

Website launched to help patients prepare for complex medical decisions

4 January 2013

A new patient-friendly online resource called [PREPARE](#) has been developed to help people make complex medical decisions. The website was developed by researchers from the San Francisco VA Medical Center, UCSF, and NCIRE - The Veterans Health Research Institute.

The PREPARE website incorporates content identified in new research to address key patient- and surrogate-identified aspects of preparing for [advance care](#) planning and decision making. The site provides concrete examples through videos and other mechanisms on how to identify what is most important in life, how to communicate that with family and friends and doctors, and how to make informed medical decisions.

The resource is being launched by researchers who recently published a study on advance care planning in the [Journal of Pain and Symptom Management](#) (Nov. 27, 2012). The paper, entitled Advance Care Planning Beyond Advance Directives: Perspectives from [Patients](#) and Surrogates, identified gaps in planning for decisions about serious illness among a culturally diverse group of patients and [surrogate decision](#) makers, or individuals who have made medical decisions for others.

"There are few resources which can adequately prepare patients and their families to face serious illness or a medical crisis – situations which often involve complex decisions over time," said lead study author Rebecca Sudore, MD, SFVAMC geriatrician and [palliative medicine](#) physician and associate professor medicine at the UCSF School of Medicine.

"Advance directives are important, but they are just one piece of the puzzle," she said. "We wanted to develop a value-driven, easy-to-use tool to prepare people to make medical decisions that reflect their values and needs while preparing them to effectively communicate these wishes with others."

This study identified key themes critical to successful advance care planning that go beyond completing an advance directive form. These include successful surrogate selection and communication with the surrogate, determination of the surrogate's role, and communication with family and doctors.

The website's audio-visual interface is tailored to typically underserved populations (including users with low health or computer literacy and/or visual or hearing impairment) and aims to incorporate a patient-centered, comprehensive and manageable approach.

The PREPARE website is written at a fifth-grade reading level, and includes voice-overs of all text, closed-captioning for the hearing impaired, and large font for the visually impaired. In preliminary pilot testing, older adults from diverse backgrounds rated PREPARE a nine out of a 10- point-scale for ease of use, according to Sudore.

"We wanted to make the website free and easy-to-use by everyone," she said. "We made sure to take advice given to us by patients and surrogates. The site doesn't merely ask people to do advance care planning, but actually shows people, through videos and a step-by-step process, how to actually have the conversation and make informed medical decisions."

The study included 69 English and Spanish-speaking patients and surrogate [decision makers](#) who reported having to make serious [medical decisions](#) for themselves or loved ones. The mean age of patients was 78 years and 61 percent were non-white. The mean age of the surrogate decision makers was 57 years, and 91 percent were non-white.

Qualitative analysis revealed that [advance directives](#) were not enough to prepare patients and surrogates for medical decision making. Many

participants stated that solely focusing on treatments, such as mechanical ventilation, was not sufficient to help with the "many decisions" with which they were facing.

Provided by University of California, San Francisco

APA citation: Website launched to help patients prepare for complex medical decisions (2013, January 4) retrieved 27 October 2021 from <https://medicalxpress.com/news/2013-01-website-patients-complex-medical-decisions.html>

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