

THE GOOD TALK TOOLKIT

Advancing the language of advance care planning



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

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TABLE OF CONTENTS

Introduction	01
Research Highlights	02
<ul style="list-style-type: none">• Research methodology• Insights about the public's attitudes toward advance care planning• Insights about the public and language to reframe advance care planning	
The Good Talk Toolkit	08
<ul style="list-style-type: none">• Terms and concepts that can backfire• Ready-to-go messaging• Good Talk campaign resources:<ul style="list-style-type: none">○ Good Talk non-editable posters and flyers○ Good Talk editable posters and flyers○ Good Talk website and social media graphics○ Good Talk logo○ Presentation-in-a-box –adaptable PowerPoint presentation○ Good Talk social media sample posts	
Appendix	18
<ul style="list-style-type: none">• Consumer segments overview	



INTRODUCTION

“Ensure that health care for everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care.” Massachusetts Coalition for Serious Illness Care Mission

The Massachusetts Coalition for Serious Illness Care (Coalition) brings together organizations that are committed to systemically improving care for those with serious illnesses and at the end of life. Member groups represent physicians, hospitals, hospices, nursing and long term care facilities, faith-based organizations, state government agencies, advocacy organizations, researchers, attorneys and other groups who are dedicated to placing individual patients at the center of discussions concerning all aspects of their care.

One of the Coalition’s animating principles is that conversations between the people who matter—whether family, friends, pastors or clinicians—about what really matters have power to transform the experience of care in the face of serious illness and at the end of life. There is strong evidence to support this, and a growing body of evidence for how to increase the frequency and quality of these conversations in the clinical setting, especially for patients facing serious illness, using palliative care best-practice communications.¹ However, there is less clarity on the right approach for the wider population, including people who are not currently facing a diagnosis or serious illness.

In 2018, the Coalition began a groundbreaking public messaging research project on advance care planning (ACP), in partnership with the Cambia Health Foundation. The research grew from our members’ need for more consistent, unified and strategic messaging to increase ACP engagement. It also grew from a growing realization that engagement in traditional ACP approaches for ‘healthy’ populations, which tend to emphasize preferences for specific medical care interventions in the face of incapacity, have seemingly remained steady for many years.²

Based on the public messaging research, we have developed the Good Talk Toolkit, a resource to supplement your organization’s capacity to build awareness and understanding for ACP. The messaging and campaign included here are intended to shift the frame of ACP away from end of life and life-sustaining treatment choices towards goals of care, quality of life and shared decision-making, and into closer alignment with palliative care principles.

To drive meaningful systemic change, it takes a movement that shares and tells a common message. **We invite you to use the Good Talk Toolkit in your work, adapt it as needed and share it with others working to ensure that every person’s health care is in accordance with their goals, values and preferences—at all stages of life, in all steps of their care.**

¹ http://ascopubs.org/doi/abs/10.1200/jco.2015.33.29_suppl.39

² (eg. <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2017.0175>)



RESEARCH HIGHLIGHTS

Initially, our research was intended to focus on Massachusetts, but over the course of extensive stakeholder engagement with national experts, the plan evolved to use nationally representative samples and populations. This stemmed from a few observations. First, where state-level comparison data existed, meaningful state or regional differences in ACP-related experiences were not observed. Second, there is significant national interest and appetite for this insight, with active state and regional coalitions eagerly awaiting the findings and toolkit. Lastly, modern messaging campaigns have strong digital and social components, channels that freely cross state boundaries. Therefore, we adjusted our methodology to ensure that the resulting messaging would work as well in Massachusetts as in it would in Maine and Missouri.

Research supporting the Good Talk Toolkit was conducted from October 2018 through April 2019, in three phases:

Consumer focus groups, gathering preliminary consumer insights with the goal of informing the design of a consumer survey.

Quantitative research via a representative national sample of 2,514 adults age 18 and over (supplemented by an additional Massachusetts oversample of 500 adults over 18 years of age), to gather data on people's beliefs and perceptions, ACP-related attitudes and behaviors, demographics, and relationships with the health care system. We included as many variables as possible that we posited, based on data and experience, could influence the public's attitudes or engagement with ACP. Survey data also informed consumer segmentation, grouping members of the public into distinct consumer segments based on:

- **Common Ground** - shared behaviors, experiences and attitudes that revealed a deeper understanding of why people have engaged (or not) in ACP, which would otherwise be buried into demographic averages.
- **Action Stage** - whether a consumer indicated that they had documented either their wishes for serious illness care, and/or their health care proxy, i.e. Action-Takers and Non-Action-Takers.

As a result, we identified five consumer segments, detailed in the Appendix section.

Qualitative research via online communities, featuring 150 highly engaged online participants representing the five distinct consumer segments, with a mix of races and ethnicities, ages, incomes and national geographies. Over four weeks, through 25 structured activities, we asked these participants to share their experiences and values.

We began by providing topical context and exploring what constitutes participants' quality of life—now and as they age—including their experience with health professionals, and the importance of having serious illness and quality of life conversations. With this foundation in place, we then asked participants to react to sample campaign concepts and messages, highlighting visuals and language that worked and didn't; selecting their most and least favored language and then explaining why.

INSIGHTS ABOUT THE PUBLIC'S ATTITUDES TOWARD ADVANCE CARE PLANNING

By segmenting the public based on their common beliefs, experiences and attitudes, as well as their action stage, and identifying which messages resonated most with those members of the public through our online communities, we were able to calibrate messages to find shared common ground. This common narrative includes guiding principles that apply co-equal messages broadly across all people, namely:

- **Independence and control are key.** Across segments, when asked about quality of life, people passionately shared how important it is to remain independent—to move, think and care for themselves. The idea of losing independence (even in small ways) causes great concern, with participants worried it would significantly impede their quality of life. Similarly, people shared the fervent desire to be in control of any decision-making related to their health care. They seek their doctor's counsel on medical questions, and lean on loved ones and friends for advice—but, ultimately, they insist, "No one knows me like I know me." Tapping into this desire for autonomy can be a leverage point to spur conversations.
- **Inertia abounds.** While many believe in the idea of ACP conversations, some are equally stuck in a thick place of inertia. The sources of that inertia are myriad—among them, overconfidence that their loved ones will know what they want; too many competing priorities (e.g. 'too many other things to worry about'); not knowing where to begin; and avoidance of the topic of death.
- **Health care system satisfaction counts.** People's individual experience as patients can be another driver of inertia. For people without a serious illness, relationships with doctors are often seen as functional, obligatory and rushed. They feel more like numbers than human beings. These feelings and experiences are magnified when people talk about hospitals and other bigger health systems. For many, they can't imagine their doctor playing a role in conversations about quality of life and serious illness.

- **Life events can be leverage points.** People seem to be most motivated to have conversations and engage in the ACP process if they've experienced serious illness and/or end of life firsthand, as a caretaker for a close friend or family member who suffered from a serious illness. Similarly, important milestones such as getting married and having children can also spur conversations—though these ACP actions are more specific, such as naming a health care proxy or writing up a living will.
- **Style and substance go hand-in-hand.** People seem to be motivated to engage in ACP conversations if the conversation is framed in less frightening or overwhelming ways—with a greater emphasis on what constitutes a good day vs. whether or not to have a DNR (do-not-resuscitate order). We saw this shift happen with a number of online community participants who began to see these conversations in a new light, and were so inspired by the language we proposed that they engaged family members, friends and other trusted people in an ACP conversation during the time the online communities were live.

INSIGHTS ABOUT THE PUBLIC AND LANGUAGE TO REFRAME ADVANCE CARE PLANNING

As we dug into responses from the research, key insights emerged that informed the development of universally appealing umbrella and supporting messages.

- **Living a good life, one's whole life, is an essential belief and public expectation.** Having control over decisions impacting one's life and care is a means to attain and preserve the quality of life they envision.
- **"Advance care planning" triggers the life-sustaining treatment mental trap.** People's default thinking focused on "pull the plug," DNRs, hospice care, etc. versus day-to-day quality of life. Unless we probed to get clarity on what constituted a good quality of life, people thought the planning that we discussed meant the very end of life—even though we only referred to serious illness and quality of life conversations.
- **Talking about "what matters" and "what a good day looks like" pulled people away from the life-sustaining treatment mental trap.** When probed further, participants reacted positively to talking about "what matters" to them and what having a "good day" meant to them if facing a serious illness, shifting the focus to quality of life associations such as: making good memories, being treated with dignity and respect, making peace with God, repairing family relations, daily indulgences like smoothies and favorite foods, among others.

- **The idea of “loved ones/family,” for many, is a loaded topic.** For those facing complex family dynamics and emotions, estrangement or loss, seeing and hearing that they need to engage “loved ones”—which many associate with family—complicates the way they receive such messages, and leads these individuals to tune those messages out.
- **While a noticeable contingent did not have family, or were estranged from family, they could name “people who mattered” in their lives.** Even those who lived alone or were estranged from family could name friends, doctors and religious leaders in their circle.

Based on these insights, we made six strategic decisions regarding umbrella messaging:

- Re-state “quality of life” into an easily understood, concrete and immediate mental picture connected to serious illness but disconnected from “pull the plug” mental traps. “What your good day looks like” is something we can all relate to.
- Normalize what it means to have “the conversation,” and re-state it as the “Good Talk,” using simple, relatable language.
- Be inclusive by using language like “people who matter most,” which could be family, friends, a doctor, a religious leader, etc. And plant the doubt for those who assume their loved ones know what they want, by posing it as a question: “If you became seriously ill, would the people who matter most really know what matters most to you?”
- Recognize that people want to have some control and power over decisions that impact their life and health care if facing a serious illness, by using an encouraging statement to prompt people to “share the kind of care that’s right for you.”
- Make the messaging relevant to people’s current life circumstances. Use language that connotes immediacy, such as, “It’s about today...no matter what happens tomorrow.”
- Be aspirational to draw people in, rather than leading with serious illness in the headline. Before participants became immersed in the issue, it became clear that they perceived thinking about serious illness as scary, off-putting, something to ignore or not applicable because one is young/healthy. Additionally, many participants had negative perceptions of the health care system. All of this indicated that if we led with serious illness in the main headline, people would tune us out.

Supporting Messages/Reasons

In addition, we presented five supporting messages to online community participants as “reasons” underscoring the importance of ACP conversations with loved ones, friends and/or health care professionals.

Each reason had additional proof points. Participants carefully read through the content and used a highlighting tool to share which words/phrases resonated and which did not. We then engaged them in discussion about their feedback, asked them to select the reason that inspired them most and least to have a conversation, and to tell us why. The supporting messages testing showed that:

- **The supporting messages connoting “power” (we can have a say in our care) and “control” (conversations clarify) were the most preferred and appealed to all consumer segments.** Notably, they appealed to people who identified as having a disability, to those who had a serious illness, millennials, and across African American, Latinx and Asian participants.
 - Power was about shared decision-making, shifting the expectations of clinical communication to highlight the subjective choices often involved in care, which can have different impacts on quality of life. Importantly, this shift is not exclusive to serious illness; it is relevant to any type of health care interaction.
 - Control in this frame was mostly about controlling who you choose to speak for you, and giving them the guiding principles for your care in the case of incapacity—more aligned with traditional approaches to ACP messaging that emphasize selecting a proxy.
- **The supporting message that referenced activating the conversation in others (“caring means learning what matters to them”) only strongly resonated for Action-Takers.** This suggests that people who have done ACP for themselves can be prompted to activate the conversation in others. Action-Takers had completed their advance directive documents (i.e., health care proxy and documented their wishes) and had also talked with loved ones about their wishes for care in a variety of contexts, including quality of life.
- **The supporting message based on “peace of mind” did not resonate at all among all participant segments.** The idea that completing ACP would provide peace of mind felt overpromising and possibly exclusionary to those in lower income households, since their financial situation may impede them from carrying out a loved one’s wishes.

- **The supporting message centered on “love,” i.e. ACP as a “gift/act of love” for loved ones did not work for the majority of participant segments.** For those estranged from or without family in their lives, the message felt alienating. For others, it felt overpromising and made them question whether loved ones would really fulfill their wishes in the way they expect them to.
- **Messaging that compared ACP to “wellness” and something you do as part of an “annual checkup” was not viewed favorably.** It seemed implausible and farfetched for participants to think of having ACP conversations every year or as part of wellness practices.

The final umbrella message and supporting messages are included in the following section: The Good Talk Toolkit.



THE GOOD TALK TOOLKIT

The messaging and campaign resources that follow are based on a research- and data-driven strategy steeped in principles of social norms marketing. To persuade people to have meaningful conversations about their preferences for care at all stages of life and health requires convincing them that the reward of such conversations is worth overcoming any obstacles. Fundamentally, that means humanizing the issue by removing medical jargon and realigning how we motivate people to act with their values, revealed by our research: quality of life, self-determination and self-advocacy.

If we frame conversations as values and preferences that stem from everyday joys that fulfill us, things that matter to us and what a good day looks like to us, people see these conversations as something everyone should do, no matter their age or health status.

The Good Talk Toolkit materials include:

- Examples of terms and concepts that can backfire with members of the public.
- “Ready to go” messaging and language that can be used as is, or adapted and repurposed for your organization’s needs.
- Good Talk campaign resources including the Good Talk campaign logo, non-editable and editable versions of posters and flyers, social media graphics for Facebook and Twitter, and sample social media posts.
- “Presentation-in-a-box,” an adaptable PowerPoint presentation that can be used to engage and educate your target audiences using elements of the Good Talk campaign.

EXAMPLES OF TERMS AND CONCEPTS THAT CAN BACKFIRE WITH MEMBERS OF THE PUBLIC

Language designed to engage and inspire people to have ACP conversations should steer clear of words and phrases that can spark fear, instead focusing on words that emphasize a good quality of life, one's whole life. Judgment is a verbal landmine to avoid, especially when speaking to people who have strained relationships. It is also better to use clear language that paints a mental picture and feels relatable over health care jargon or language that feels like it is overpromising.

Term/Concept	Why it backfires
Health care as a "right"	It suggests people should go to battle and fight for their care, putting them in a defensive mindset.
"Loved ones"	Many people do not have family or are estranged from family. To them, the idea of "loved ones" is closely associated with "family" which makes them reject messaging referring to "loved ones."
Have the "conversation"	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"	"Honest conversation" can feel judgmental, while "open conversation" does not introduce judgment.
"Health care consumer"	"Health care consumer" felt dehumanizing, as people don't see themselves as "consuming care."
"Lessen/ease the burden"	People believe it should not be a burden to care for a loved one. For some, having the conversation doesn't really ease the burden of having loved ones who are seriously ill.
"Peace of mind," suggesting that ACP provides a sense of relief	"Peace of mind" feels overpromising and possibly exclusionary to those in lower income households, who may not be equipped to carry through wishes of a loved one given their financial situation.
Comparing ACP to "wellness" and something you do as part of an "annual checkup."	It seems implausible and farfetched for people to think of having ACP conversations every year or as part of wellness.


READY-TO-GO MESSAGING AND LANGUAGE

The following messaging is designed to support and encourage the public's motivation to have ACP conversations—which will be spurred by the umbrella message. It is intended to be used in a modular way to support specific communications needs by providing “reasons” to help put meaningful conversations about care, values, preferences and shared decision-making into practice.

We've used “our” and “we” for the narrative to create a sense of collective whole (we're all in this together) and avoid using “you,” which can feel overly directive and prescriptive. The idea is that these words and messages can be tailored by organizations to align with your own communication channels and materials.

Messaging for all members of the public

As illustrated in the diagram, the umbrella message is supported by two supporting messages and additional proof points that resonated with all members of the public. Therefore, this language can be used in communications to persuade people to engage in meaningful conversations and take ACP action.

<p>UMBRELLA MESSAGE</p>	<p>RESONATES WITH ALL CONSUMER SEGMENTS</p> 	
<p>SUPPORTING MESSAGES/ REASONS WHY</p>	<p>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.</p> <p>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.</p>	<p>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.</p>
<p>PROOF POINTS</p>	<p>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.</p> <p>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.</p>	<p>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.</p> <p>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.</p>

SECONDARY MESSAGING

RESONATES MOSTLY WITH 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

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.

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.



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GOOD TALK CAMPAIGN RESOURCES

HOW TO USE THE CAMPAIGN

We developed a number of resources (posters, flyers, social media graphics and a presentation-in-a-box) to help you use the Good Talk campaign in your own organization and community. It is worth noting that the materials depict a range of real people and situations that can be relatable to all members of the public.

To help you most effectively reach your audiences, below is a series of options for the materials:

- Editable print-ready versions: Add your contact information or logo.
- Non-editable print-ready versions: Use all campaign materials exactly as they are.
- Twitter and Facebook graphics and posts: Use for social media posts or website.

To edit the posters and flyers:

- Use Adobe Acrobat Pro. (If you do not have Adobe Acrobat Pro, you can go to <https://acrobat.adobe.com/us/en/acrobat.html> to download it or try a free trial.)
- Open the “Editable Version” you wish to edit in Adobe Acrobat Pro.
- Click on “Edit PDF” and enter brief text and/or your organization’s logo in the EDITABLE AREA). Then click “Save.”

Tips for using the Good Talk campaign resources:

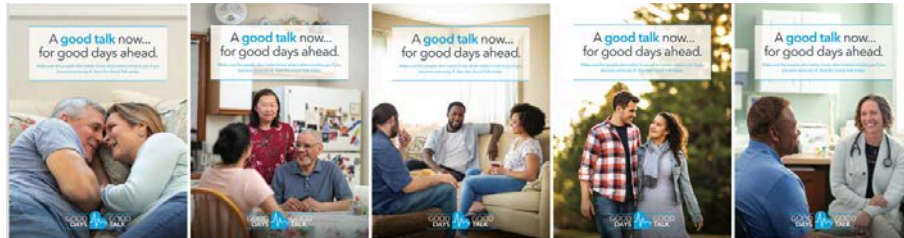
- Use at least three out of the five posters/flyers to make the campaign relatable to more audiences when using the materials in outreach/engagement efforts.
- Promote the campaign in your Facebook and Twitter channels and use the social media graphics/sample posts provided to get started.
- Tag all of your posts using the hashtag #ourgoodtalk

You can access these materials by going to <http://www.maseriouscare.org/toolkit> which will direct you to the Massachusetts Coalition for Serious Illness Care Website’s Toolkit page.

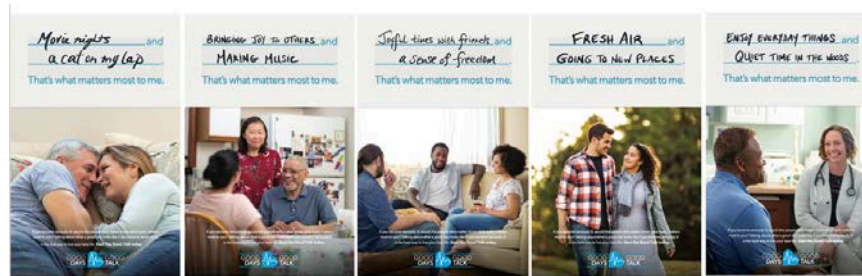
Non-Editable Posters

Multiple images available. All posters can be printed digitally.

Awareness Building Posters: Posters can be used as they are to build awareness by displaying around your organization and/or using at events.

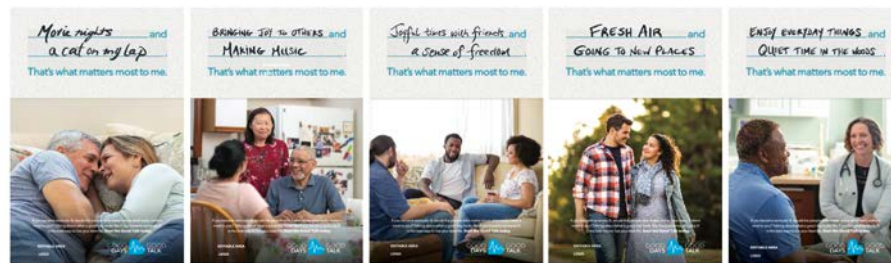


Educational Posters: Multiple images available. Posters be used at group or information sessions with members of the public to illustrate examples of how to think about advance care planning beyond the life-sustaining treatment mental default.



Editable Posters

Multiple images available. All posters can be printed digitally and can be customized by adding your organization's logo and/or contact information in the editable area using Adobe Acrobat Pro.



Social Media Graphics

Twitter and Facebook graphics for use in your social media channels. Multiple images available.



Presentation-in-a-Box

An adaptable PowerPoint presentation that can be used to engage with members of your organization and/or the public.



Good Talk Logo

The Good Talk logo usage guidelines and various file formats that can be used on your organization's materials, website, etc.



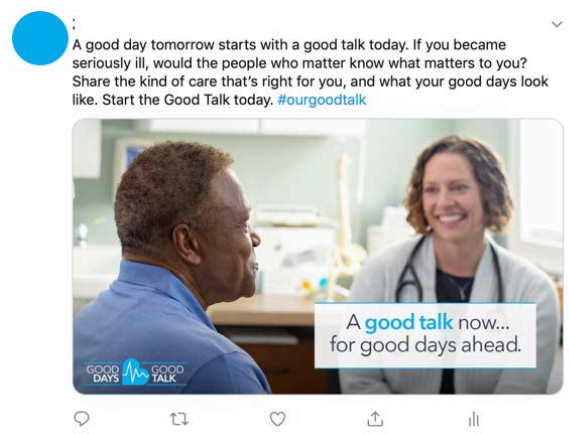
Sample Facebook and Twitter posts

Choose graphics from the Facebook and Twitter collections and pair them with these sample posts. Feel free to edit them to meet your communication style.

- **A good day tomorrow starts with a good talk today.** If you became seriously ill, would the people who matter know what matters to you? Share the kind of care that's right for you, and what your good days look like. Start the Good Talk today. #ourgoodtalk
- **What is the Good Talk?** It's when we talk to family, friends, pastors or clinicians about things that matter to us—living well, the everyday joys that fulfill us, what a good day looks like—and we share the kind of care that is right for us. #ourgoodtalk
- **Conversations clarify.** We can help manage life's unknowns by talking about what matters to us and what we'd want if we became seriously ill. Conversations about things we can't control can actually help to give us a sense of control. Start the Good Talk today. #ourgoodtalk
- **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. #ourgoodtalk
- **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. Start the Good Talk today. #ourgoodtalk
- **If we don't say it, they won't know.** We can help manage life's unknowns by talking about what matters to us and what we'd want most if we became seriously ill. Talking about things we can't control can give us a sense of control. Start the Good Talk today. #ourgoodtalk
- **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 if we become seriously ill. Start the Good Talk today. #ourgoodtalk
- **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. Start the Good Talk today. #ourgoodtalk

- **Information is power.** If you became seriously ill, would the people who matter know what matters to you? Share the kind of care that's right for you, and what your good days look like. Start the Good Talk today. [#ourgoodtalk](#)

Examples



■ APPENDIX: CONSUMER SEGMENTS OVERVIEW

To construct our segments, we conducted a nationally representative survey of 2500 adults, along with a 500 Massachusetts oversample.

While we used the survey to identify demographic data, the goal was to design a survey that included as many variables as possible that we had reason to believe would influence a person's engagement in advance care planning:

- from their experiences as a caregiver,
- their confidence in their own abilities to navigate their health and the health care system,
- their views and feelings about the health care system,
- their personalities,
- the importance of religion in their lives,
- and their own health conditions.

And while demographics are certainly important, this kind of segmentation is about grouping people based on their experiences, attitudes, beliefs, and personalities. Allowing us to get a deeper understanding of why people have engaged (or not) in ACP that would otherwise be buried into demographic averages. It also allows us to create messaging that resonates across all types of people.

5 CONSUMER SEGMENTS

We explored different ways of clustering people together and found that the first, most important split was between "Action Takers" and "Non-Action Takers"

Action Takers completed both a health care proxy and had also documented their wishes. In doing the analysis it became very clear that the people who had done both were different from the ones who hadn't. But there are two different kinds of Action Takers: Worried Action Takers and Self-Assured Action Takers. And they are very different.

The other three segments together are the Non-Action Takers – none of them have completed both their documents but that's where their similarities largely end.

Following is an overview of the 5 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.