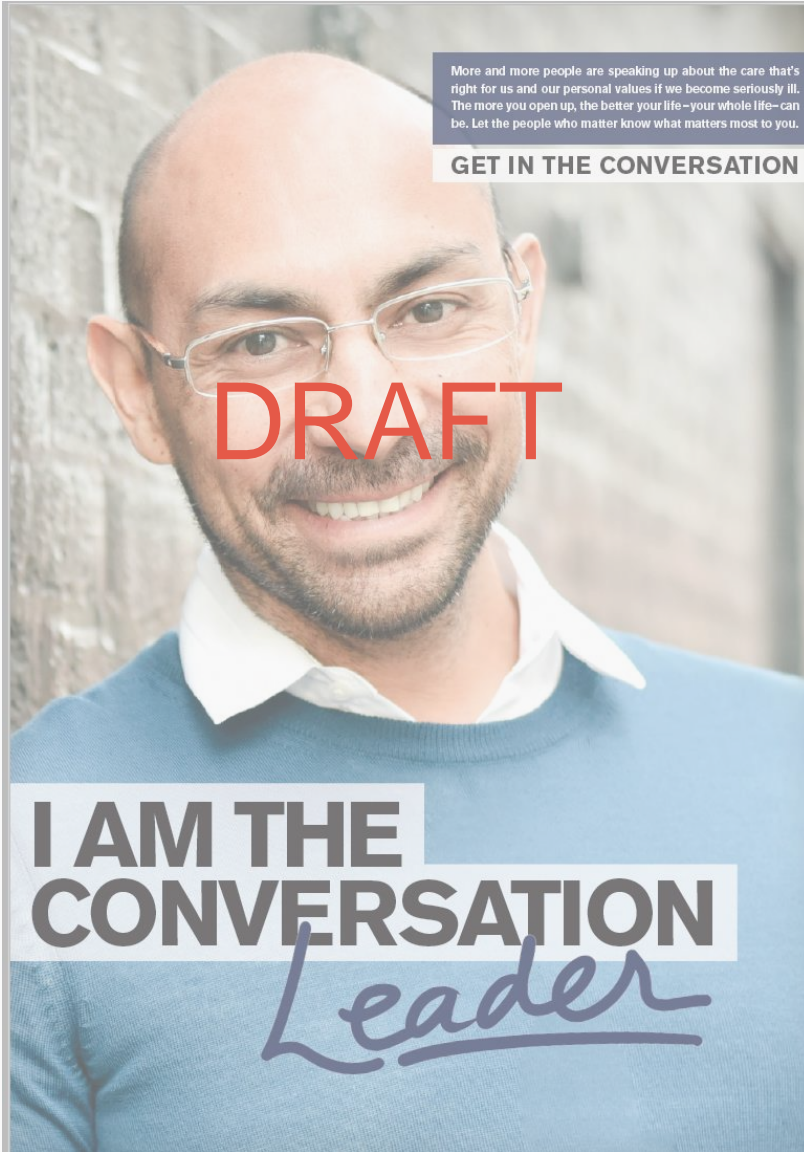
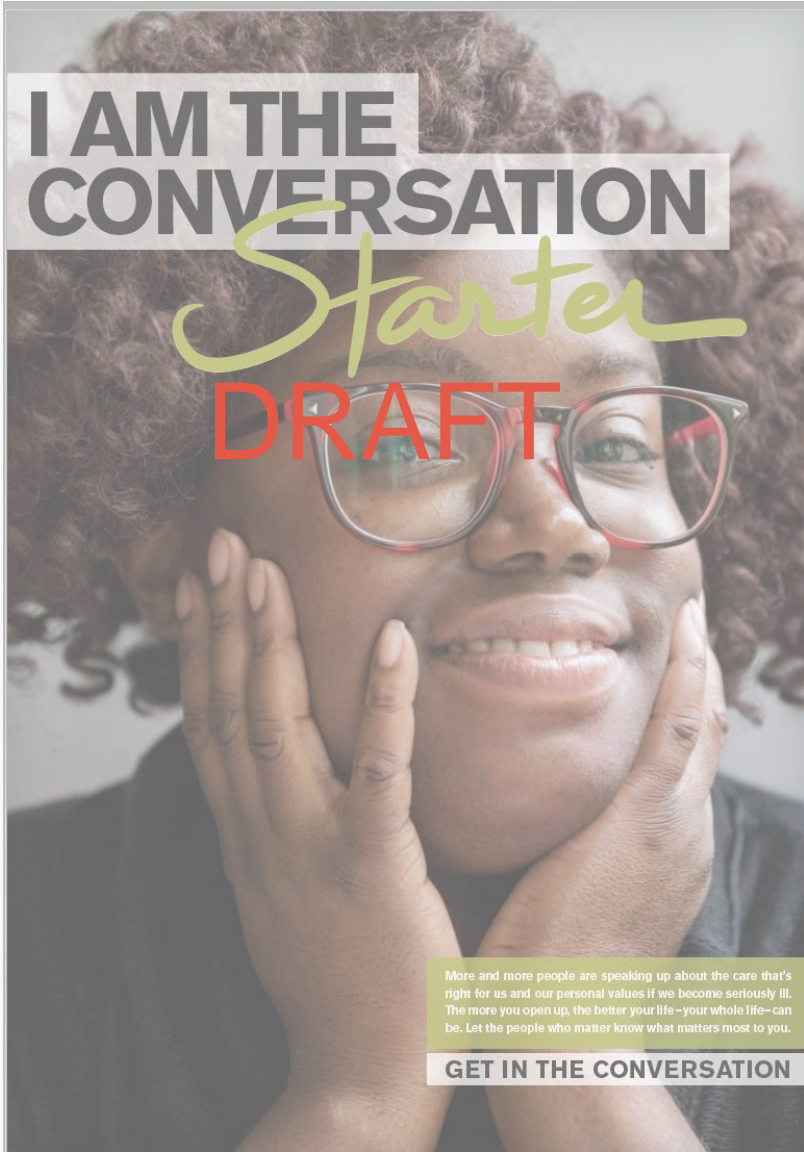
family time

=

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 haven't already, it will be easier when you meet with your care team. From this list of questions, pick the one that matters most to you. Then, share your answer with your care team. It's a good start to a good day.

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

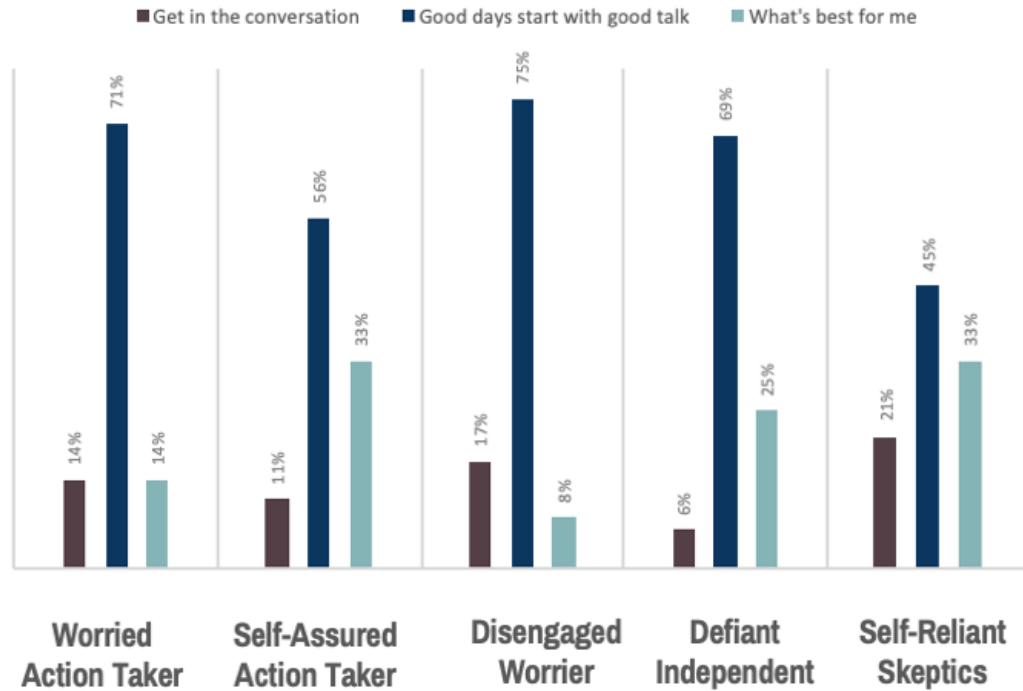
“Get in the conversation” ranked in third place



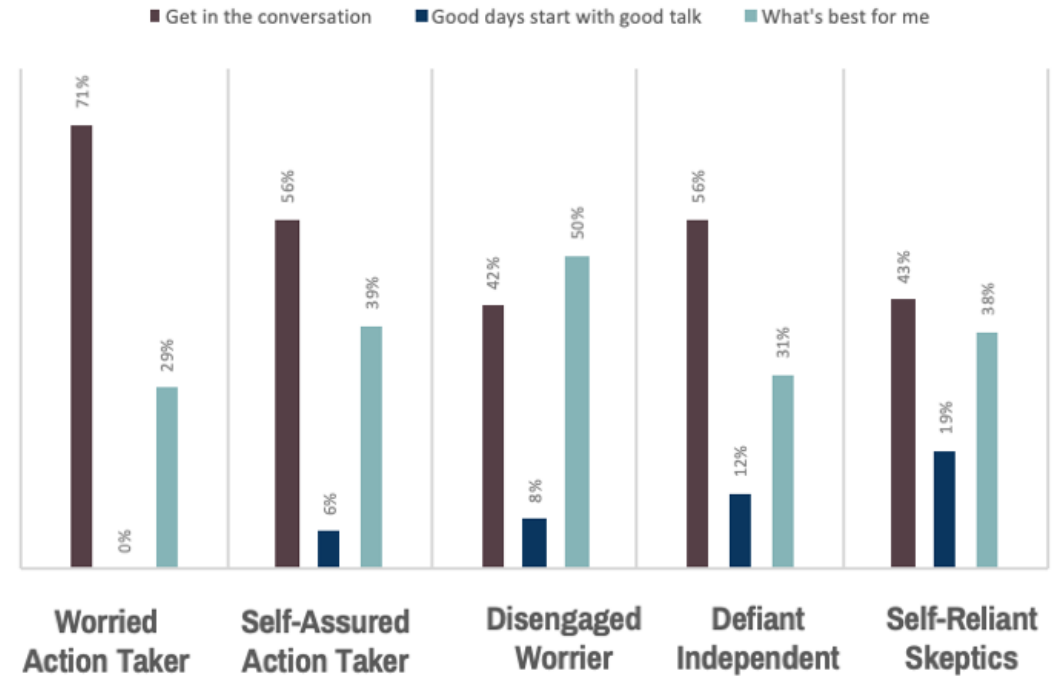
- Absence of other people in the photo
- Health care decisions shouldn't be made solo



MOST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



LEAST APPEALING UMBRELLA CAMPAIGN BY SEGMENT



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.

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

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.



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.



Control and Self-Advocacy “reasons” were preferred by most

	To gain control <i>Conversations clarify</i>	To demand shared decision-making <i>We can have a say in our care</i>	To help advocate for others <i>Caring means learning about them</i>	To get peace of mind <i>There is no need to wonder</i>	To give a gift to loved ones <i>Love means speaking up</i>
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.”

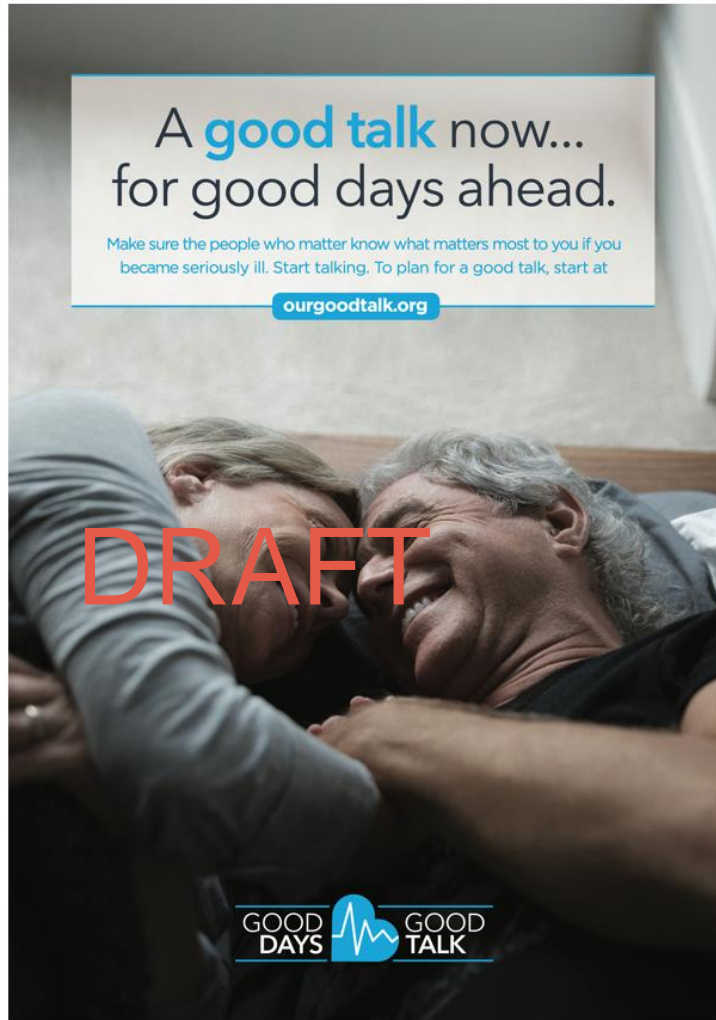
- Emphasis on expectation/demand for shared decision making by the patient as part of clinical process
- Less traditional approach
- **Not exclusive to serious illness** – relevant for active treatment of any condition/stage of illness or health status



Updated campaign testing

Additional campaign testing with 120 participants in August 2019


Campaign A - Direct



A **good talk** now...
for good days ahead.

Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org

DRAFT

GOOD DAYS  GOOD TALK

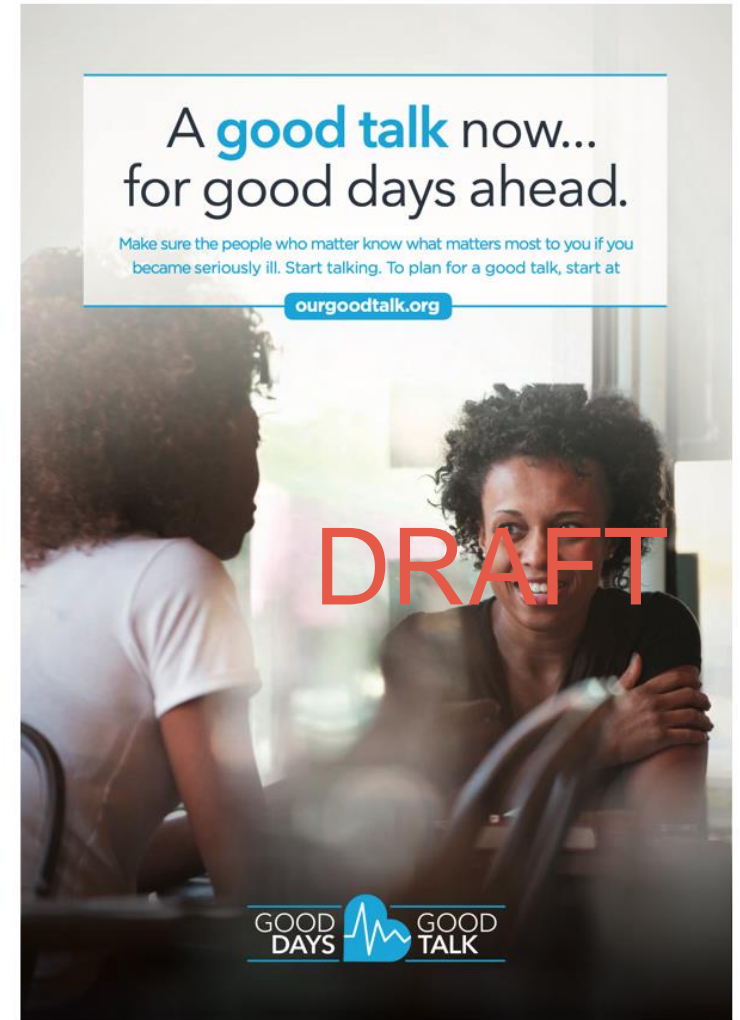


A **good talk** now...
for good days ahead.

Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org

DRAFT


GOOD DAYS  GOOD TALK



A **good talk** now...
for good days ahead.


Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org

DRAFT

GOOD DAYS  GOOD TALK




Campaign B – Quotes

GOOD DAYS  GOOD TALK

"I want to hold onto what makes me, me."

Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org


DRAFT

GOOD DAYS  GOOD TALK

"I want to keep my mind active and stay positive."

Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org

DRAFT

GOOD DAYS  GOOD TALK

"I want to be treated like a person and not a problem."

Make sure the people who matter know what matters most to you if you became seriously ill. Start talking. To plan for a good talk, start at ourgoodtalk.org


DRAFT



Campaign C – “Madlibs”

Movie nights and
family time.

That's what matters most to me.




DRAFT

If you became seriously ill, would the people who matter know what really matters most to you? Talking about what a good day looks like if you became seriously ill is the best way to live your best life. Get started at ourgoodtalk.org

GOOD DAYS  GOOD TALK


FRESH AIR and
MAKING MUSIC.

That's what matters most to me.




DRAFT

If you became seriously ill, would the people who matter know what really matters most to you? Talking about what a good day looks like if you became seriously ill is the best way to live your best life. Get started at ourgoodtalk.org

GOOD DAYS  GOOD TALK


Joyful meals with friends and
a cat on my lap.

That's what matters most to me.



DRAFT

If you became seriously ill, would the people who matter know what really matters most to you? Talking about what a good day looks like if you became seriously ill is the best way to live your best life. Get started at ourgoodtalk.org

GOOD DAYS  GOOD TALK



Campaign A was preferred overall and by most segments and groups

- Campaign A slightly edged out the others due to its 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



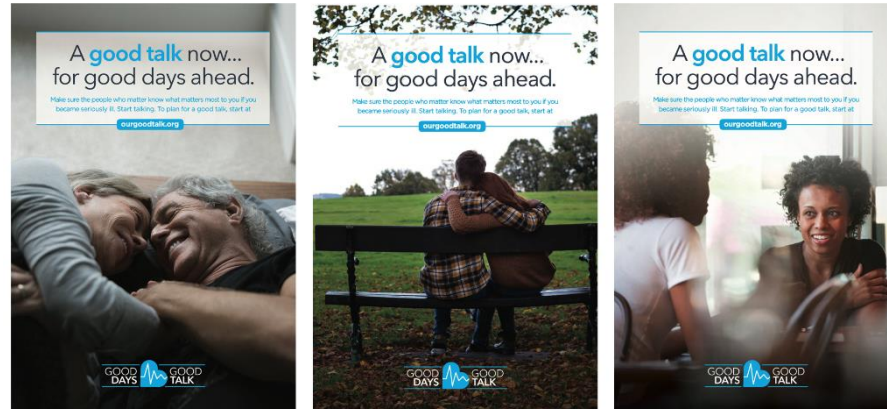
Campaign C was a close second to Campaign A

- 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.”

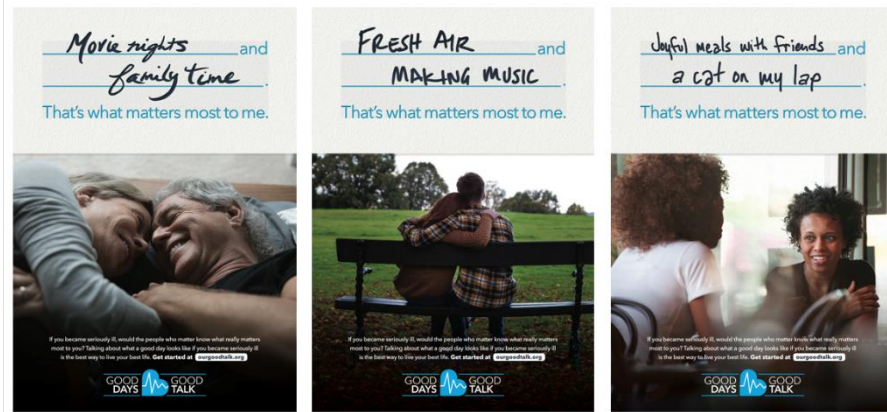


Value in all three campaign versions

- Lead with Campaign A as the umbrella awareness building campaign



- Use Campaign C as a secondary educational and engagement tool



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.

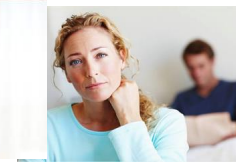
If we don't say it, they won't know. Our caregivers may need to make decisions for us, whether we've told them what we want or not. We can't simply assume they know.

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.

