



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

Summary

Goals: Ensure that care received by everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care.

Challenge: Increase awareness and influence actions of the public and health professionals around end-of-life and serious illness.

Leadership: Founded by The Conversation Project, Ariadne Labs, and Blue Cross Blue Shield of Massachusetts. Two lead staff.

Funder: Private corporate and grant support.

Members: 90 Massachusetts-based healthcare stakeholders (as of January 2018).

Achievements & Outcomes: Membership has expanded organically to 90 organizations. Strong growth in attendance, media awareness, and critical reception of its annual meetings. Established a solid basis for measuring progress through its annual surveys. Has built partnership with state government. Efforts at developing corporate and foundation funding streams have shown promise.

Overview

The Massachusetts Coalition for Serious Illness Care was formed in 2016 to ensure that everyone in Massachusetts receives care that is in accordance with their goals, values and preferences at all stages of life and all steps of care. As of January 2018, the Coalition includes 90 Massachusetts-based organizations representing physicians, nurses, hospices, counselors, clergy, hospital and health plan administrators, social workers, attorneys, policymakers, researchers, advocates, and community-based organizations. In the years since its founding, the Coalition has demonstrated early success in convening groups interested in serious illness care reform, facilitating buy-in from c-suite level leaders, setting targeted and manageable goals, attracting media attention, and changing the discussion about how we care for vulnerable people. This model can serve as an example for other states interested in forming similar coalitions devoted to delivering high-quality, person-centered care for people with serious and advanced illness.

Background

Massachusetts has often been on the frontlines of healthcare reform. Over the last ten years, the state has introduced universal individual coverage, established various public health initiatives, and set the pace of progress on payment reform. Building on previous efforts in the state, in 2011, the state appointed a panel to investigate and offer recommendations on how to improve care for those with serious illness. The panel found that the health care system did not always consider patient wishes about end-of-life care. The report recommended: coverage by insurers for comprehensive palliative care; more physician training on discussions of end-of-life care; greater emphasis on treatment based on informed patient wishes; and standardization of advance care planning.

In 2014, the landmark “Dying in America Report” report was released by the Institute of Medicine, followed by Atul Gawande’s “Being Mortal.” Conversations on end-of-life care that had been frozen by stigma and political rhetoric began to thaw with new enthusiasm and optimism. The conversation shifted from how people wanted to die to what it meant to live well. Moreover, across the state, various groups including regional partnerships and grassroots organizations were already at work increasing consumer awareness, training providers in documenting patient wishes, and providing the structural support necessary for high quality care.



Atul Gawande
Author, *Being Mortal*

At the same time, the coalition’s founding organizations – the Conversation Project and its partner, The Institute for Healthcare Improvement, Ariadne Labs, and Blue Cross Blue Shield of Massachusetts (BCBSMA) – realized that despite the encouraging landscape, greater connectivity and collaboration was necessary. By convening key stakeholders, and establishing measurable, and actionable goals, the founders seized upon the opportunities offered by existing health care infrastructure, cultural shifts, mission convergence, and a history of leadership in health care reform and public health initiatives. In just two years, Coalition membership has expanded from 20 to 90 organizations, media attention has increased, and data collected from Massachusetts residents indicates that public awareness of advance care planning is rising.

Goals

Over a series of meetings in 2015, the three founding organizations came together to conceptualize the structure and function of a statewide coalition dedicated to serious illness care. They wanted to bring together various organizations across the state to complement and accelerate the work already occurring. They did not want to create altogether new infrastructure or start a new organization. Instead, they sought to strategically leverage the existing programs, knowledge, and expertise of their partners. Notably, they knew that the groups involved would not be exclusively health care related. As such, the founders knew they needed to develop goals that were clear yet flexible enough to welcome participation from many stakeholders.



Ellen Goodman
Co-Founder, The Conversation Project

Though the founders shared in the broad vision of high-quality, person-centered care for all, they narrowed their initial focus to documentation and communication of preferences. In so doing, the leadership group made a conscious choice to focus on fostering and supporting advance care planning, rather than the equally worthy endeavor of strengthening the actual delivery of care for those with serious illness. Over the course of several meetings, six priority goals that would form the foundation of the Coalition's work were identified.

COALITION GOALS

1. Each person in Massachusetts was to have a designated health care proxy
2. Normalize ongoing conversations with health care proxies to clarify goals, values, and care preferences
3. More training in care planning and serious illness communication for providers
4. Everyone was to have an informed conversation with their care team
5. All providers were to institute systems for soliciting and documenting patient wishes
6. Results of planning conversations should be readily shareable across care settings

Membership

With its goals in place, the Coalition began reaching out to organizations throughout the state. Coalition leaders initially approached existing statewide associations, such as the Massachusetts Health & Hospital Association and the Massachusetts Medical Society, because these groups had the broad networks to reach key stakeholders. As the Coalition's activities and outreach expanded, individual hospitals and other provider organizations got more directly involved and became members in their own right.

When pursuing new members, the Coalition effectively utilized their surrogates' influence. Andrew Dreyfus, Atul Gawande, Maureen Bisognano, Ellen Goodman, and Harriet Warshaw commonly made contact with the leadership of potential members. Their credibility and expertise made opening doors to new membership much easier across the state. This early use of executive contacts would provide significant returns on membership and raise public awareness about the Coalition and its agenda.

Importantly, the Coalition was mindful of the experience in this space of the palliative care community, as well as that of leaders from previous statewide and regional advance care planning and end-of-life care initiatives. Coalition leaders actively sought their insights on both the coalition goals and activities. This outreach improved the Coalition's work and helped achieve additional buy-in regarding the value and purpose of the new endeavor, while still keeping the group's core decision making group small and flexible.



Andrew Dreyfus
President & CEO, BCBSMA

Initially, an organization could join the Coalition if they publically committed to working towards at least one of the Coalition's goals. This allowed for the inclusion of a diverse set of members working on a variety of programs and initiatives. To join, an organization would publically state their goals and action plan, which in turn would help build public awareness and accountability for the Coalition. This membership model also ensured senior-level involvement, since commitment announcements typically required high-level sign-off.

Over time, the Coalition has shifted away from this "commitment" style model. It became clear that rather than focusing on new initiatives, which could sometimes create barriers to entry, it was more productive to concentrate instead on documenting existing member activities. Providing information about their current programs and activities is relatively easy for members to do, and it generates information that is useful for networking and sharing best practices. If an organization can show that its participation furthers the Coalition's goals, it is welcome to join. The Coalition is in the process of making the information about member activities easily available on its web site.

Staffing and Funding

During the Coalition's early development, staff from each of the three founding organizations provided operational support. After approximately six months, it became clear that a fully dedicated staff person was required. BCBSMA covered the salary of this Executive Director position, as well as providing additional in-kind support. The core group of founding members continues to serve as the organization's planning group, while the Executive Director frequently consults with members to benefit from their expertise. This approach simultaneously encourages participation from the diverse membership while also still keeping the core planning group small and nimble, rather than being reliant on larger group consensus regarding detailed operational issues.

Initial funding came from BCBSMA along with a two-year grant from a local family foundation. The early staff support and operating funds were critical in establishing a solid foundation for the Coalition and demonstrating the commitment of the founding organizations. This signaled to other groups that the Coalition was a serious project and had the backing of important institutions within the state.

Currently, the Coalition is pursuing a broader development plan aimed at obtaining corporate sponsorships for the annual summit and foundation grants to support research and programmatic efforts.

Developing the Organization

Originally, the founders intended to limit annual Coalition activities to convening a major public event and administering a statewide consumer research survey to track progress. However, the organization's activities expanded over time to take advantage of emerging opportunities for member engagement. For example, the group began to host smaller - but no less engaging and activating - annual members-only meetings, which have become a key forum to share activities and ideas, and to provide an opportunity to shape the organization's strategic direction.



Most of the Coalition's initiatives thus far have involved engaging health professionals in efforts to foster systemic change. An example is a current initiative involving all four Massachusetts medical schools aimed at strengthening the curriculum around care for serious illness. The project will include:

- Defining the specific skills all medical students need to communicate effectively and empathetically with patients and families dealing with serious illness;
- examining techniques for teaching these skills and evaluating students' competency; and



- exploring medical students' attitudes and personal experiences around end-of-life care.

A similar effort is underway involving the deans of major nursing schools in the Massachusetts, as well as discussions regarding related curriculum for divinity schools. Another significant Coalition activity is a collaboration with the Massachusetts eHealth Institute and the Commonwealth's Executive Office of Elder Affairs to promote electronic sharing of advance care planning materials.

During the spring of 2017, the Coalition was actively engaged in a public education campaign tied to National Health Care Decisions Day (NHDD). The Massachusetts Executive Office of Elder Affairs was a key partner in this effort, providing leadership

and enlisting participation from colleagues in state government. Experience with NHDD underscored the fact that grassroots public campaigns typically require significant budget and staff commitments that would be difficult for the Coalition to sustain over time. As an alternative, the Coalition will promote future NHDD campaigns through regular communications channels, and by raising awareness among industry stakeholders and thought leaders. This will augment the individual efforts of members, many of whom have a long history of involvement in NHDD. In the meantime, Coalition leaders are continuing to explore other options for advancing public education about advance care planning, which remains an area of interest to members.

Evaluating Progress

Because coalition members all contribute to its goals in different ways, the Coalition decided it would use a recurring consumer survey as a key measure of success.

In 2016, the first baseline survey was conducted with nearly two thousand interviews of Massachusetts residents to determine consumer attitudes and knowledge of advanced and serious illness. The survey results showed that despite interest and growing willingness to have advance care planning conversations with doctors, only 15% of the healthy population and 25% of those facing serious illness had engaged in them. Researchers also identified which respondents had a loved one die in the past year, and explored the quality of care at the end of life. More than one-third said that their loved one's wishes were only partially followed at end of life, with fully 15% indicating that their wishes were only honored "a little bit," or "not at all."



Maureen Bisognano
President Emerita and Senior Fellow
Institute for Healthcare Improvement

In 2017, a second survey was conducted involving follow up with respondents from 2016. It found that awareness and perceived importance of end-of-life issues had risen; 15% of those with a health care proxy had selected them during the past year, and of those who'd spoken with health care providers about care planning, approximately 40% had done so in the past year. However, most of those who had engaged in planning conversations had to initiate them themselves. Importantly, the results also showed that consumers were concerned with quality of life over volume of treatment, and that they believed it was the duty of physicians to begin planning discussions.

The leadership found the survey to be a powerful tool in assessing progress not only from the direct measurement of consumer perceptions but also due to media interest in the results and subsequent increases in member participation.

In 2018, the Coalition will field the first true follow-up survey, which will assess how far the state has come in the last two years on such issues as health care proxy completion, conversations with loved ones and clinicians, and experiences with the death of a loved one.



Lessons Learned

Below are some lessons learned from the Coalition in its early development. While every organization and locality is different, these are some of the factors that contributed to success in Massachusetts.

The moment must be right

To build initial momentum, the environment – both political and cultural – must be conducive to change.

Set clear, measurable goals

Goals should be specific enough that they reflect the interests of participating organizations and can be measured over time.

Broad coalition

A diverse coalition is a healthy coalition. Varied membership validates this type of work and expands organizational reach. Lowering barriers to entry is critical to attracting smaller organizations such as non-profits and individual providers.

Executive level outreach and the right surrogates

Executive-level outreach and star power provides easy and early wins in membership and public awareness.

Adhere to core competencies

Even with extensive membership and secure funding, a coalition will still need to stay focused on its primary value proposition to be successful.

Tap into big networks

Executive-level outreach and star power provides easy and early wins in membership and public awareness.

Respect the trailblazers

In any community, there will be leaders who have been doing this work for years. They have important perspectives regardless of how small their organization is, and cultivating relationships with them yields returns to both membership and convening ability.

Small planning group

Broad membership that is consulted regularly builds trust and a culture of collaboration, but for operational effectiveness it is important to keep the core decision making group small and flexible.

Early resources make the difference

Securing funding from foundations and big players early on is key to expanding bandwidth and achieving sustainability.

Data drives the narrative

Measuring success is important, and having a way to collect data on progress and outcomes garners media attention and builds a sense of positive momentum.

Intentionality around diversity

Recognize that it continues to be a challenge to bring advance care planning to underserved populations, and sustain the commitment to address this issue.

Outcomes

Since its founding, the Coalition has achieved a number of crucial developmental milestones: its membership has expanded to include 90 organizations; attendance, media awareness, and critical reception of its annual meetings has grown; it has established a strong basis for measuring progress through its annual surveys; it has built a strong partnership with the state government; and early efforts at developing corporate and foundation funding streams have shown promise. A sampling of Coalition-related media coverage can be found at: maseriouscare.org/news

In 2018, the Coalition will be exploring ways to build on its early successes by expanding opportunities for members to stay involved in its work. The group will update its digital platforms to enhance communication among members, and it will continue the high-level executive and opinion leader outreach that has served it so well. Finally, the Coalition will continue to define success through indicators such as: new member recruitment; improved survey results; progress on current programmatic initiatives; increased media attention and Summit attendance; and achieving fund raising targets.

“Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. And above all, it takes a willingness to try.”

- Atul Gawande



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