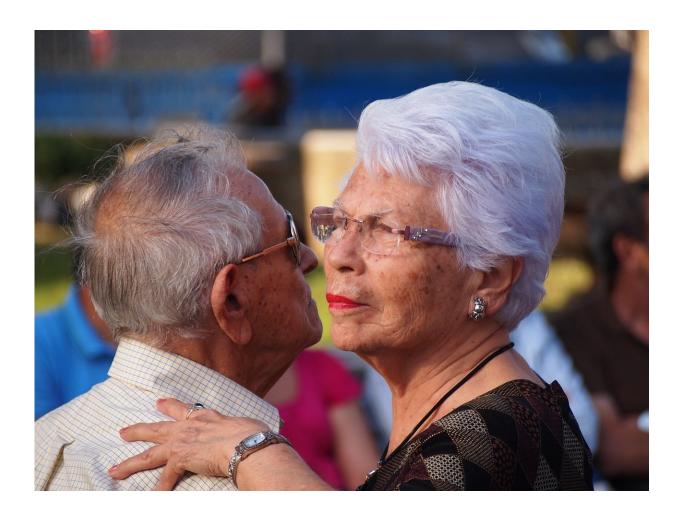


User-friendly tools help older adults guide future medical care

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A user-friendly website on advance care planning, as well as easy-to-read



advance directives, can be highly effective in empowering both Englishand Spanish-speaking older adults to plan for their future medical care, according to a study by researchers at UC San Francisco.

In the study of almost 1,000 older adults—of whom 541 spoke English and 445 spoke Spanish—researchers found that 98.1 percent reported increased engagement in advance care planning after reviewing an easy-to-read advance directive and website called PREPARE For Your Care, and 89.5 percent reported greater engagement after reviewing the advance directive alone. Advance care planning engagement included having discussions with family, friends and clinicians, and feeling more confident and ready to have these conversations.

The researchers also found that the medical records of both groups had high levels of new advance care planning documentation at 15 months, but was higher among those who reviewed PREPARE (43 percent) versus only the advance directive (32 percent).

"To our knowledge, this is the largest, most culturally diverse trial of patient-facing advance care planning interventions," said lead author Rebecca Sudore, MD, professor of medicine in the UCSF Division of Geriatrics, and staff physician at the UCSF-affiliated San Francisco Veterans Affairs Health Care System. "This is important because, historically, advance care planning rates have been very low among Spanish-speaking and diverse populations. These results suggest we can empower patients to plan for their future medical care in very scalable ways."

The study, which appears online Oct. 29, 2018, in *JAMA Internal Medicine*, showed that patient-driven initiatives can be effective in empowering both populations, even without clinician-driven interventions—a key factor for patients receiving care in resource-limited health settings.



Advance care planning allows people to prepare for future medical decision-making and communicate their values, goals and preferences for that care. Studies have shown that patients who complete such planning have greater satisfaction with their care and are more likely to receive medical care aligned with their wishes.

However, roughly two-thirds of U.S. adults—including those with serious illnesses—have not engaged in advance care planning, according to the Centers for Disease Control and Prevention. Efforts to encourage such planning have faltered because many clinicians lack the training, time and resources to have these discussions, and patients often feel unprepared for medical decisions and intimidated by legal advance-directive forms.

In the *JAMA Internal Medicine* study, Sudore and her colleagues conducted a randomized trial from February 2014 to November 2017 that studied 986 older patients living with chronic illness. Of those, 505 received an easy-to-read advance directive, and 481 received the advance directive and PREPARE website. Neither intervention required clinician involvement, training or education.

Launched by UCSF in 2013 with input from patients and caregivers from culturally diverse populations, PREPARE is a free, bilingual, online program that uses lay language and videos to guide users through five planning steps for medical decision-making, focused on exploring their wishes and learning how to discuss them with family, friends and medical providers. The site also provides tools to create a printable "Summary of Wishes," as well as privacy-protected, legally binding advance directives for all 50 states, in English and Spanish.

Study participants averaged 63 years old and were recruited from four primary care clinics in the San Francisco Health Network, a public health delivery system. More than half of the participants reported fair-



to-poor health, 40 percent had limited health literacy, and only 10 percent had documentation of advance care planning in their medical record in the prior 12 months.

At one year after enrollment, participants given PREPARE self-reported higher engagement in advance care planning at each follow up and had higher rates of advance care documentation in the medical record.

"Advance care planning is all about empowering patients to have a voice in their health care, to feel empowered to speak up about who they are as a person and what is most important in their life," Sudore said. "What most excites us about this study is that we were able to break down barriers to advance care planning by providing easy-to-use resources that English- and Spanish-speaking older adults can use on their own. We were able to do this by co-creating materials with and for diverse patients and without the need for additional clinical or health care system input."

More information: *JAMA Internal Medicine* (2018). <u>DOI:</u> 10.1001/jamainternmed.2018.4657

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