MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

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

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MASSACHUSETTS

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Short history of our public experience research and lessons learned

2016 Baseline Survey (n=1800)

2017 open-ended follow up survey (n=500)

2018 tracking survey w/ national comparisons (n=1500)

- The public strongly equates advance care planning with death, DNRs and life-sustaining treatment choices
- Despite significant attention, energy and activity, Massachusetts is similar to the rest of the nation with respect to levels of advance care planning engagement
- There are significant disparities in ACP engagement and inequities in experiences at end of life across race/ethnicity and income/education
- Changes in outcomes – experiences of care at the end of life – can improve despite no population-level changes in traditional advance care planning activities

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

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%

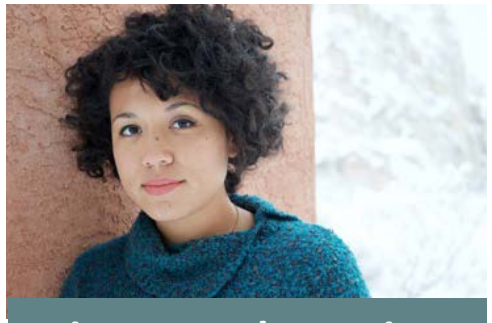
Younger, diverse, most educated. Nearly half identified as having a disability.

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 self-reported health; lowest confidence in 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. Lower confidence in their health care self-management and navigation skills.

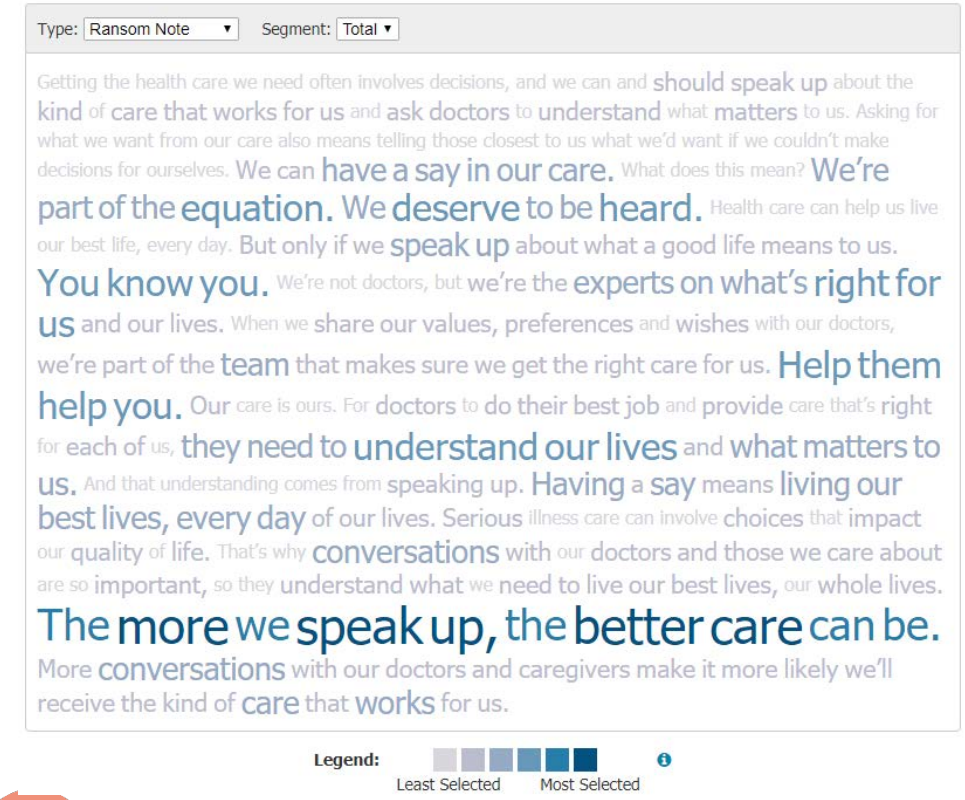
Five Supporting Messages/"Reasons" Were Tested

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.

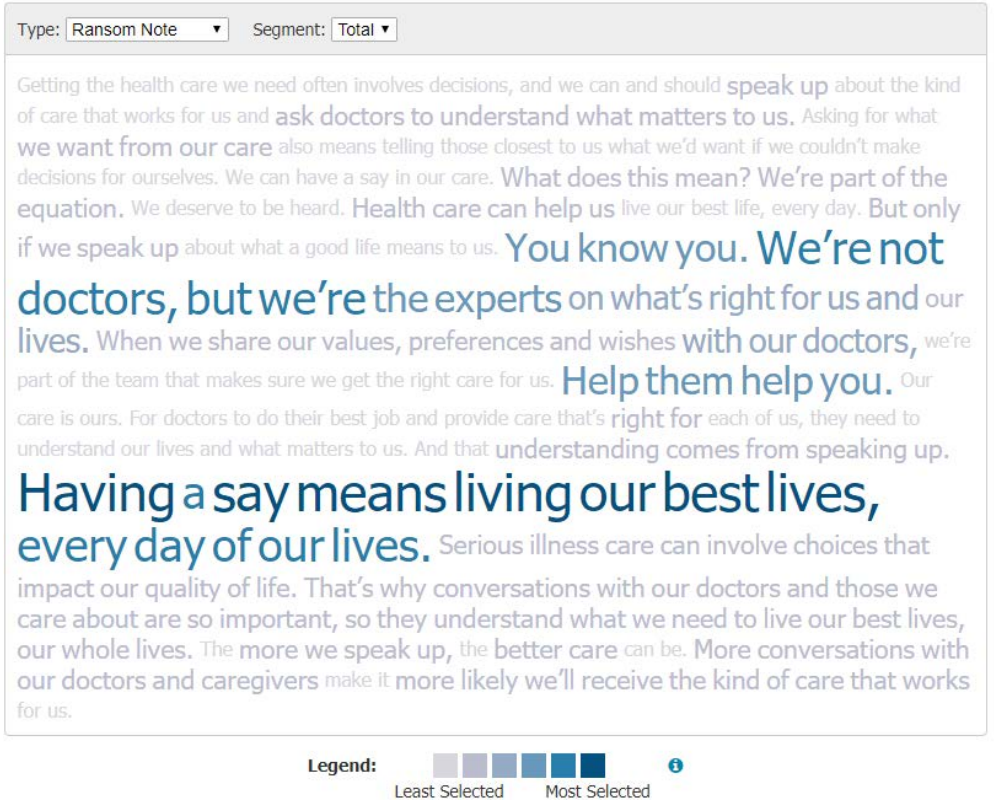
Participants read the content and did a highlighting exercise.

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

Words that resonate



Words that don't resonate



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.

Control and self-advocacy "reasons" were preferred by most

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

Different concepts underlie the top "reasons"

"Conversations clarify."

- Emphasis is on selecting surrogate decision maker in the case of unexpected 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

Take home reflections: a new way to move upstream for all?

- Everyone needs a health care proxy but…unexpected incapacity is unlikely for younger/healthier groups and they may (*logically*) put other life priorities first: so keep it light and make it easy

- Maybe the best way to *prepare* people for serious illness decisions is a lifelong experience with, and expectation of, shared decision making with trusted health care clinicians in health care systems focused on **cultural humility**, respect, aligning care with priorities, and identifying and addressing bias and structural racism