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VOLUME X Spring 2021

## FOCUS on Research

### Building the Foundation to Make Critical Decisions

For Rebecca Sudore, a Geriatrician and Palliative Medicine Physician, the scene in hospitals and critical care units had become all too familiar – family members confused and anguished as they decided with doctors the next medical steps for their seriously ill loved one. She described the grim stares as “a deer in headlights.” “What would mom (or dad) want?” was an often-uttered question that begged an answer.

Forms in the medical charts offered some instruction, but they were more bureaucratic than personal. Guidance was limited to checkboxes next to questions about do-not-resuscitate (DNR) and cardiopulmonary resuscitation (CPR). Sometimes, there were no forms at all.

In so many instances, an intensive care unit (ICU) patient had no friends or family present. “Clinicians, faced with making medical decisions, were morally distressed not knowing the wishes of the patient,” said Sudore, a UCSF Professor of Medicine and SFVAHCS Physician.

So, for more than the last 15 years, Sudore has dedicated much of her research to advance care planning, which allows people to designate a surrogate decision-maker for when a patient might be too ill or unable to voice those preferences. It also allows people to prepare for future medical decisions-making and to learn to communicate their values, goals and preferences for that care.



*Rebecca Sudore M.D.  
Professor of Medicine, Geriatrician, SFVAMC  
Professor of Medicine, UCSF*

“Studies show that only about one-third of U.S. adults, including those with serious illnesses, have engaged in advanced care planning. At the same time, three-fourths of adults will need someone to make a medical decision for them at some point in their lives,” said Sudore.

#### Making it understandable

First, she tackled the forms – advanced care directives – usually filled out and signed by patients before or when admitted to hospitals. The forms had tiny print fonts and scary legal language that even people with college degrees found difficult to understand.

Sudore worked with patients, family members, caregivers, social workers, nurses, doctors, lawyers, and community advocates to rework these forms into language that people, especially older people and patients with limited health literacy, could grasp.

In 2005, Sudore created California's first easy-to-read advance directive form in 10 different languages, which became a model for other states. Since then, Sudore and her team have created easy-to-read, legally valid advance directives for all U.S. states in English, Spanish, and for some states in Chinese.

She realized, however, that static forms alone were not enough. In 2010, she published a study calling for a shift in advance care planning from checklists to actively preparing patients and their loved ones for communication and medical decision making.

"Advance directives are important, but they are just one piece of the puzzle," she said.

But at that time there were few resources, tools and information that people could draw on to open the dialog on such difficult topics as serious illness, or even end-of-life care.

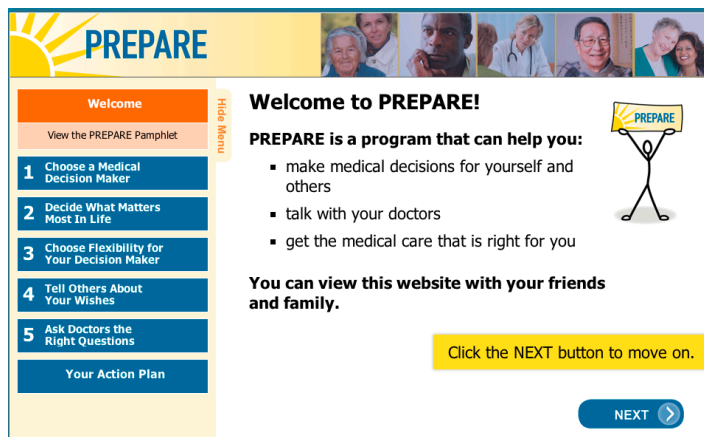
Sudore conducted focus groups of older people who had struggled with medical decision making for themselves and also included individuals who had made difficult medical decisions for other family and friends.

In these discussions, Sudore found that they were more concerned about what their lives would be like after a serious illness or injury, major treatment, or hospitalization. Their thoughts and questions ranged from: "I want to still run that marathon" and "Can I go out with my friends?" to "Can I care for myself?" or "Will I be a burden to my family?"

"Advance care planning is much broader than many may think. Traditionally, it was associated with end-of-life-care, but it is a process to support people at any age or stage of health," said Sudore.

Planning can assist when decisions have to be made about a blood pressure medication, post-surgical care, a cancer therapy, or when a loved one may have dementia.

"It's all about conversations, learning what's important to someone, and empowering patients to make choices for their health care," she said. "It's about asking "How do I want to live?"



## An online resource

With the feedback from the numerous conversations with patients and surrogate decision-makers, Sudore at UCSF and SFVAHCS developed a free, easy-to-understand advance care website – called PREPARE For Your Care ([www.prepareforyourcare.org](http://www.prepareforyourcare.org)) that launched in 2013.

In a step-by-step process, the website teaches users how to identify a potential surrogate or proxy decision maker, determine what is most important in life, talk to loved ones and make informed medical decisions.

PREPARE uses video stories to raise topics and demonstrate conversations, and the content is easy to understand. Like the advanced directives that Sudore and her team had remodeled earlier, the information is written at a fifth-grade level. It includes voiceovers of all text, closed-captioning for the hearing impaired and large fonts for those with poor vision. The website is culturally sensitive and features people from many ethnic backgrounds.

The PREPARE online program helps get to the crux of what matters most to people. Perhaps it's family and friends, hobbies, being able to work or volunteer, not wanting to be a burden to loved ones, or spirituality and religion.

Many people may not be ready to make decisions about their health. This is okay. PREPARE can help get the conversation going and build the foundation for future medical decision-making. If people are ready, the program can help people devise a written summary of their wishes or an advanced directive, including listing a surrogate to help communicate the patient's wishes if they become unable to do so.

Helping patients learn to communicate their wishes, either in conversation with clinicians or in written advance directive forms, certainly also serves frontline clinicians, who want to make sure a patient's care aligns with their wishes.

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### Testing the tool

Like any good research, however, it's not enough to develop tools and interventions – you have to find out if they work. And subsequent randomized trials have found promise and success.

Sudore and co-researchers conducted two separate trials with older adults from 2013 to 2017 – one with more than 400 Veterans at SFVAHCS and the other with 1,000 patients at the Zuckerberg San Francisco General Hospital. More than 500 of the patients were Spanish-speaking and 40 percent had limited health literacy.

The studies found that of those who used the PREPARE website and the easy-to-read advance directive, a remarkable 98 percent were able to engage in some form of advance care planning. When researchers looked at their medical records, they saw that those who reviewed PREPARE had increased advance care planning documentation rates by 43 percent. The increase was 32 percent for those who used only the advance directive.

“This is important, because historically, advance planning care rates have been very low among diverse and Spanish-speaking populations,” said Sudore. “The results show that we can empower people to plan for their future medical care in scalable ways.”

Over the years, PREPARE, which includes the interactive online program and video stories and the easy-to-read advance directives, continues to be refined, updated and improved based on feedback from the community. The online program is bilingual (English and Spanish), and developers hope to add additional languages when funding is available. To date, the website has attracted more than 350,000 visitors from 115 countries. And it now has advance directive forms for all 50 states in English and Spanish. Some forms, depending on the U.S. state, are in multiple languages.

### Important during pandemic

The COVID-19 crisis has brought to light the importance of advance care planning. Last spring, Sudore, along with a coalition of national and state health leaders, launched a public health awareness campaign to inspire people to talk to their families about their health care wishes and to designate a medical decision maker.

“During this pandemic, many hospitalized people may not be able to speak for themselves, and sadly, family and friends often cannot visit,” said Sudore, who co-led the coalition with UCSF members of the PREPARE for Your Care Program. “Our frontline health care providers are desperate for any information about their patients' medical wishes.”

One of the most time-consuming challenges health care workers were facing was finding their patients' health care proxy, and the PREPARE website has been a very important resource during the pandemic.

Sudore remains a vocal advocate for advance care planning. She often addresses health care, legal and civic organizations who are pushing efforts in their sectors. She is also a frequent guest speaker at senior and community organizations, where she demonstrates the PREPARE website.

She hopes someday that advanced care planning will be “normalized.” “If it is focused on preparing people to get the medical care that is right for them, who wouldn't want that?”

## Deprescribing Medications



*Michael Steinman, M.D.  
Director of Research Training Programs, Division of Geriatrics  
Geriatrician, SFVAMC  
Professor in Residence, Geriatrics, UCSF*

The proliferation of prescription drugs over the years has been a blessing and a curse.

For nearly every illness and discomfort, we now have multiple medications that can relieve symptoms and extend lives.

But those same drugs can cause harmful side effects, especially in older people who cram their medicine cabinets with prescribed remedies for ailments that come with age. Pills for high blood pressure, diabetes, cholesterol, pain, heartburn, anxiety, sleep, bone strength, memory – the list goes on.

“The more medications you take, the greater chance that at least one will cause an adverse effect,” said Michael Steinman, a UCSF Professor of Medicine and SFVAHCS Physician. “Plus, some medicines become more harmful when they interact with other medications.”

According to national data an estimated 40 percent of the U.S. adults 65 and over are taking five or more prescription drugs. This does not include over-the-counter drugs and supplements, which add to the conundrum. About 750 people 65 years of age and over are hospitalized every day in the U.S. because of prescription drug side effects, according to a 2019 report by the Lown Institute, a nonpartisan think tank.

During his internal medicine training in the early 2000s, medications were emphasized as the primary way to help patients, said Steinman. A few years later, as a practicing Geriatrician, he began to see first-hand the complications of polypharmacy.

Today, Steinman is a national leader in improving the quality of medication prescribing for older, sick people. Much of his research now focuses on “deprescribing,” which is the systematic process of reducing problematic medicines in a way that is safe, effective, and improves the health and well-being of older people.

There are many reasons for the cascade of prescriptions into a person’s regimen. During and after a hospitalization, drugs – for pain, transient changes in blood pressure that occur during hospitalization, or something that should be temporary – are added to a patient’s medication list, and they may never come off. Perhaps a previous specialist ordered a drug, and the current primary care doctor is wary of a health decline if the patient is taken off the medicine. Or a drug has been prescribed to combat the side effect of another drug.

Moreover, people often don’t link possible side effects such as fatigue, dizziness, muscle weakness, or even cognitive decline to a drug. “Sometimes, they may think that these are just symptoms of getting old,” said Steinman.

“They may also have so much trust in their doctors – and the drugs – that they just let it go,” he said.

In some cases, a drug is not working for the condition for which it was prescribed. Diabetes drugs, for example, may lower blood sugar to even dangerous levels. “Some sleep drugs don’t help people rest better at night; instead they can make you feel drowsy during the day,” said Steinman, who co-chairs an American Geriatrics Society panel which lists and advises on drugs that should often be avoided for older adults.

While prescribing drugs is easy, deprescribing them is complex.

“Halting a medication abruptly may cause harm. Some medications may need to be tapered slowly or require extensive follow-up to make sure patients don’t relapse or encounter a new set of side effects,” said Steinman.

“A good practice,” he said, “is scheduling a doctor visit specifically to go over every medication, what it’s prescribed for, the side effects, whether it’s working, if they really are needed, or what are non-drug options if you do decide to drop a medication.”

The health care system, however, is not built to deprescribe medications properly. While many would like to make an effort, many primary care doctors don’t have the time and resources to do so.

### National research effort

“We don’t know enough yet about how to best identify which medications are prime for deprescribing, how to best stop them, and how to engage clinicians, patients and our health system in the effort,” said Steinman.

To this end, Steinman is co-principal investigator of the U.S. Deprescribing Research Network, funded by a \$7.8 million grant from the National Institute on Aging. “What we need are evidence-based strategies to deprescribe drugs for older people who are overmedicated,” he said. And it’s not just about dropping drugs. “We’re really trying to optimize medications, stopping those that do harm, and if medications are necessary, prescribing them and ensuring they are properly used.”

Important in the research, led by UCSF and Johns Hopkins University researchers, is collaboration among many experts – doctors of various specialties, pharmacists, health systems administrators, advocates for older people – and patients themselves.

Researchers are already collecting and considering the patient perspective. They’re finding out that clinicians often fail to investigate what is important to the patient as they prescribe medications.

Maybe patients would rather forego the diuretic in favor of long car rides to visit grandchildren or other activities not interrupted by bathroom breaks. They have concerns– which may or may not be accurate but are nonetheless potent sources of worry - that aren’t often probed. What about long-term side effects? What will my liver, heart, or brain look like in 20 years if I keep taking this drug?

Perhaps there are non-drug alternatives. A walker or cane instead of pain medication for ailing knees. Decaf coffee or meditation instead of sleeping pills.

Any strategy or intervention to deprescribe drugs must be patient-centered, Steinman emphasized.

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A key research topic is how to discuss the possible signs and dangers of overmedication and with whom. They can be with doctors, pharmacists, informed family members, and others in the community. And how do health systems build the proper communication and rapport between patients and their providers?

“There’s much to uncover and research, if we are to develop effective interventions,” said Steinman.

An often-weary population of older people will be grateful for the research results.

**To learn more about the UCSF Department of Geriatrics, please go to:**

**<https://geriatrics.ucsf.edu/>**

## Q and A: An Interview with Dr. John R. McQuaid



*John R. McQuaid, PhD  
UCSF Vice Chair for the SFVAHCS,  
Associate Chief of Staff for Mental Health,  
SFVAHCS*

**Q: Before taking on important administrative duties, you were an active researcher. What are your areas of research interest?**

**A:** I am particularly interested in how to apply well-established, scientifically based principles of behavior change to a broad range of mental and physical health problems. I started my clinical research studying the role of stress in depression and substance use disorders, which led to studies of cognitive behavior therapy for comorbid depression and substance use disorders.

Other areas of research have included developing cognitive-behavioral social skills training for treatment of psychotic disorders, working on a treatment that combined motivational interviewing and cognitive-behavioral therapy for reducing high risk sex behaviors, and evaluating treatments for phantom limb pain.

I have also participated in research evaluating how to most efficiently screen for and detect mental health disorders in primary care settings,

given the importance of detection to allow treatment.

For most of this research I served as a Co-Investigator rather than the Principal Investigator and focused on the treatment or assessment development and evaluation component. Part of what I love about being in the VA is how it supports folks working together in collaborative groups to address key questions that are a direct benefit to Veterans.

**Q: How do your duties support the missions of SFVAHCS, UCSF and NCIRE?**

**A:** As Chief of Mental Health at SFVAHCS, I am responsible for assuring that all or our staff have the resources to meet all three ongoing VA missions: clinical care for Veterans, education, and research. Part of what is great being here is that the SFVAHCS is clearly dedicated to all three missions and the presence of NCIRE dramatically strengthens our ability on the research front and the affiliation with UCSF enhances both our research and education missions.

I have a number of pragmatic ways to support those mission both in terms of specific activities through the VA role and through facilitating coordination between the partner organizations. As chief, I am able to support faculty and staff by advocating for and accessing resources such as space, equipment and additional staff. I also can send the message that all three missions are co-equal and connect in our great responsibility of supporting Veterans.

As a member of the NCIRE Board and as a Vice Chair in the Department of

Mental Health, I can work across all three systems to help these partners to compliment and support each other.

**Q: How important is the research arm of these missions?**

**A:** I see the three VA missions as critical to each other. We have a responsibility to both provide the best clinical care possible to Veterans, and to train new providers how to be better than we are now.

To best achieve these missions requires not just reviewing research but being actively engaged in creating the new knowledge that is going to make possible that excellent care and education. The research mission continually drives excellence in the entire mission.

**Q: What makes the SFVAHCS a successful research institution? How do Veterans contribute to this success?**

**A:** These are two distinct questions. The SFVAHCS is particularly strong for three reasons. First, the leadership of the hospital has continuously recognized the value that the research mission brings to the Veterans we serve and therefore has committed to prioritizing that mission consistently. Without that consistent commitment, it is difficult to maintain a stellar research institution.

Second, the partnerships with both UCSF and NCIRE have been particularly effective in aligning with the VA mission. There are many strong academic affiliates and research institutes throughout the VA system, but I think what I see here is a

combination of institutional excellence in all three settings combined with a focus on collegiality and collaboration that makes us more efficient and effective than other sites of which I am aware.

Third, because of these first two points we continuously recruit and support exceptional scientists who are drawn to that environment. Having a place where these values are put into action makes meaningful differences in the day-to-day lives of the researchers. In terms of the role of Veterans, one of the most inspiring aspects of doing science in the VA is the commitment of Veterans to serving other Veterans. We call Veterans and active-duty military “service members.” Service to others and country is central to their identity and DNA. The willingness

of Veterans to serve in this role is part of that long commitment to their country, and our research and mission would be weaker without all they do.

**Q: What are some of the challenges in maintaining a strong research enterprise?**

**A:** I think the big challenges vary a bit across services. For us in mental health, I think continuing to have adequate resources, and particularly space is critical. The VA has invested heavily in infrastructure here, and as that comes to fruition it will provide us with a pathway to an excellent future. Second, continuing to make sure we are supporting scientists at all levels of the career ladder from trainees through our senior international experts keeps a fertile, vibrant intellectual

environment creating new work and generating exciting advancements.

**Q: What would most people be surprised to know about you?**

**A:** I guess one thing might be my heavy commitment to nerdism, having been a committed Dungeons & Dragons player in high school and college and even engaging in some live action role playing (LARPing) back in college as well. I also love studying U.S. History, and part of what I love being in the VA is that I am serving people whose lives directly helped shape the world we live in today.

## In the Helix



Ryan Calica  
Buyer III, NCIRE



Daisy Chow  
Administrative Analyst IV, NCIRE



Julia Yu  
Accounts Payable Specialist, NCIRE

**Q: What’s the best piece of advice you’ve ever been given?**

**A:** When times are rough, going through the ups and downs of life, always remember to smile through the pain, be brave for the unknown, and be disciplined to keep moving forward. At the end of the day, you have to live your own life.

**Q: What’s hardest part about working virtually for you? Easiest?**

**A:** Hardest part: Internet and computer access can be challenging sometimes. Also, to come up with lunch ideas for the kids. Easiest part: Flexibility and no need to commute. I can work in my PJs.

**Q: If you could eat only one meal for the rest of your life, what would it be?**

**A:** I would pick fried rice because it is a comfort food that has a little of everything to keep me going, vegetables, eggs, meat, and rice.

# NCIRE introduces the ClinCard as an alternative method to pay research subjects



On December 1, 2020, NCIRE launched the ClinCard as a more efficient way to pay research subjects. The ClinCard is a reloadable debit card and through the ClinCard portal, research coordinators can seamlessly pay subjects with a few clicks. The goal of the ClinCard is to optimize clinical trial performance by improving participant engagement and retention while eliminating the administrative burdens that can distract from research execution.

Benefits of the ClinCard:

- Instant payment execution; no need to submit paper requests
- Save time and effort for site staff
- Enhance patient engagement and retention
- Eliminate cash and checks

For further details, please contact Newton Ong [newton.ong@ncire.org](mailto:newton.ong@ncire.org) or Christy Huang [Christy.huang@ncire.org](mailto:Christy.huang@ncire.org)

## Message from the Chief Executive Officer

We are very proud to bring you the first issue of DNA for 2021. The content was specifically chosen to reflect the current situation, the one-year mark since the start of the COVID-19 era.

March 5th is one of the annual standard NIH application deadlines, and our Contracts and Grants Department worked diligently with the research community to submit this year's applications. It is very reassuring to see that there was no change in the number of applications submitted between March 2020 and March 2021. NCIRE submitted seven prime applications and one subcontract. While it will be at least nine months before there is a funding decision, we wish all applicants the best!

In February NCIRE launched an [employee satisfaction survey](#). The survey is aimed at securing employee feedback on a wide range of areas. We take this feedback seriously and will take all comments into consideration. The data compiled will be made transparent and will be used to compare with future survey results.

Thank you for taking time to read our 2021 Spring Newsletter and learn about recent NCIRE activities. We look forward to seeing you again in the coming months as the COVID crisis abates.

Rebecca Rosales, MBA, CRA  
Chief Executive Officer

## About NCIRE

NCIRE - The Northern California Institute for Research and Education has one mission and one goal: Advancing Veterans Health. We sustain a scientific community of clinicians and researchers and support over 200 researchers who have joint faculty appointments at the University of California, San Francisco (UCSF) and the San Francisco VA Health Care System (SFVAHCS) and are working to foster innovation through leadership in the field of Veterans health research. Our broad portfolio of projects receives generous support from the National Institutes of Health, the Department of Defense, and individual donors, making us the largest nonprofit research institute devoted to Veterans health in the US.

NCIRE is a 501(c)3 nonprofit. (Tax ID #94-3084159). Visit NCIRE at [www.ncire.org](http://www.ncire.org)



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