

New Research Finds Collaboration and Connection Between Clinicians, Patients and Families is Key to Improving Serious Illness Care and Health Equity

Survey finds what patients want most is to be listened to and included in their health care. But barriers within the health care system often prevent this, especially for those with serious illnesses and from marginalized communities.

BOSTON, Oct. 14, 2021 /PRNewswire/ -- 87% of adults say it's important that doctors know their patients' priorities and what is important to them - but people with serious illness report that clinicians tend to know their priorities and health goals less well than those without serious illness.



MASSACHUSETTS COALITION FOR SERIOUS ILLNESS CARE

These were among the findings released today at the 6th Annual Summit of the [Massachusetts Coalition for Serious Illness Care](#) ("Coalition"). Over the last year, Coalition researchers engaged with nearly 2,500 people nationwide in a multi-phase project designed to drive improvements in communication and care for people and families facing serious illnesses. Researchers focused specifically on the experiences of Black and Hispanic adults, people with serious illnesses and disabilities, and their caregivers.

"People are telling us loud and clear what they want from the health care system: to be heard," said Dr. Atul Gawande, co-chair of the Coalition; Surgeon, Brigham and Women's Hospital; Professor, Harvard T.H. Chan School of Public Health; and Chair, Ariadne Labs. "There are many things we need to do differently to dismantle inequities in health care experiences. These data are showing us that a clear place to start is investing in systematic approaches to improving the communication and connection that seriously ill patients and clinicians both want."

The nationally representative survey of 1,854 adults covered many facets of health care experiences related to serious illness care and decision making. The team explored further with 580 adults in qualitative research sessions throughout the summer. The research was funded with support from [The John A. Hartford Foundation](#), [the Cambia Health Foundation](#) and [Blue Cross Blue Shield of Massachusetts](#). Participatory design methods were used to help align the questions and approaches with the lived experiences of marginalized communities.

Major findings include:

- 19% of people with serious illness report often *leaving health care appointments unsure about what to do next* compared to 9% for those without a serious illness; this was similar to the 19% of people with disabilities, 15% of Black and Hispanic respondents, and 17% of the lowest income respondents who reported often having this experience
- 21% of people with serious illness report often *feeling afraid to speak up or ask questions* compared to 11% for those without a serious illness; similar to the 17%-18% of Black and Hispanic respondents and the 23% of the lowest income respondents who reported often having this experience.
- 31% of people with serious illness report being *treated unfairly* in the last year, compared to 12% without serious illness; 31% of people with disabilities likewise reported being treated unfairly in the last year, as did 21% of the lowest income adults, 17% of Hispanic adults and 19% of Black adults.
- The survey found flat to slightly lower rates of engaging in conversations with friends or family about documenting wishes for care and preferences on health care decision makers. This is despite consistent media attention and encouragement from clinicians throughout the Covid-19 pandemic to do engage in these actions. And while conversations with clinicians on these issues did increase slightly since 2017 - up from 18% to 23% - fewer than half of Black and Hispanic respondents said they would want to talk to a doctor about their wishes for care if they hadn't already done so, down from

about 60% four years ago

- Qualitative research participants, including those with serious illness and their caregivers, overwhelmingly selected a collaborative approach to their care as what matters most to them – even more than a clinician's expertise
- When asked about the most impactful action they could take to improve their health and well-being, almost all participants selected speaking up to ensure their doctors understand their life and priorities

"We need to hear and honor all patients in a respectful way. Developing these new ways of care means we need to invest in and support our workforce differently, too, especially given the tremendous toll that COVID has taken on clinicians," said Maureen Bisognano, co-chair of the Coalition, and Senior Fellow and President Emerita, Institute for Healthcare Improvement. "We can and should create a health care culture that encourages and empowers patients and families to speak up and share *what matters most*¹ to them."

"Collaborative communication between patients and clinicians leads to better health outcomes and is especially needed for people to live well with serious illness," said Terry Fulmer, PhD, RN, FAAN, president of The John A. Hartford Foundation. "Recognizing that disparities were grossly exposed by the pandemic, we have an opportunity to improve processes and standards so that all people, no matter their race or income level, feel heard, safe and fairly treated in their health care encounters."

"Listening to lived experiences is a critical component to improving the health care system, as is honoring the personal connection between patients and their providers" said Peggy Maguire, President of the Cambia Health Foundation. "We are honored to partner with the John A. Hartford Foundation in supporting this research, and we applaud the Coalition for highlighting opportunities to remove barriers for people with serious illness."

At the Coalition Summit, participants will reflect on the research findings and engage in interactive breakout sessions exploring how to systematically support culture change at the individual, organization and state and federal policy level. Visit the [Coalition's website](#) for full research findings and to learn more about ensuring that everyone gets care that supports what matters most, especially those facing serious illness.

About the Research

The quantitative survey was conducted using the AmeriSpeak panel at the National Opinion Research Center (NORC) at the University of Chicago. Survey was offered in English and Spanish, with options to complete online or over the phone.

Online qualitative research sessions were conducted over three weeks in June, July, and August.

About the Massachusetts Coalition for Serious Illness Care

The Massachusetts Coalition for Serious Illness Care includes over 125 member organizations committed to ensuring that we all get care that supports what matters most to us throughout our lives, especially if we're seriously ill. These organizations represent physicians, nurses, hospice workers, counselors, clergy, hospital and health plan administrators, social workers, attorneys, policymakers, researchers, and other health professionals. The Coalition is funded by Blue Cross Blue Shield of Massachusetts and a variety of sponsoring organizations. To learn more, visit maseriouscare.org.

About The John A. Hartford Foundation

The John A. Hartford Foundation, based in New York City, is a private, nonpartisan, national philanthropy dedicated to improving the care of older adults. The leader in the field of aging and health, the Foundation has three areas of emphasis: creating age-friendly health systems, supporting family caregivers, and improving serious illness and end-of-life care. To learn more, visit johnahartford.org.

About Cambia Health Foundation

Cambia Health Foundation is the corporate foundation of Cambia Health Solutions. Founded in 2007, the Foundation has funded over \$80 million in grants to advance person-focused and economically sustainable healthcare. We support whole person health at every stage of life to build a just and inclusive health care system for all. Learn more at www.cambiahealthfoundation.org and follow us on Twitter [@CambiaHealthFdn](https://twitter.com/CambiaHealthFdn).

¹ Susan Edgman-Levitan and Michael Barry described this as shifting from 'what's the matter' to 'what matters most'.

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