Making Advance Care Planning Easier for Vulnerable Populations

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UCSF

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Consensus Definition of ACP

- **Definition:** “ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

- **Goal:** The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”

Sudore et al., Delphi Panel Consensus Definition. JPSM 2017

ACP is a Process

Readiness to Engage

Life Course

Advance Care Planning (ACP)

- Why is ACP so hard?

- Can we make it easier?

Objectives

- Health literacy, language, culture

- Make ACP easier:
  - Consider an alternative approach
    - Use a 3-step process
  - Easy-to-use, patient-facing tools
  - Getting ACP out to the community

- ZSFG Ethics
- > 15% ICU pts unrepresented
- Low ACP rates

White DB, Crit Care Med. 2006

CALIFORNIA
ADVANCE HEALTH CARE DIRECTIVE

Explanation

You have the right to give instructions about your own health care. You also have the right to name someone else to make health care decisions for you. This form lets you do either or both of these things. It also lets you express your wishes regarding donation of organs and the designation of your primary physician. If you use this form, you may complete or modify all or any part of it. You are free to use a different form.

Part 1 of this form is a power of attorney for health care. Part 1 lets you name another individual as agent to make health care decisions for you if you become incapable of making your own decisions or if you want someone else to make those decisions for you now even though you are still capable. You may name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to make decisions for you. (Your agent may not be an operator or employee of a community care facility or a residential care facility where you are receiving care, or an employee of the health care institution where you are receiving care, unless your agent is related to you, is your registered domestic partner, or is a co-worker. Your supervising health care provider can never act as your agent.)

Unless the form you sign limits the authority of your agent, your agent may make all health care decisions for you. This form has a place for you to limit the authority of your agent. You need not limit the authority of your agent if you wish to rely on your agent for all health care decisions that may have to be made. If you choose not to limit the authority of your agent, your agent will have the right to:

(a) Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition;
(b) Select or discharge health care providers and institutions;
(c) Approve or disapprove diagnostic tests, surgical procedures and programs of medication; and
(d) Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation;
(e) Make anatomical gifts, authorize an autopsy, and direct the disposition of your remains.

Part 2 of this form lets you give specific instructions about any aspect of your health care, whether or not you appoint an agent. Choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, as well as the provision of pain relief. Space is provided for you to add to the choices you have made or for you to write out any additional wishes. If you are satisfied to allow your agent to determine what is best for you in making end-of-life decisions, you need not fill out part 2 of this form.

Part 3 of this form lets you express an intention to donate your bodily organs and tissues following your death.

Part 4 of this form lets you designate a physician to have primary responsibility for your health care.

After completing this form, sign and date the form at the end. The form must be signed by two qualified witnesses or acknowledged before a notary public. Give a copy of the signed and completed form to your physician, to any other health care providers you may have, to any health care institution at which you are receiving care, and to any health-care agents you have named. You should talk to the person you have named as agent to make sure that he or she understands your wishes and is willing to take the responsibility.

You have the right to revoke this advance health care directive or replace this form at any time.

Health Literacy

- "The degree to which individuals have the capacity to obtain, *process,* and understand basic health information and services needed to make appropriate health decisions."

- Average reading level = 8th grade
  - Medicaid and the **elderly = 5th grade**

National Adult Literacy Survey: http://nces.ed.gov/naal/

Language Considerations

- 61 million people in U.S. (~20%) speak language other than English at home
  - 40 million Spanish, 3.4 million Chinese

- Lack of linguistically-appropriate materials

2012, US Census Bureau; Pérez-Stable, EJ & Karliner, LS,. J Gen Intern Med 2012; Sudore, et al., Patient Educ Couns 2009 June; Schenker Y, et al., Ann Intern Med. 2008 Aug

Cultural Considerations

- Non-Western views on autonomy & decision making
  - ~20% do not want to make own medical decisions

- Experiential racism & mistrust

Crawley L, et al.,. JAMA. 2000; Kwak J, et al., Gerontologist. 2005; Singh JA,et al.. Am J Manag Care. 2010; Smith AK, et al. JAMA. 2009 ; Gordon HS, et al. Cancer. 2006; Rhodes R, Teno JM. J Clin Oncol. 2009

Easy-to-Read Advance Directive (AD)

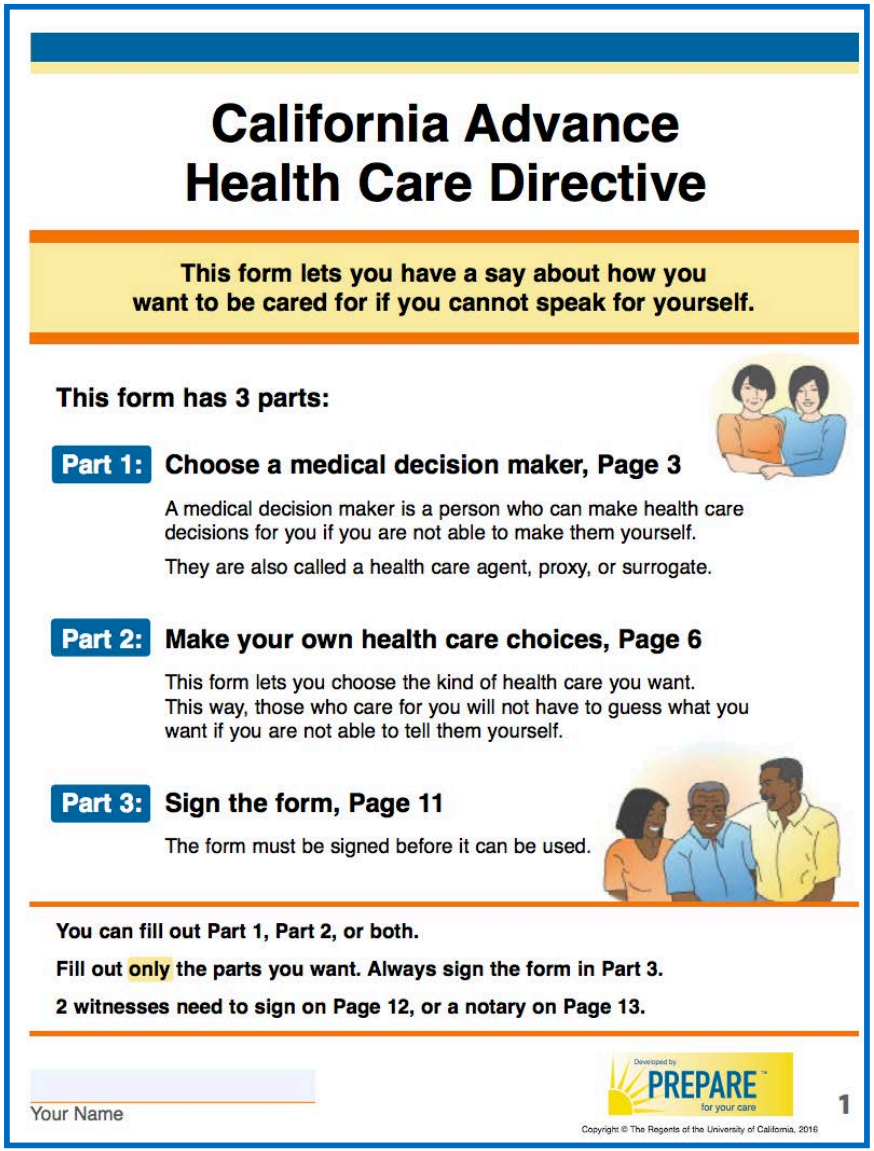
RCT:

- Doubled completion rates
- Overwhelmingly preferred

regardless of literacy/ language

10 languages

www.PrepareForYourCare.org



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1: Choose a medical decision maker, Page 3

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

They are also called a health care agent, proxy, or surrogate.

Part 2: Make your own health care choices, Page 6

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3: Sign the form, Page 11

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 12, or a notary on Page 13.

Your Name

Developed by PREPARE for your care

1

Sudore RL et. al., Patient Educ Couns 2007

Objectives

- Health literacy, language, culture

- Make ACP easier:
  - **Consider an alternative approach**
    - **Use a 3-step process**
  - Easy-to-use, patient-facing tools
  - Getting ACP out to the community

Traditional Objective of ACP

- To have patients make treatment decisions in advance of serious illness in an attempt to provide care consistent with their goals.

- Advance directives/POLST most often used
  - Clinicians & lawyers like check boxes
  - Are you DNR/DNI…yes or no?

Advance Directives Are Helpful

- Teno J. et. al., JAGS 2007
  - AD = better communication between surrogate & doctor, but still high stress
- Silveira M. et.al., April 2010 NEJM:
  - AD preferences = care received "last days"
  - But, all proxy report 2 yrs later (recall bias)
  - What is still unknown:
    - Do ADs shape decisions in last months or years?

Problems with only Advance Directives

- Not available when needed (POLST, EMR may help)
- Do not improve knowledge of patients' preferences
- Do not always affect care/costs at the end-of-life
- Do not prevent surrogate stress or conflict

Hickman SE. J Am Geriatri Soc. 2010; **Perkins HS**. Ann Intern Med. 2007; **Fagerlin A**. Hastings Cent Rep. 2004; Halpern SD, JAMA IM 2012

Are Advance Directives Enough?

“We got the DNR in writing. But in making the decisions, which there were many, that was just one. Because the first decision was to put him in a nursing home. We were married 30 years and I could no longer take care of him (tearful). Then the second decision was whether to put him on a feeding tube because he had stopped eating and I wasn’t ready to let him go.”

Sudore RL et. al., J Pain and Symptom Management, 2013

Forms and checkboxes

- No form or checkbox will ever eliminate the uncertainty and the complexity of the human condition.

- People need better preparation

First Steps

What Do We Discuss?

- For terminal patients who are not ready?
- For non-terminal patients with chronic illness?
  - Focused on LST, or more than that?
- How do we help **prepare people** for these discussions & decisions?

Problems with Treatment Decisions

- Focus on treatment decisions is flawed:
  - -Prediction
  - -Adaptation
  - -Extrapolation

McMahan, et. al. Journal of Pain & Symptom Manage. 2013

Problems with Prediction

- People cannot predict what will have for dinner/buy
- Predictions do not reflect one's current
  - Medical
  - Emotional
  - Social context
- Preferences change during:
  - Changing AND stable health, & end-of-life

Halpern J, et. al.,J Gen Intern Med. 2008; **Loewenstein G**. Med Decis Making. 2005
Ubel PA. Med Decis Making. 2005; **Fried TR, et. al.,** Arch Intern Med. 2006

Uncertainty @ Hypothetical Scenarios

- 50% of diverse older adults who reported a treatment preference based on a hypothetical scenario were uncertain about their decision

- Uncertainty associated with:
  - Limited literacy, lower education
  - Latino, Asian/Pacific Islander, African Am.
  - Poor health status

Sudore RL & Schillinger D, et. al., J Health Comm. 2010 in press
Allen RS. **et.al.,** *J Am Geriatr Soc, 2008*; **Volandes AE, et. al,**. Med Decis Making. 2005

Prediction

"I don't think people know how they're going to feel until they're faced with the situation. They may have all kinds of theoretical ideas or something they read in Dear Abby, but when the time comes, you may be very surprised at your own reaction to something….I mean it's not as easy as black and white. There are so many gray areas."

McMahan, et. al. Journal of Pain & Symptom Manage. 2013

Problems with Adaptation

- People cannot envision being able to cope with disability…but they can.
  - Report desire to forgo treatment in such states
  - Once in states, more willing to accept invasive tx

Ubel PA, et. al., Health Psychol. 2005; **Fried et. al**., Arch Intern Med. 2006
Winter L, et. al., Int J Aging Hum Dev. 2003

Problems with Extrapolation

- Decisions about less invasive treatments
  - Surgery, chemotherapy, nursing home

- Prior wishes in light of unforeseen clinical circumstances
  - e.g., DNI in setting of cancer may need to be re-evaluated during acute heart failure

Gillick MR. N Engl J Med. 2004; **Perkins HS**. Ann Intern Med. 2007

Adaptation & Extrapolation

"Nothing's written in stone and you can't know to say, "Well this is what I want. Do not resuscitate." But then the situation at hand can be totally different to where you do or don't have a chance of them resuscitating you."

McMahan, et. al. Journal of Pain & Symptom Manage. 2013

Now What?

Why Not Just Designate a Surrogate Decision Maker?

Why Not Just Designate a Surrogate?

- Surrogates do not know they were chosen
- Knowledge of preferences no better than chance
- Stress, anxiety, PTSD
- Use own hopes, desires and needs

Berger JT, et.al., Ann Intern Med. 2008; **Fagerlin A, et.al.,** Health Psychol. 2001
Fried TR, et. al., J Gen Intern Med. 2008; **Sudore RL.,** JAMA, 2009

Why Not Just Designate a Surrogate?

Grandfather: “I am tired and not afraid of dying. No breathing tubes!” “No shocks and no pushing on my chest. Just let me go.”

Grandmother: “Of course I would tell the doctors to do everything possible to keep my husband alive.”

Sudore RL., JAMA, 2009

Now What?

Why Do Anything in Advance?

Why Prepare Patients & Surrogates?

- Clinicians cannot make recs or guide in decision making w/o patients' values and needs.
  - Highly individual
  - Can only be provided by patient/surrogate

- Without **preparation**, patients and surrogates not able to communicate values effectively
  - Stress & no prior relationship with doctors

Perkins HS.. Ann Intern Med. 2007; **Torke AM, et. al.,** J Gen Intern Med. 2009

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Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

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Life sustaining treatments

Preparation for communication & decision making

Prepare For In-The-Moment Decision Making

- Shifts focus away from only asking people to make treatment decisions (only AD/POLST)

- Seeks to also **PREPARE** people with skills to:
  - identify what is most important to them (evolving)
  - communicate with surrogates & providers
  - make informed medical decisions over time

- **Advance directives should be a marker of full preparation & reflect discussions over time**

Sudore RL. & Fried TR. *Ann Intern Med, 2010*

How Best to PREPARE

What Matters Most→ the Outcome

- What matters most is not the treatment BUT the **<u>outcome of treatment</u>**
- Not intubation or CPR (the cart)

but how their life will be after treatment (the horse).

Fried TR, et. al., N Engl J Med. 2002; **Quill TE.** JAMA. 2000; McMahan. J of Pain & Symptom Manage. 2013; **Lockhart LK, et. al**., Death Stud. 2001 & **Pearlman RA, et. al.,** Arch Intern Med. 2005

What Matters Most→ the Outcome

"Are we reviving him – sticking the tube in – so that he can suffer more? I guess it goes back to what happens IF you revive him? Is he going through that whole process again? It's the end result."

McMahan, et. al. Journal of Pain & Symptom Manage. 2013

Stories Frame Values About Outcomes

- Prior stories about self, friends/family

- Media (e.g.,Terri Schiavo)
  - 92% English/Spanish-speakers heard of Terri
  - Due to the case and media coverage:
    - 61% clarified own goals of care
    - 66% spoke to family
    - 8% spoke to their doctor (missed opportunity)

Quill TE. JAMA. 2000; **Sudore RL, Schillinger D, et. al.** J Gen Intern Med. 2008

Reflect on Changes in Their Story

- Reflect on whether changing or adapting to serious illness
  - Helps better predict preferences

- As disease trajectory progresses, more specific:
    - "When you were in the hospital with heart failure…, when you were in the ICU/intubated"

Ubel PA, et. al., J Exp Psychol Appl. 2005; **Goldstein NE, et. al.,** Arch Intern Med. 2008

Surrogates Need Preparation

- 50-76% of patients will be unable to participate in some or all of their own decisions at the EOL

- Surrogates report:
  - Unprepared to make med decisions
  - Never asked, do not know their role
  - Process as highly stressful

Silveira MJ,et. al., N Engl J Med. 2010; **Torke AM, et. al**., J Gen Intern Med. 2009
Vig EK, et. al., J Gen Intern Med. 2007; **Fried TR, et. al.,** J Gen Inte

Surrogates Need Preparation

"The only thing that I managed to talk to my father about was if anything should happen and his heart should stop…That was the extent of how much I knew what his wishes were. The other stuff we were guessing at is to, you know, whether he would want to be home or in a hospice…"

McMahan, et. al. Journal of Pain & Symptom Manage. 2013

Surrogate Leeway

- Surrogates may need to make decisions that conflict with patient's preferences
  - Cannot honor wish to die at home
  - Asked to w/d care or may benefit from transient treatment
- Surrogate burden eased by giving them permission to consider factors other than prior wishes during in-the-moment decision making = **Leeway**

Vig EK, et. al., J Gen Intern Med. 2007; **Fried TR, et. al.,** J Gen Intern Med. 2008
Lo B, et. al., Arch Intern Med. 2004

Surrogate Leeway

- How much leeway should your physician and surrogate have to override this advance directive if overriding were in your best interest?
  - 39% no leeway
  - 19% a little leeway
  - 11% a lot of leeway
  - 31% complete leeway
- **Ethically**, still an extension of patients autonomy

Sehgal A, et. al. *JAMA.*1992

Surrogate Leeway

"I am ready to go but if it helps your grandmother to feel that she did everything possible for me, even if it is because she doesn't want me to go, that is OK. She is the one who has to go on living with her decision. If this is what she wants, then this is what I want because I love her."

Sudore RL., JAMA, 2009

3 ACP Steps for Clinicians

1) Choose a surrogate, ask the surrogate

2) Clarify values about the outcome of treatment
   -how their life will be…not just about CPR
   -re-assess over time for changes in wishes

3) Establish leeway in surrogate decision making
   -permission to change prior decisions

Sudore RL., Fried TR. Redefining the 'Planning' in Advance Care Planning.
Ann Intern Med, 2010

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Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

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Table 2. Steps to Prepare Patients for In-the-Moment End-of-Life Decision Making*

Step 1: Choosing an appropriate surrogate decision maker

Opening: "As your clinician, it would be helpful to know who to contact if you were to become really sick."

Step 1 Surrogates→ Stories

"Is there anyone you trust to make medical decisions for you?"

"Does this person know you chose him/her for this role?"

"What have you talked about?"

Step 3: Establishing leeway in surrogate decision making

Opening: "If your loved ones have to make medical decisions for you, they have to think about what you said in the past, but also about what the doctors are telling them about your medical condition and what they are able to do for you. If these differ from one another, this can be very stressful for your loved one."

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Step 2 Values: →Stories

"How do you define good quality of life?"

"Have you seen someone on TV or had someone close to you who had serious illness?"
What went well/did not go well? Why?

"If you were in this situation (again), what you would you hope for?

Step 3: Establishing leeway in surrogate decision making

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Step 2: Clarifying Values

SPECTRUM

- Some people say that life would **always be worth living** no matter what type of serious illness, disability, or pain they may be experiencing.
- Other people feel that there **may be some health situations** or experiences that would make life not worth living, such as never being able to wake up from a coma or never being able to talk to family or friends.
- What type of person are you? Why?

ACADEMIA AND CLINIC

Annals of Internal Medicine

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Step 3 Leeway:

"Is it is OK to use your medical wishes as a general guide – to change your decisions if your doctors think it is best at that time?"

"Or, are there some decisions you **never** want changed even if the doctors are recommending it?"

Step 3: Establishing leeway in surrogate decision making

Opening: "If your loved ones have to make medical decisions for you, they have to think about what you said in the past, but also about what the doctors are telling them about your medical condition and what they are able to do for you. If these differ from one another, this can be very stressful for your loved one."

Translating Their Story

- "Based on what you told me about:"
  - What brings your life meaning
  - How you felt about your loved one's experience
  - How you felt about your last hospitalization

- "It sounds as though X may be something that you would/would want for yourself. Is this correct?"

Objectives

- Health literacy, language, culture

- Make ACP easier:
  - Consider an alternative approach
    - Use a 3-step process
  - **Easy-to-use, patient-facing tools**
  - Getting ACP out to the community

Missing Puzzle Piece

- **PREPARE** people with skills to:
  - identify what is most important and how they want to live
  - talk with family and friends
  - talk with medical providers
  - make informed decisions
  - get the care that is right for them

Online Advance Care Planning Tool in English & Spanish

www.prepareforyourcare.org

Creating PREPARE

- Social Cognitive Theory
- Health Belief Model
- Theory of Planned Behavior
- Stages of Change

Theory at a Glance: A guide for health Promotion Practice, NCI

Why a Patient-facing Website?

- Lack time/resources, dissemination, tell a story

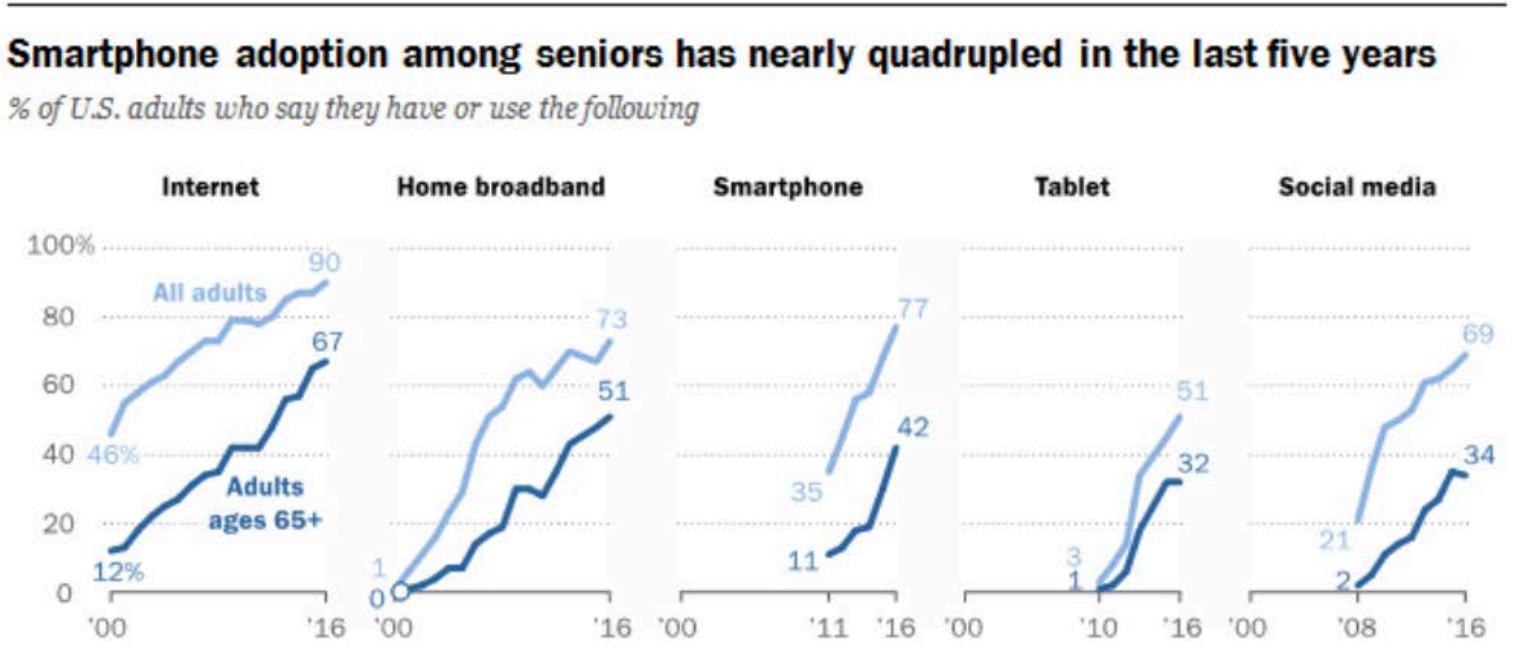


Image: Pew Research Center

Creating PREPARE

- Expert panel
  - Health Literacy
  - Geriatrics & Palliative Care
  - Behavior change
- 13 focus groups*
  - Patients, surrogates
- Cognitive interviews
- **Videos that model behavior: *HOW***

* **Sudore RL et. al.,** J Pain and Symptom Management, 2012

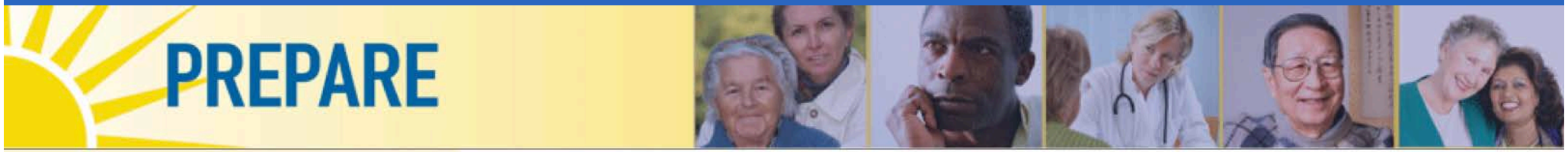
Creating PREPARE

- Easy to understand
  - 5th-grade reading level, large font
  - Voice-overs & closed captioning

- Balanced content of videos:
  - Race/ethnicity, gender
  - Aggressive vs. comfort care
  - Surrogate availability, ~ 15% socially isolated
  - Decision making preferences, ~ 20% no decisions

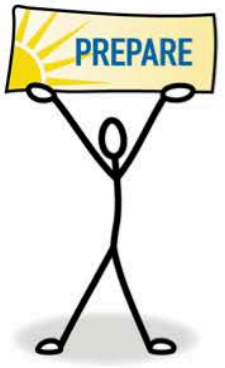
* **Sudore RL et. al.,** J Pain and Symptom Management, 2012

Interactive, multi-media website
prepareforyourcare.org



Hide Menu

Welcome to PREPARE!



PREPARE is a program that can help you:

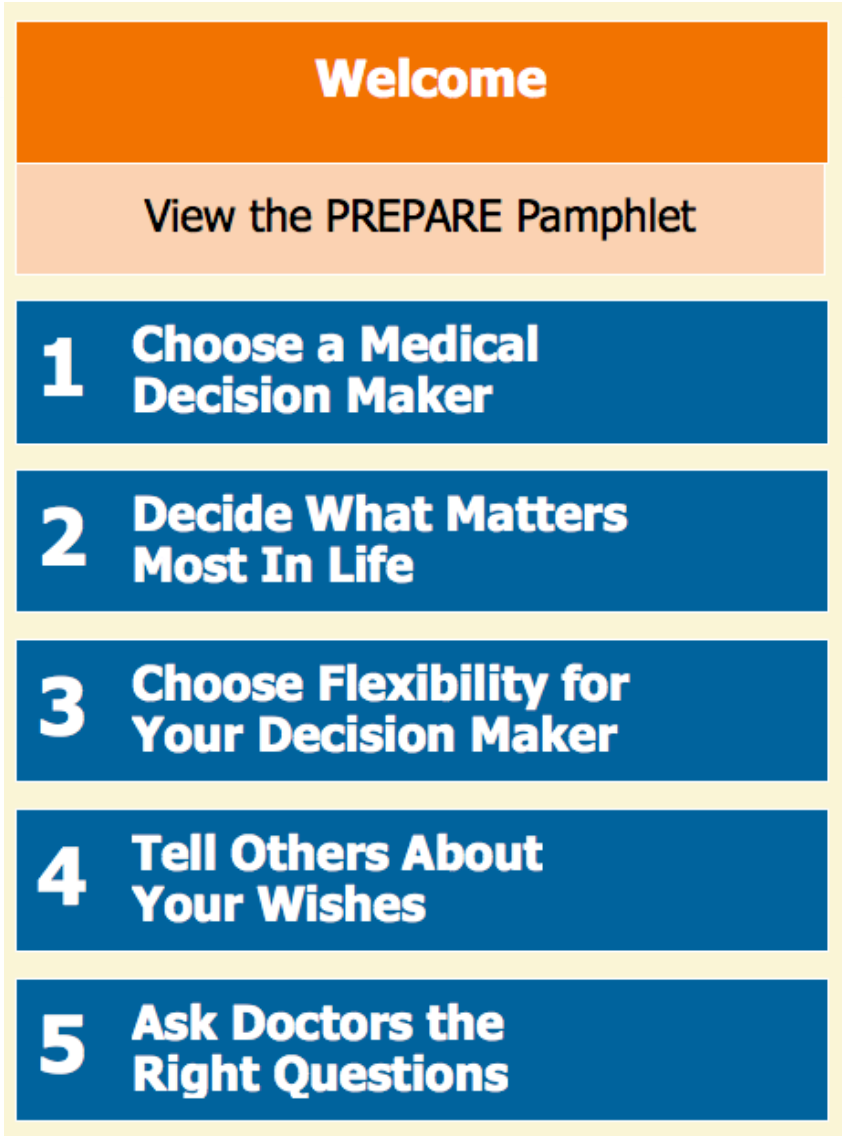
- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.

NEXT

5-Steps of PREPARE



How to do it

Show Menu

How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.

How to Say It

PREPARE

Show Menu

How to Ask Someone to be Your Decision Maker

How to say it:

"My doctor thinks it is important to choose someone to help make medical decisions for me in case I get sick in the future and cannot make my own decisions. If this happens, would you be willing to work with my doctors to help make medical decisions for me?"

This is one example. Your situation may be different.

GO BACK

NEXT

How to Overcome Barriers

PREPARE

Show Menu

Choosing a decision maker can be hard.

Here are some examples of how other people made it easier.
Click the pictures to see their stories.

For **Jorge**, thinking about it was scary

Click to Play

Helen would rather leave her health to prayer

Click to Play

Click the NEXT button to move on.

GO BACK

NEXT

How to Tell Others

PREPARE

Show Menu

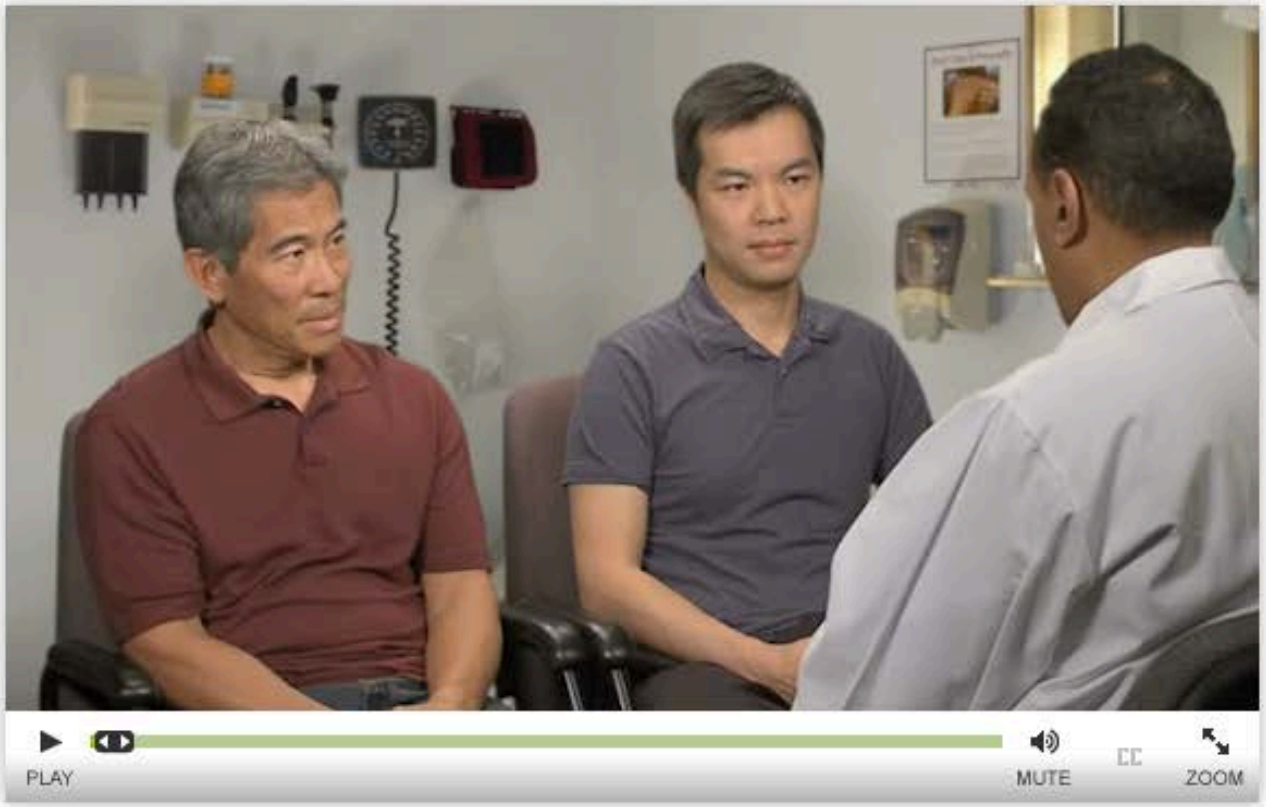
How To Tell Others About Your Wishes

How to Ask Questions

PREPARE

Show Menu

How To Ask Doctors the Right Questions



Name: Rebecca S

Summary of My Wishes

Step 1: Choose a Medical Decision Maker

- You have chosen and asked John Doe (your spouse/partner) to be your decision maker
- You want John Doe to make medical decisions for you only if you cannot make your own decisions

Step 2: Decide What Matters Most in Life

- What is most important to you are: family and friends, religion, living on your own and caring for yourself, not being a burden on your family
- You feel that there may be some health situations that would make your life not worth living, such as never being able to wake up from a coma
- You want to try treatments for a period of time, but stop if you are suffering

Step 3: Choose Flexibility for Your Decision Maker

- You chose TOTAL flexibility in medical decision making for your decision maker

Step 4: Tell Others About Your Wishes

- You told your decision maker about your wishes. But you have not yet told your doctor and family and friends

Step 5: Ask Doctors the Right Questions

- When making decisions with your doctor, you want to share decision making with your doctor
- You **WOULD** want your doctor to tell you how sick you are or how long you have to live

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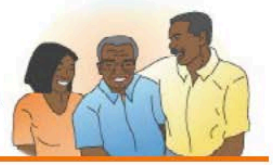

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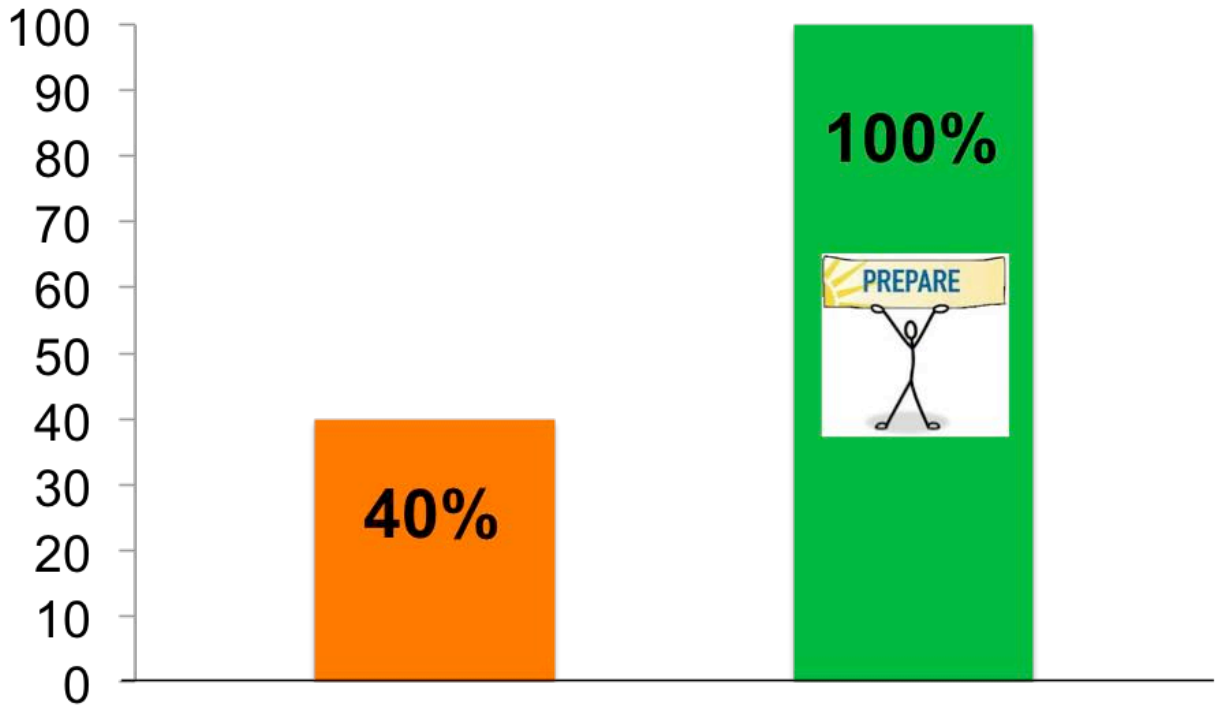
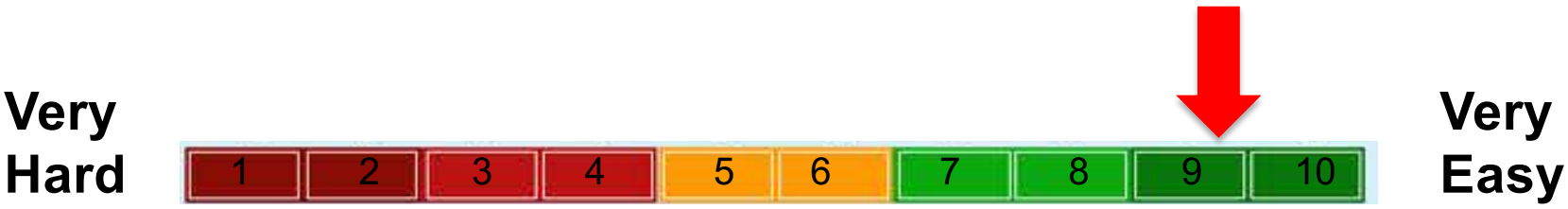
Your Name

Developed by PREPARE for your care

PREPARE Improves Patient Engagement in ACP

- Senior centers, 70 years, 92% never used a computer





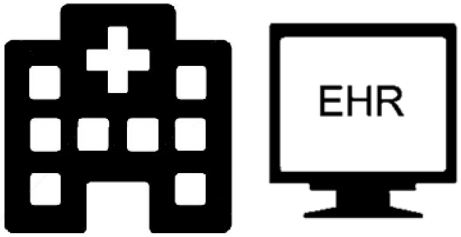
Sudore, et al., Journal of Pain & Sympt Manag, 2013

JAMA Internal Medicine

2 RCTs : 1400 patients
- VA
- Safety net, English & Spanish

ACP

Clinician or Facilitator

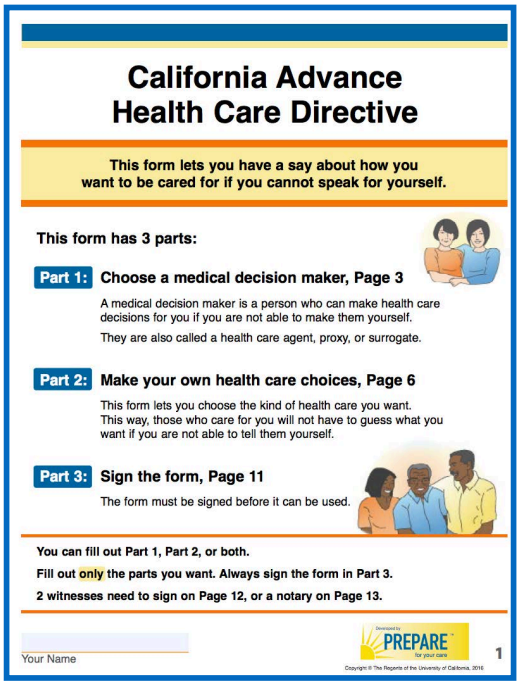


Healthcare System

Patient

UCSF San Francisco VA Medical Center
Division of Geriatrics

Intervention: Patient-facing ONLY



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1: Choose a medical decision maker, Page 3

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

They are also called a health care agent, proxy, or surrogate.

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This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3: Sign the form, Page 11

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 12, or a notary on Page 13.

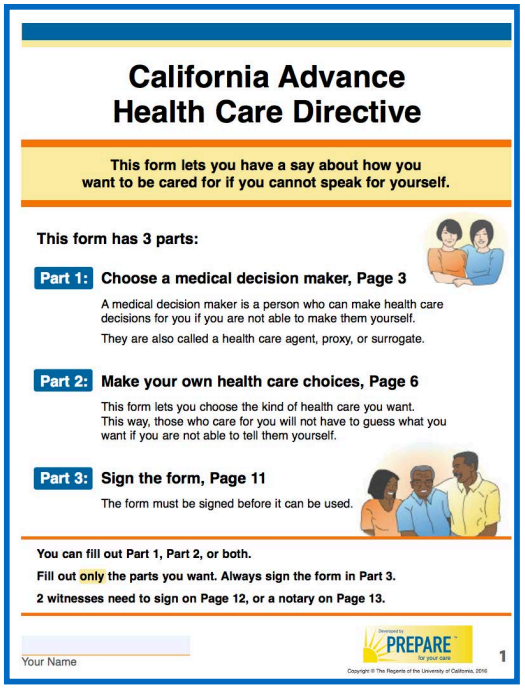
Your Name

PREPARE

1

vs.

+



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Your Name

PREPARE

1

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VA: PREPARE Increased ACP Behavior Change > AD Alone, VA n =414

- Self-efficacy
- Readiness
- Discussions

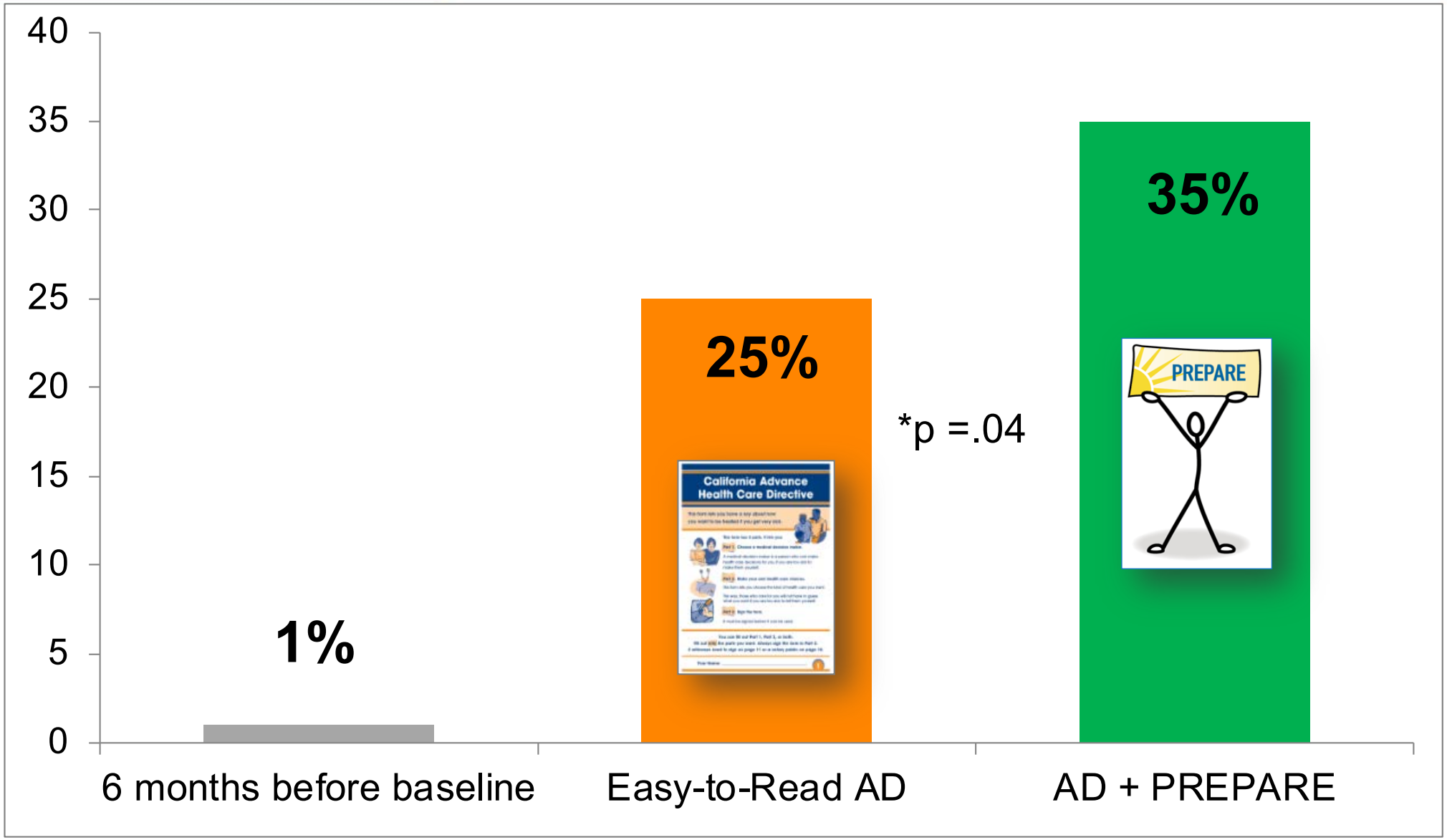
PREPARE+AD

AD-only

Overall p< 0.001

- **>90% engaged**

PREPARE & Easy-to-Read AD Increase ACP Documentation in the EMR

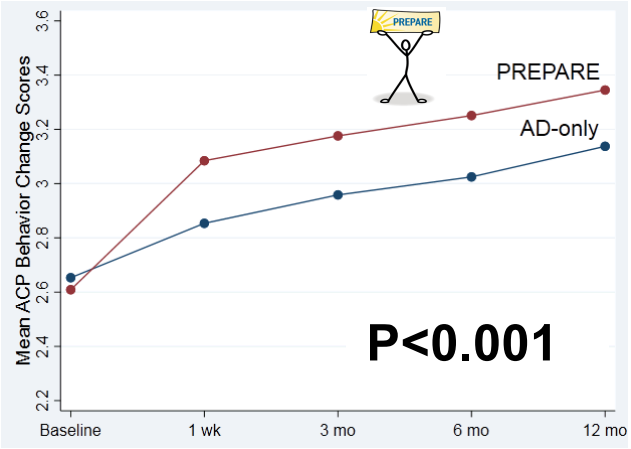


ZUCKERBERG SAN FRANCISCO GENERAL Hospital and Trauma Center

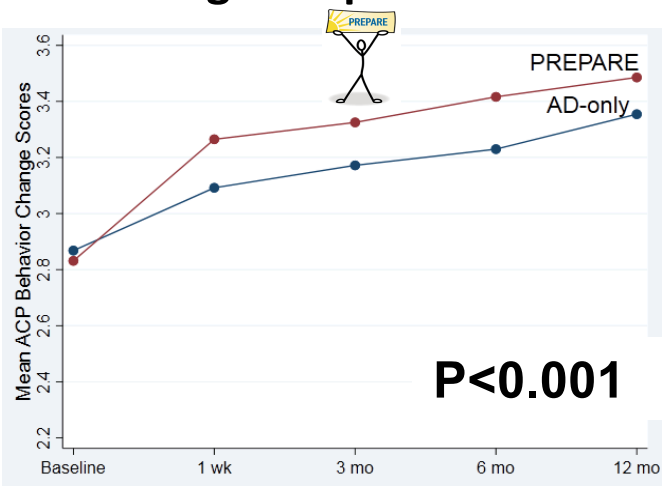
ZSFG Patients, n=986		
	AD-only n=505	**PREPARE+AD n=481**
Mean Age (SD)	63 (6)	63 (6)
Women	62%	62%
Spanish-speaking	**45%**	**46%**
White, non-Latino	20%	17%
Fair-to-poor health	49%	53%
Limited health literacy	**40%**	**39%**
Internet access	53%	48%

PREPARE Increased Behavior Change > AD Alone

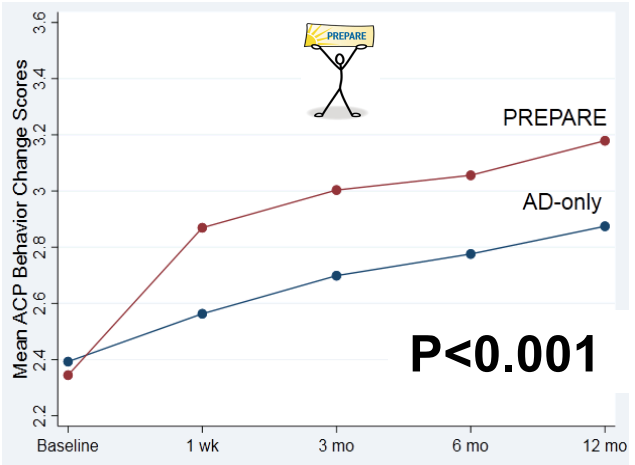
All Participants



English-Speakers



Spanish-Speakers



>98% engaged

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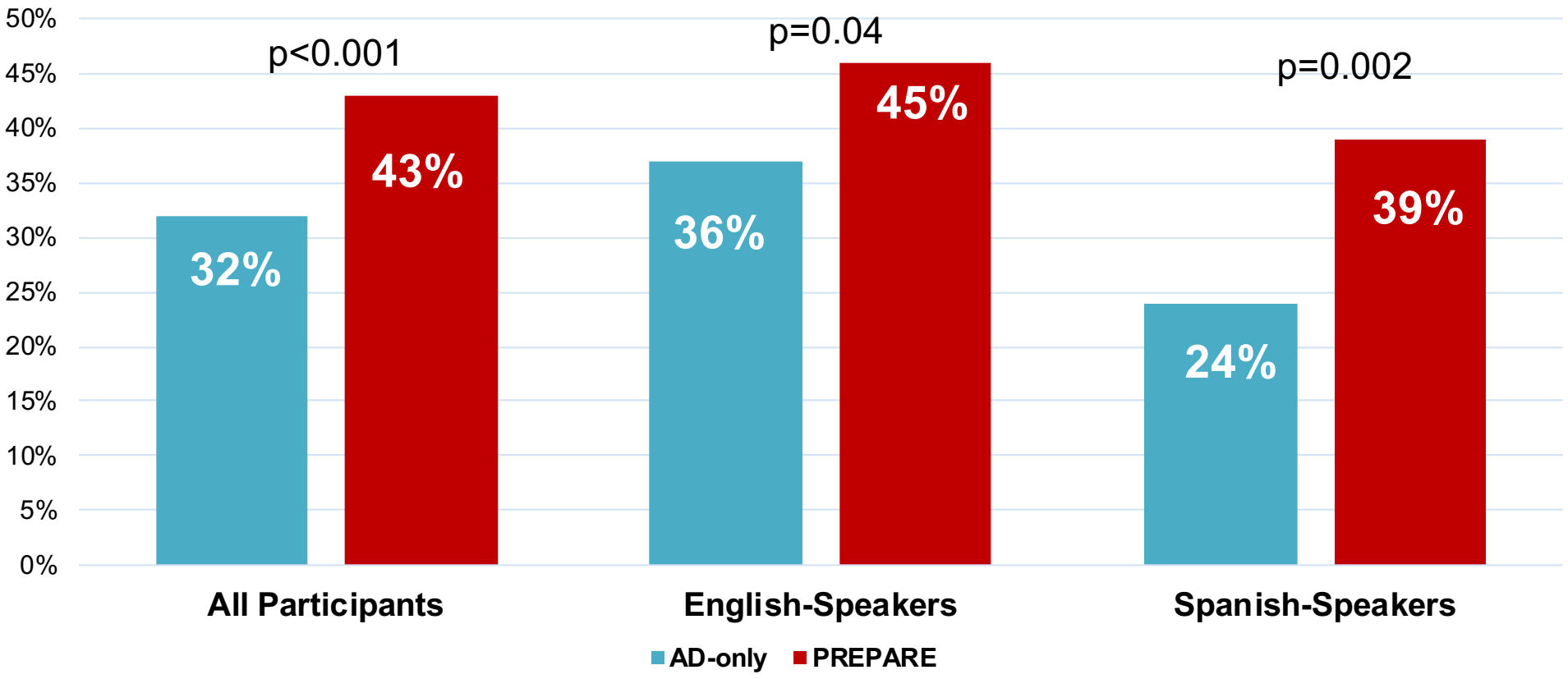
PREPARE & Easy-to-Read AD Increased ACP Documentation in the Medical Record



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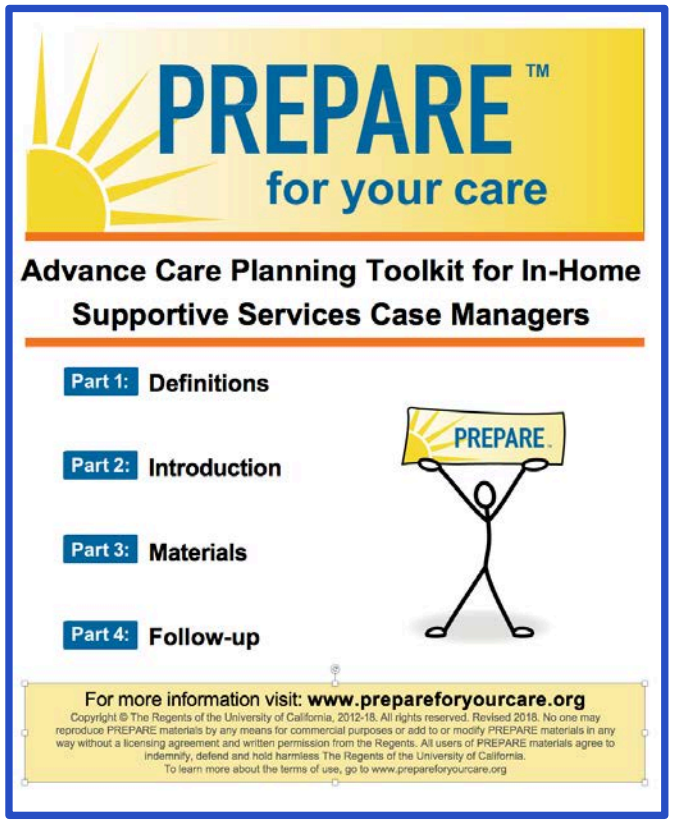
Current Collaborations



Dept of Aging and Adult Services

Incarcerated
Brie Williams, MD

Cognitive Impairment & Caregivers

Homeless Supportive Housing
Margot Kushel, MD

Seeking Funding

- Chinese PREPARE　準備

Objectives

- Health literacy, language, culture

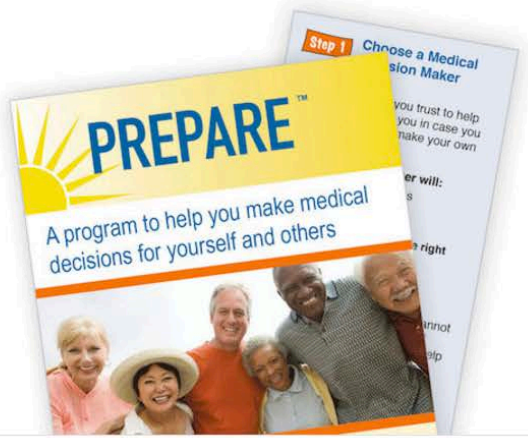
- Make ACP easier:
  - Consider an alternative approach
    - Use a 3-step process
  - Easy-to-use, patient-facing tools
  - **Getting ACP out to the community**

ACP Out to the Community

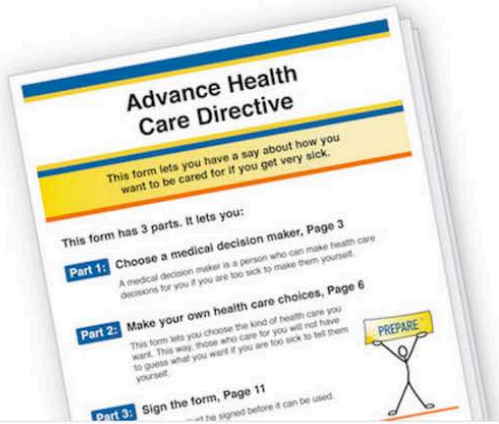
- PREPARE Tools
- PREPARE Movie Events
- Epic EMR
- Pragmatic Trials UC
- Community Dissemination

FREE PREPARE Tools

Get the PREPARE Pamphlet



Get the PREPARE Easy-to-Read Advance Directive

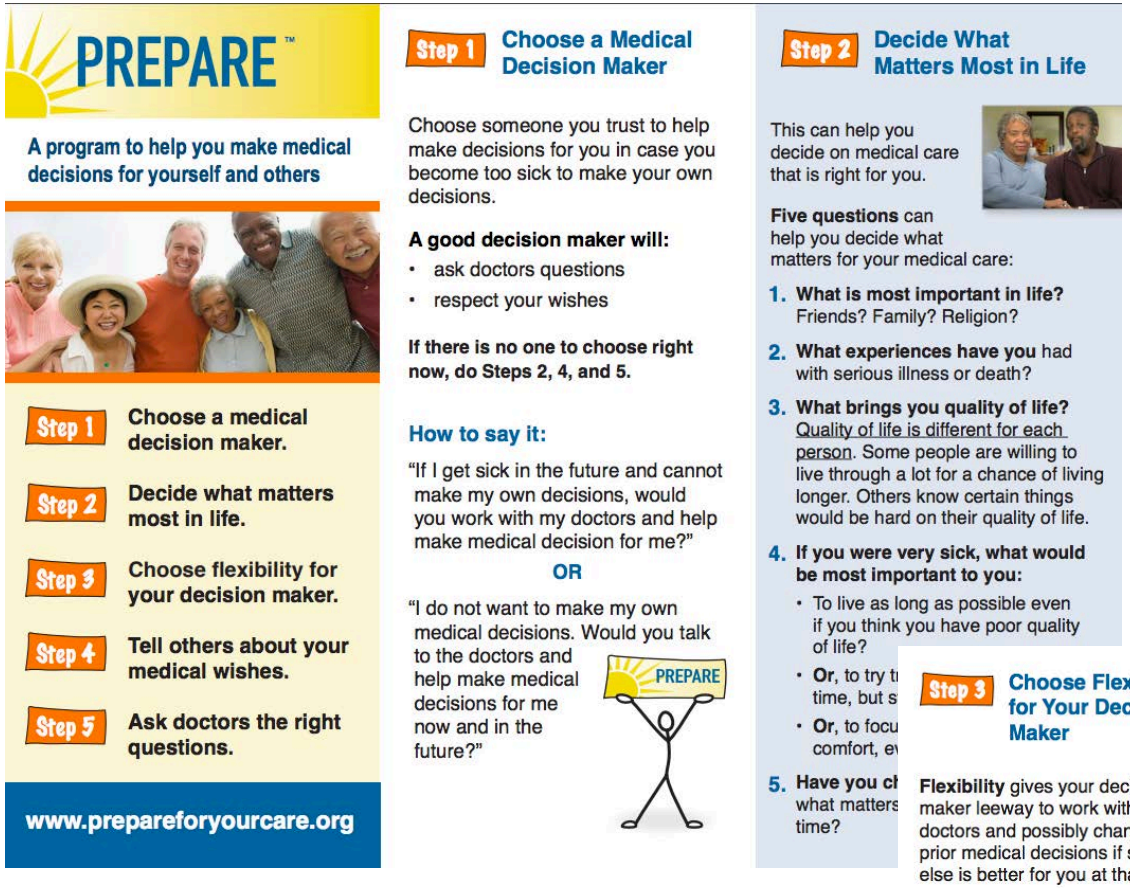


PREPARE™ for your care

PREPARE Question Guide

UCSF San Francisco VA Medical Center
Division of Geriatrics

PREPARE Pamphlet



PREPARE™

A program to help you make medical decisions for yourself and others

Step 1 Choose a medical decision maker.

Step 2 Decide what matters most in life.

Step 3 Choose flexibility for your decision maker.

Step 4 Tell others about your medical wishes.

Step 5 Ask doctors the right questions.

www.prepareforyourcare.org

Step 1 Choose a Medical Decision Maker

Choose someone you trust to help make decisions for you in case you become too sick to make your own decisions.

A good decision maker will:

- ask doctors questions
- respect your wishes

If there is no one to choose right now, do Steps 2, 4, and 5.

How to say it:

"If I get sick in the future and cannot make my own decisions, would you work with my doctors and help make medical decision for me?"

OR

"I do not want to make my own medical decisions. Would you talk to the doctors and help make medical decisions for me now and in the future?"

Step 2 Decide What Matters Most in Life

This can help you decide on medical care that is right for you.

Five questions can help you decide what matters for your medical care:

1. **What is most important in life?** Friends? Family? Religion?
2. **What experiences have you** had with serious illness or death?
3. **What brings you quality of life?** Quality of life is different for each person. Some people are willing to live through a lot for a chance of living longer. Others know certain things would be hard on their quality of life.
4. **If you were very sick, what would be most important to you:**
   - To live as long as possible even if you think you have poor quality of life?
   - **Or**, to try t… time, but s…
   - **Or**, to focu… comfort, e…
5. **Have you ch…** what matters… time?

Step 3 Choose Flexibility for Your Decision Maker

Flexibility gives your decision maker leeway to work with your doctors and possibly change your prior medical decisions if something else is better for you at that time.

How to say it:

Total Flexibility:

"I trust you to work with my doctors. It is OK if you have to change my prior decisions if something is better for me at that time."

Some Flexibility:

"It is OK if you have to change my prior decisions. But, there are some decisions that I never want you to change. These decisions are…"

No Flexibility:

"Follow my wishes exactly, no matter what."

Step 4 Tell Others About Your Medical Wishes

This will help you get the medical care you want.

How to say it:

To your decision maker and doctors:

"This is what is most important in my life and for my medical care…"

To your doctor and family and friends:

"I chose this person to be my decision maker and I want to give them (TOTAL, SOME, or NO) flexibility to make decisions for me."

Your doctors can help you put your medical wishes on an advance directive form.

Step 5 Ask Doctors the Right Questions

- **Write down** questions ahead of time.
- **Bring someone** with you.
- Tell doctors at the **start of the visit** if you have questions.

How to say it:

If your doctor recommends something, ask about the:

- **Benefits** – the good things that could happen
- **Risks** – the bad things that could happen
- **Options** for different kinds of treatment
- **What your life will be like** after treatment

Make sure you understand:

"What I'm hearing you say is… Is this right?"

Your Action Plan

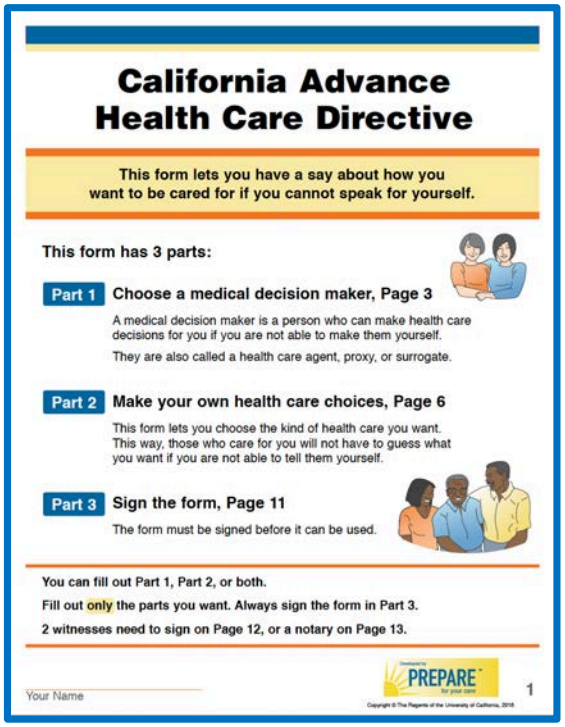
Action Plan

By _____

I will _____

Trifold
English, Spanish,
Chinese

New Easy-to-read ADs for all 50 States in English & Spanish



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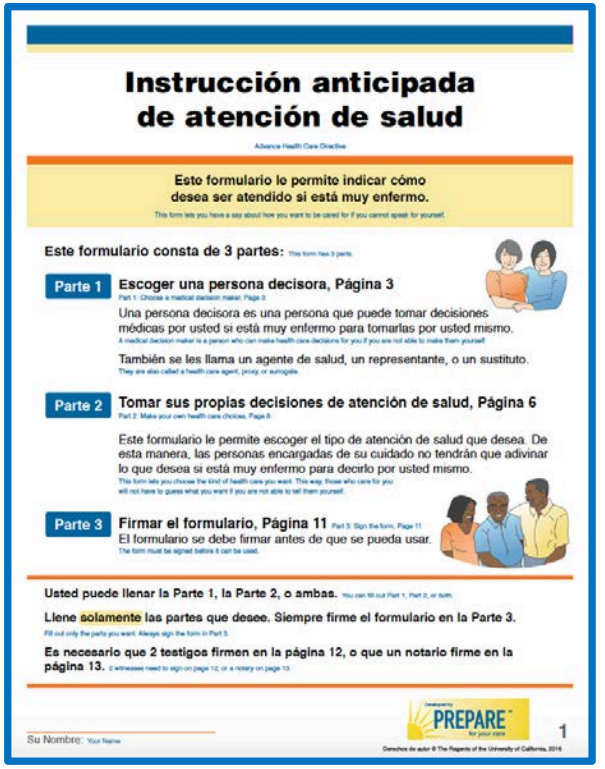
Your Name

PREPARE

1



Instrucción anticipada de atención de salud

Este formulario le permite indicar cómo desea ser atendido si está muy enfermo.

Este formulario consta de 3 partes:

Parte 1 **Escoger una persona decisora, Página 3**

Una persona decisora es una persona que puede tomar decisiones médicas por usted si está muy enfermo para tomarlas por usted mismo.

También se les llama un agente de salud, un representante, o un sustituto.

Parte 2 **Tomar sus propias decisiones de atención de salud, Página 6**

Este formulario le permite escoger el tipo de atención de salud que desea. De esta manera, las personas encargadas de su cuidado no tendrán que adivinar lo que desea si está muy enfermo para decirlo por usted mismo.

Parte 3 **Firmar el formulario, Página 11**

El formulario se debe firmar antes de que se pueda usar.

Usted puede llenar la Parte 1, la Parte 2, o ambas.

Llene solamente las partes que desee. Siempre firme el formulario en la Parte 3.

Es necesario que 2 testigos firmen en la página 12, o que un notario firme en la página 13.

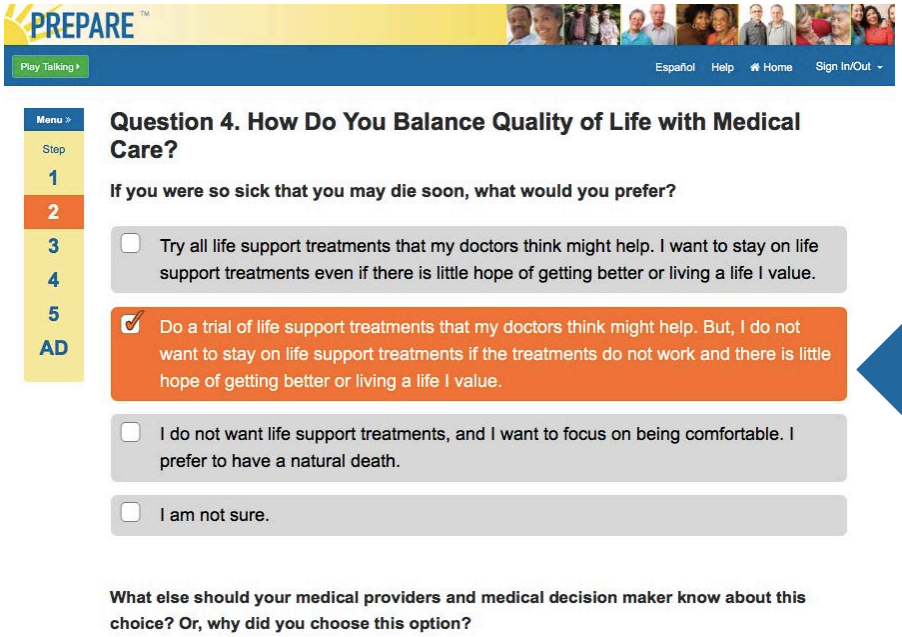
Su Nombre:

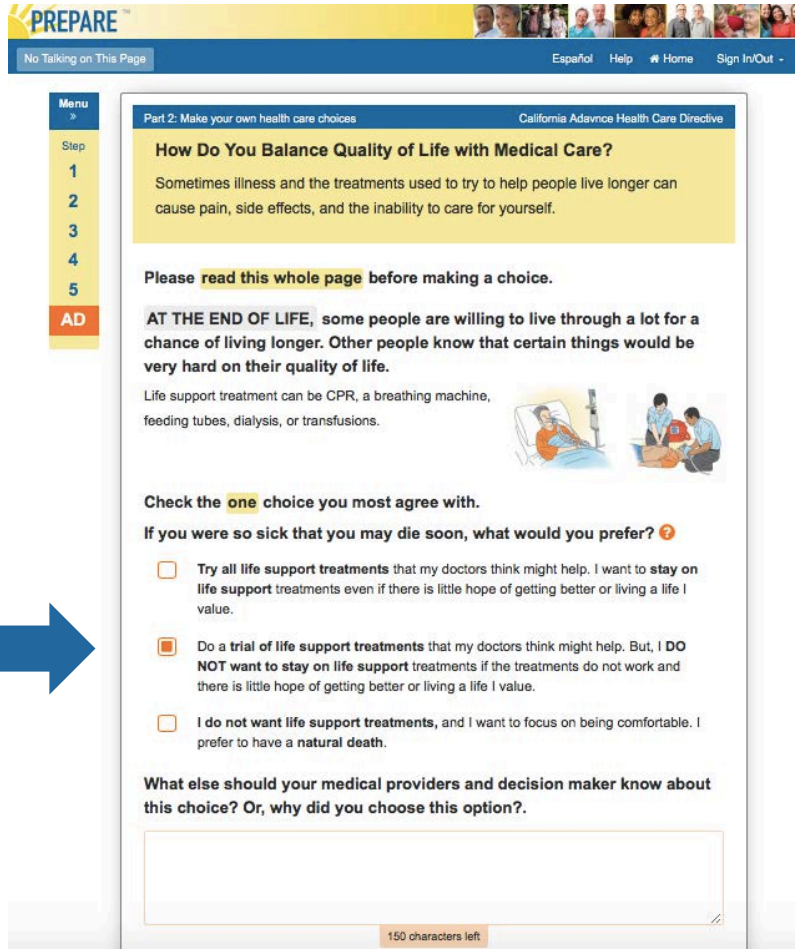
PREPARE

1

PREPARE Pre-populates an AD

- Tailored answer automation





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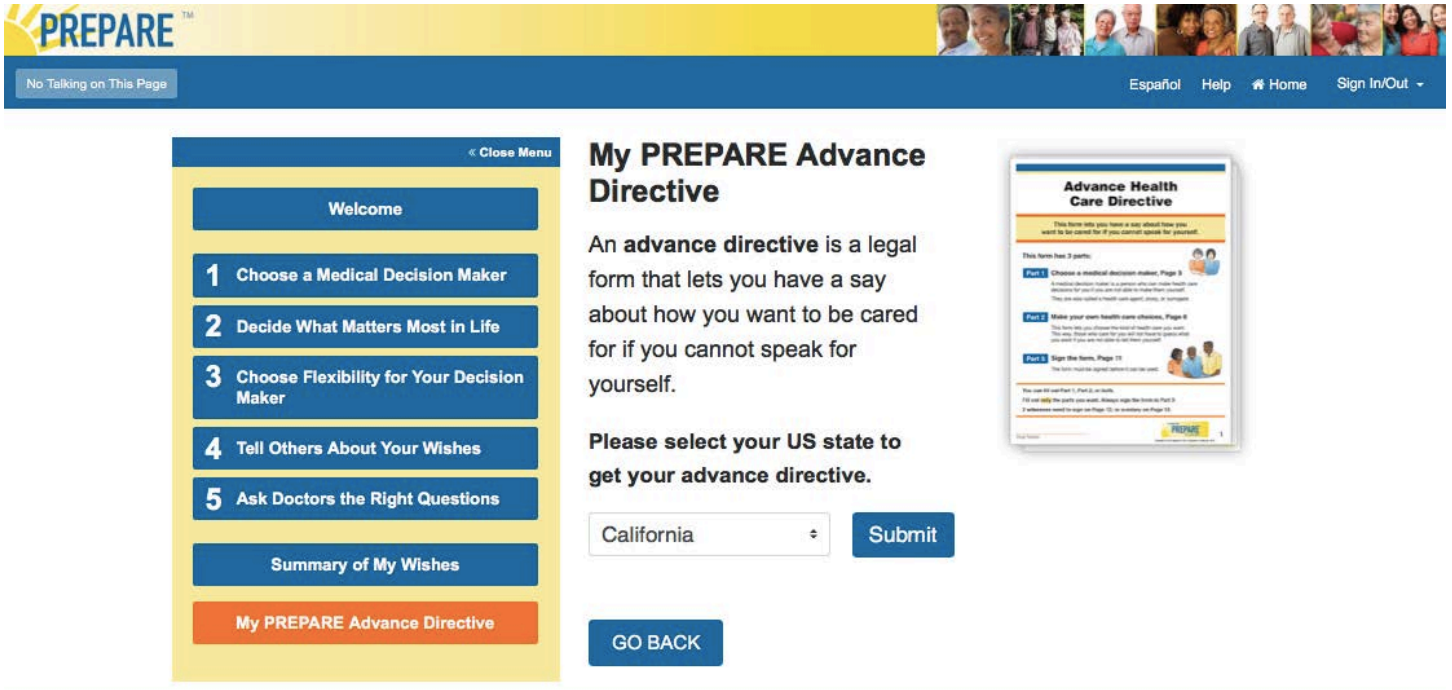
Division of Geriatrics

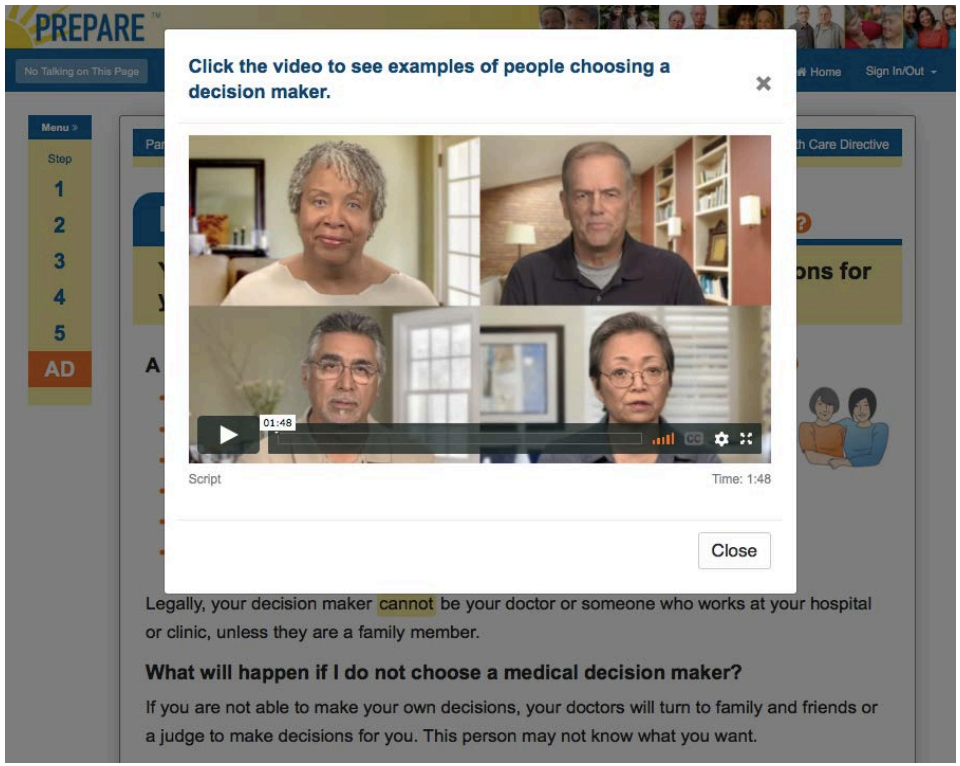
Guided AD Step

- Integrates and guides users to complete the AD



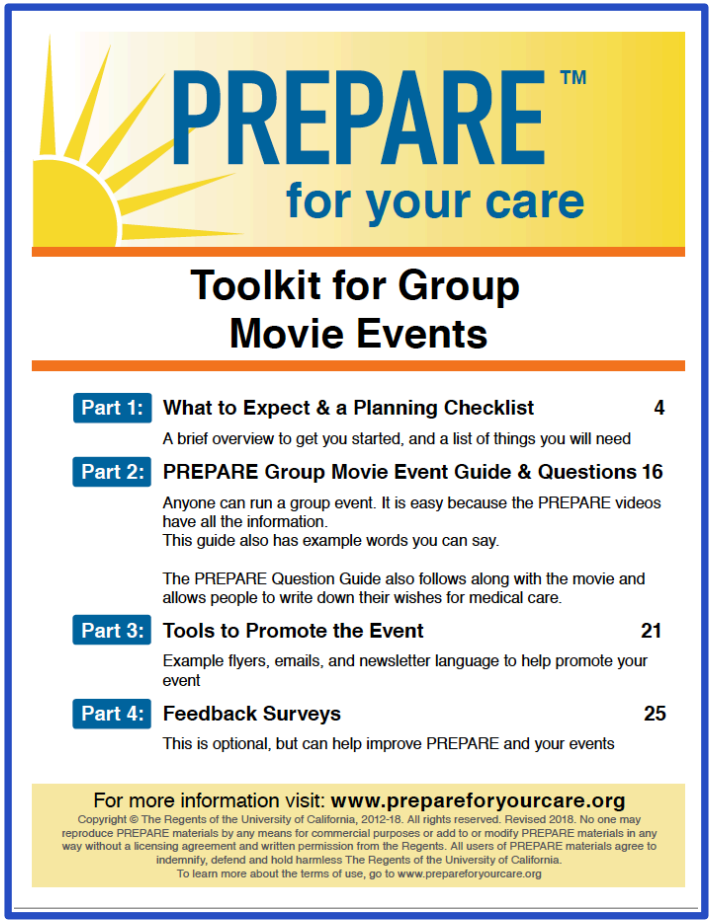
Guided AD Step

- Additional information and videos available if needed



UCSF San Francisco VA Medical Center
Division of Geriatrics

PREPARE as a Movie



PREPARE™
for your care

Toolkit for Group Movie Events

For more information visit: **www.prepareforyourcare.org**

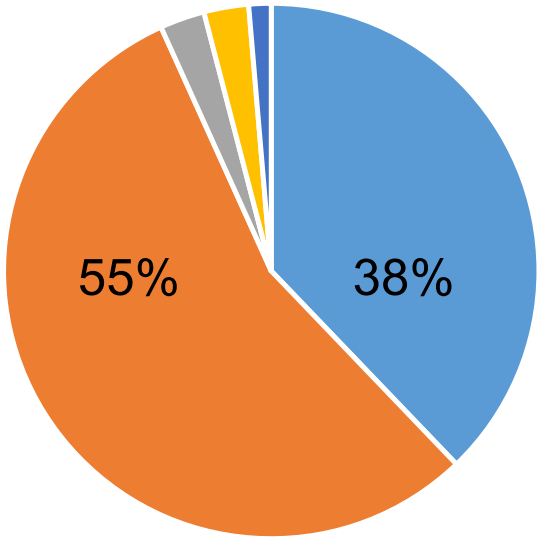
<u>Toolkits</u> for creating movie events for libraries, churches, senior centers, group medical visits

→ **NO TRAINING REQUIRED**

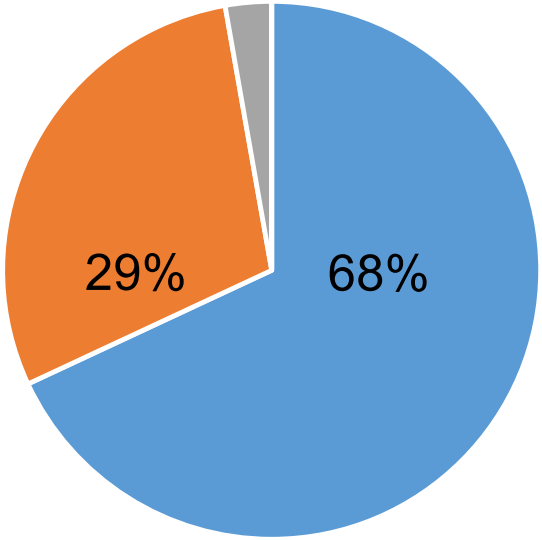
Movie Toolkit Testing
100% rated easy to understand

N=75

Ready to answer questions about preferences (93%)



Recommend session (97%)

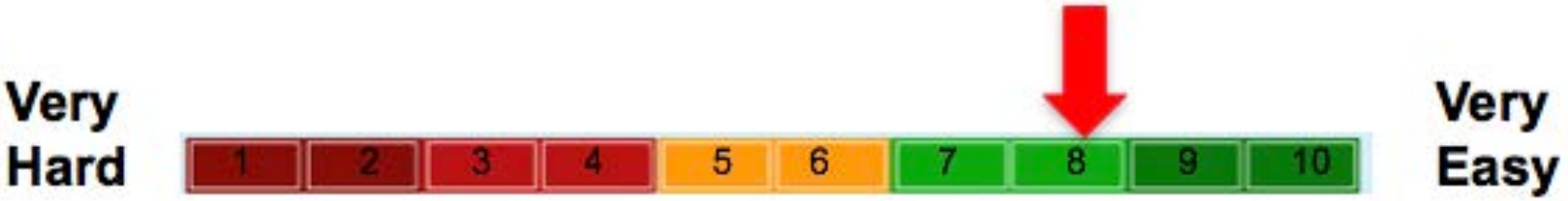


- Strongly Agree
- Agree
- I have no opinion
- Disagree
- Strongly Disagree

UCSF San Francisco VA Medical Center
Division of Geriatrics

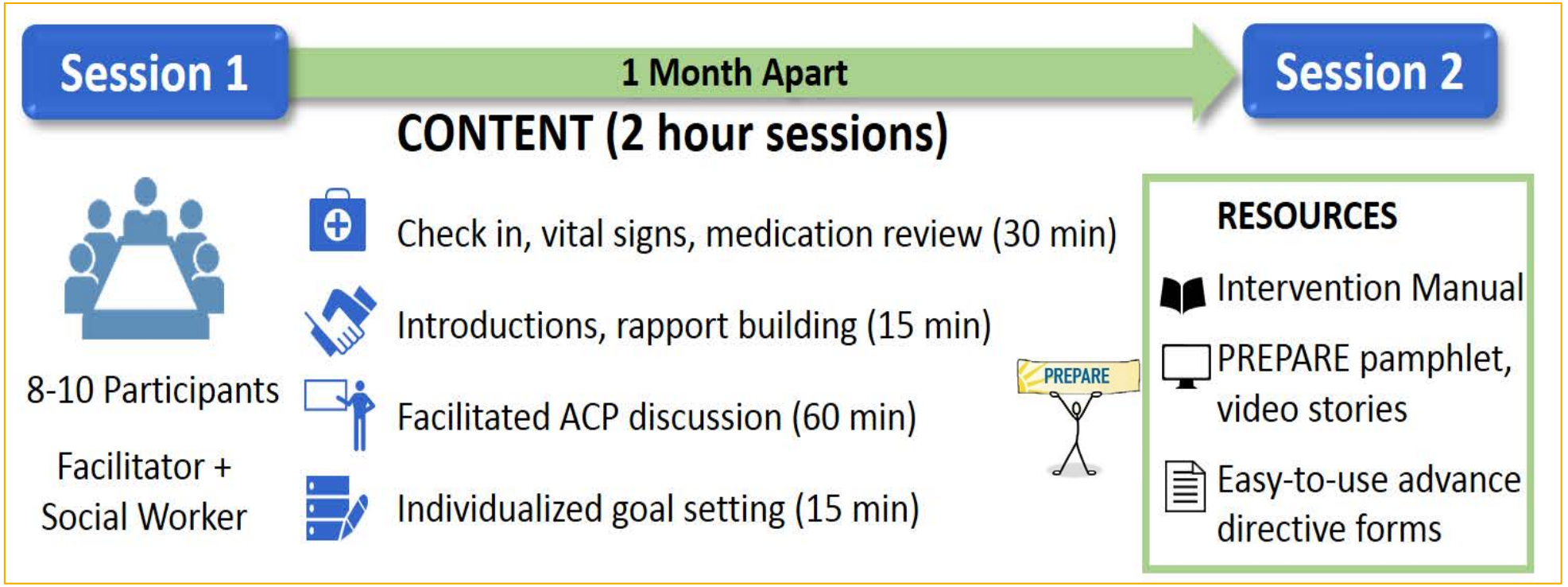
Group Medical Visits ZSFG, n = 22

- Minimal facilitation: PREPARE videos
- Pre-to-post: 1 week
  - Surrogate designation 48% to 85%, p = 0.01
  - AD form completion 9% to 24%, p =0.21



Zapata, Wistar, Lum, **Horton**, Sudore, Journal of Palliative Medicine, 2018

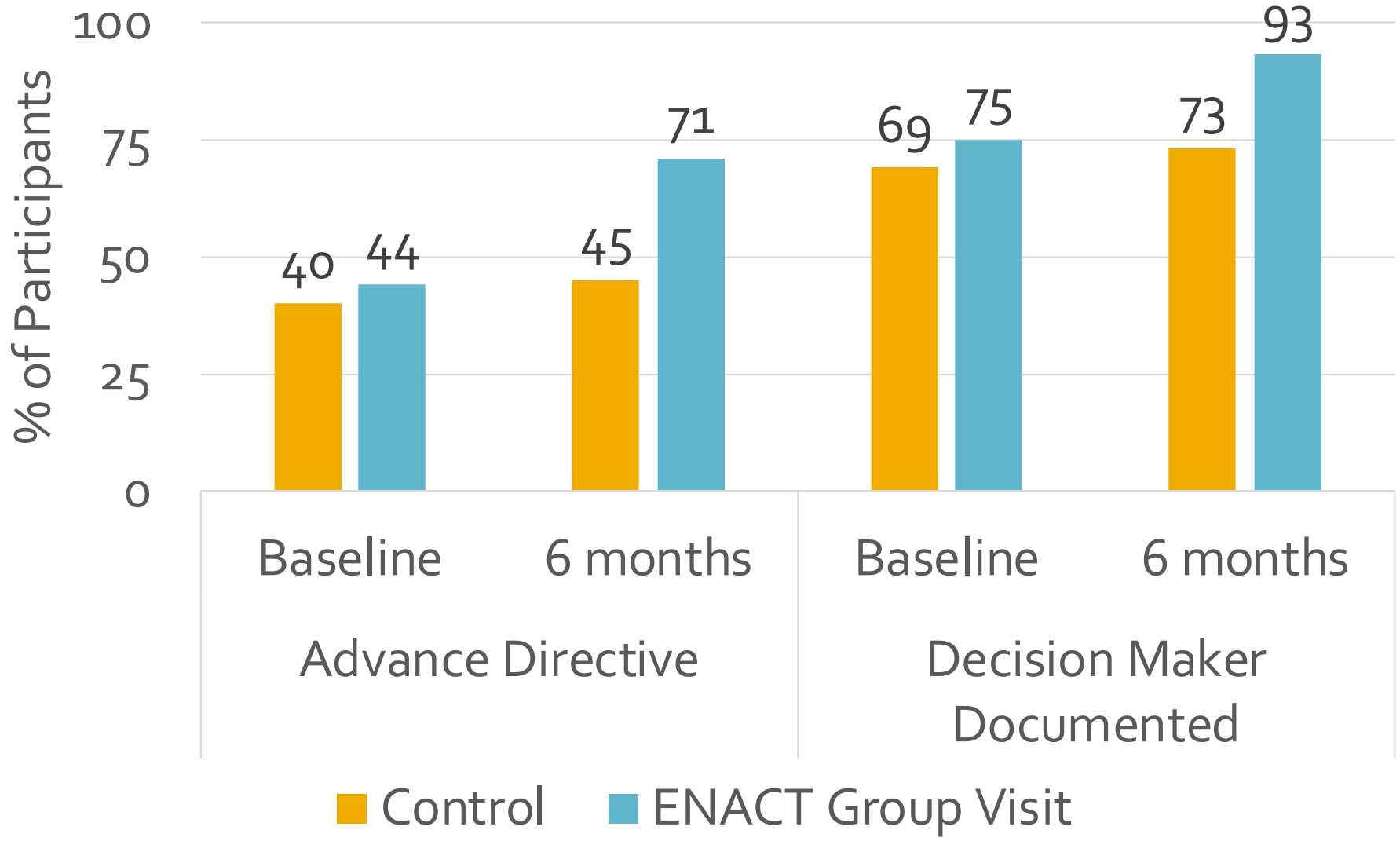
Hillary Lum, MD
ENACT Advance Care Planning Group Visits



Lum HD, Jones J, Matlock DD, et al. (2016) "ACP Meets Group Medical Visits: The Feasibility of Promoting Conversations." *Annals of Family Medicine.*

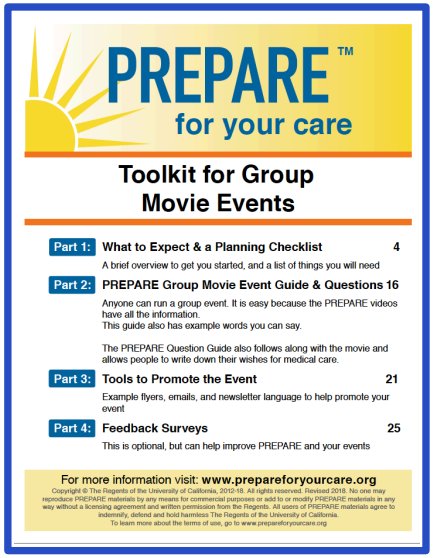
https://coloradocareplanning.org/university-of-colorado-innovations-in-advance-care-planning/

Slides by Hillary Lum, MD
ACP Group Visit Outcomes, n=110



National Healthcare Decisions Day

- Partnering with SF Palliative Care Work Group
- **Public Libraries** hosting PREPARE Movie Events


PREPARE™
for your care

Toolkit for Group Movie Events

Part 1: What to Expect & a Planning Checklist 4
A brief overview to get you started, and a list of things you will need

Part 2: PREPARE Group Movie Event Guide & Questions 16
Anyone can run a group event. It is easy because the PREPARE videos have all the information.
This guide also has example words you can say.

The PREPARE Question Guide also follows along with the movie and allows people to write down their wishes for medical care.

Part 3: Tools to Promote the Event 21
Example flyers, emails, and newsletter language to help promote your event

Part 4: Feedback Surveys 25
This is optional, but can help improve PREPARE and your events

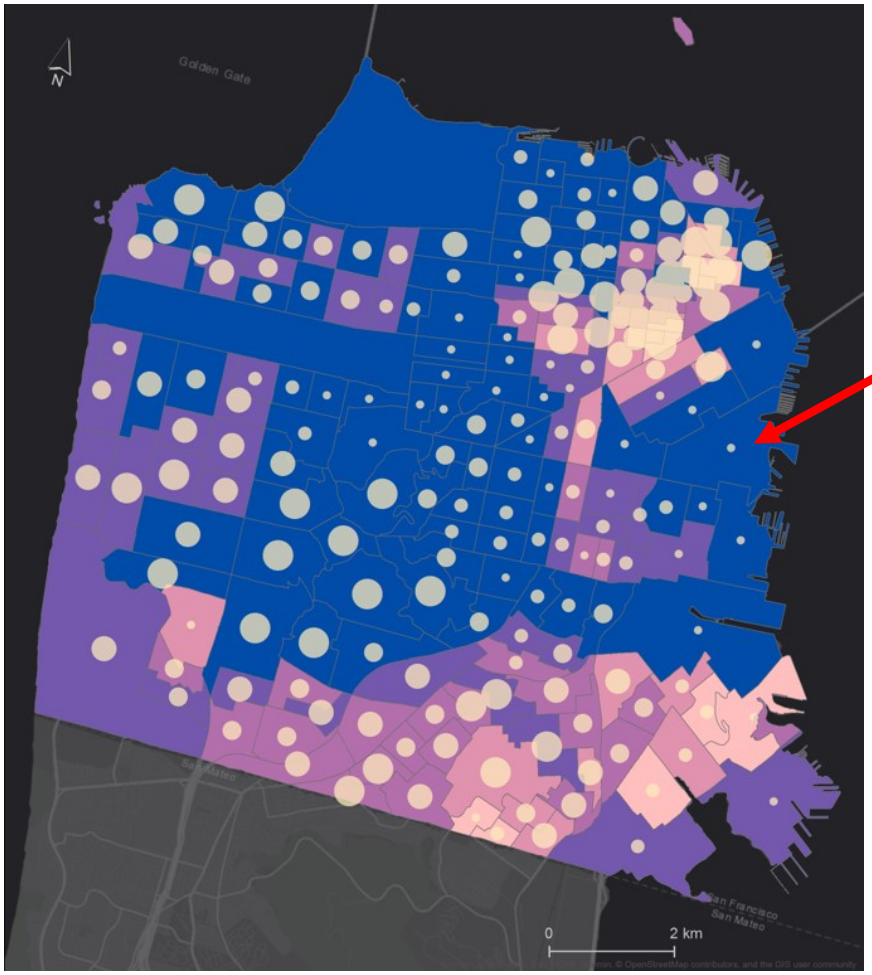
For more information visit: **www.prepareforyourcare.org**

Geocoding

Slides by Courtney Lyles, PhD

Neighborhoods

65+ years of age & SES



ACP

Proportion of UCSF Health population 65+ years of age

- 0 - 18.4
- 18.5 - 22
- 22.1 - 25
- 25.1- 27.8
- 27.9- 57

nSES

Low — High

Source:
UCSF Population Health Data Initiative

Maps and analyses by:
UCSF DREAM Lab

Gomez, SL, et al. *Cancer Causes & Control*. 2011.

Census 2000 Summary File 3 Technical Documentation/prepared by the U.S. Census Bureau, 2002.

American Community Survey. 2011. Available from: http://www.census.gov/programs-surveys/acs/data.html

JAMA Internal Medicine

ACP

Clinician or Facilitator

Healthcare System

Patient

UCSF Learning Health System Grant

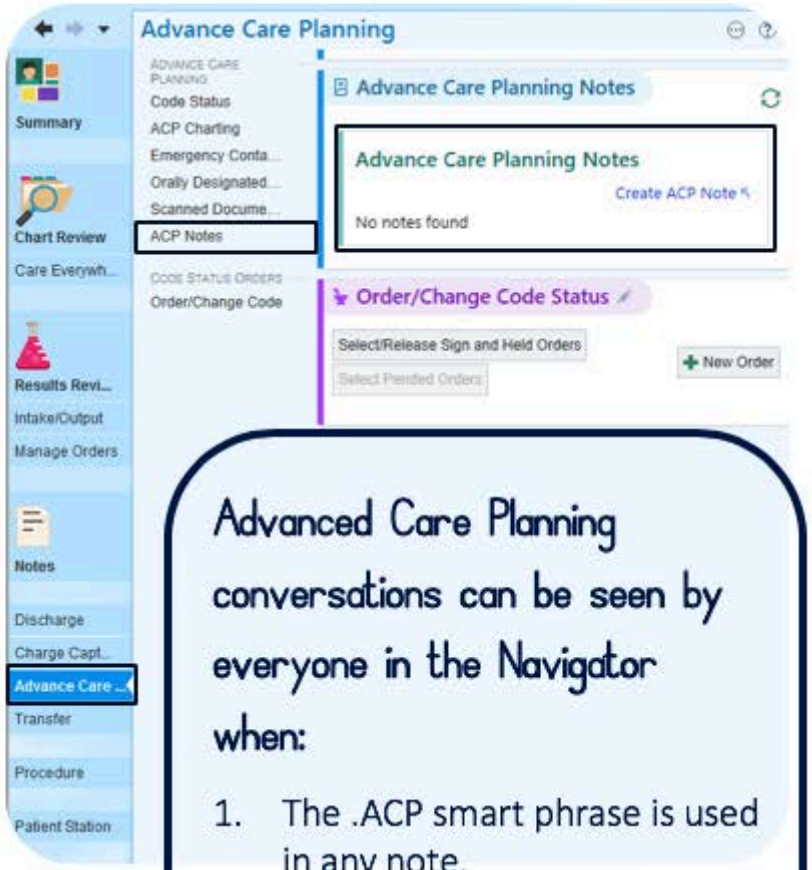
Slide, Michelle Mourad & Maria Byron

WISHES FOR MEDICAL CARE?

Documenting wishes is as simple as

.ACP

in *any* of your notes. Use of this dot phrase will put advanced care planning conversations in the ACP Navigator.

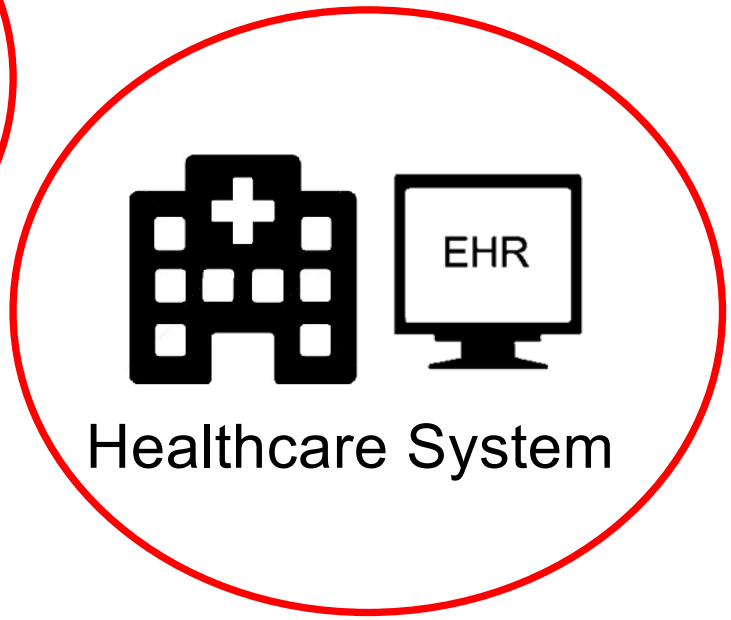


Advanced Care Planning conversations can be seen by everyone in the Navigator when:

1. The .ACP smart phrase is used in any note.
2. An ACP note is used.
3. An Advanced Directive or POLST form is scanned into the chart.

JAMA Internal Medicine

ACP



PCORI: Pragmatic Trial in Primary Care
n= 6500 with Serious Illness

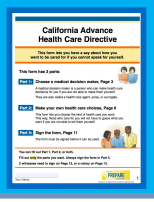
UCLA

UCSF

UCI

45 clinics

AD



AD + PREPARE

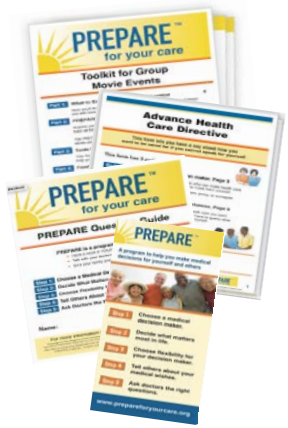
AD + PREPARE + Navigator

Automated Epic MyChart Messages

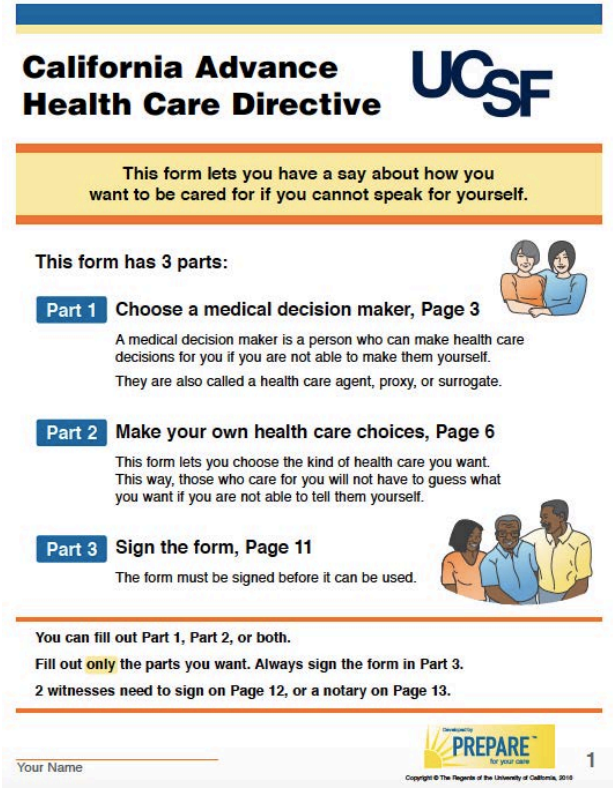
Automated Mail Messages

Licensing - Partnering with PREPARE

- **Licensing**
  - **Who:** researchers, hospitals, universities, ACOs, health plans, community organizations (large & small, public & private)
  - **Types**: research, data reporting, white-labeling, translation, raw materials of PREPARE (videos, questions)
  - **How:** licensing agreement with UCSF
  - **Timeline**: ~2 months



White-labeling



UCSF San Francisco VA Medical Center
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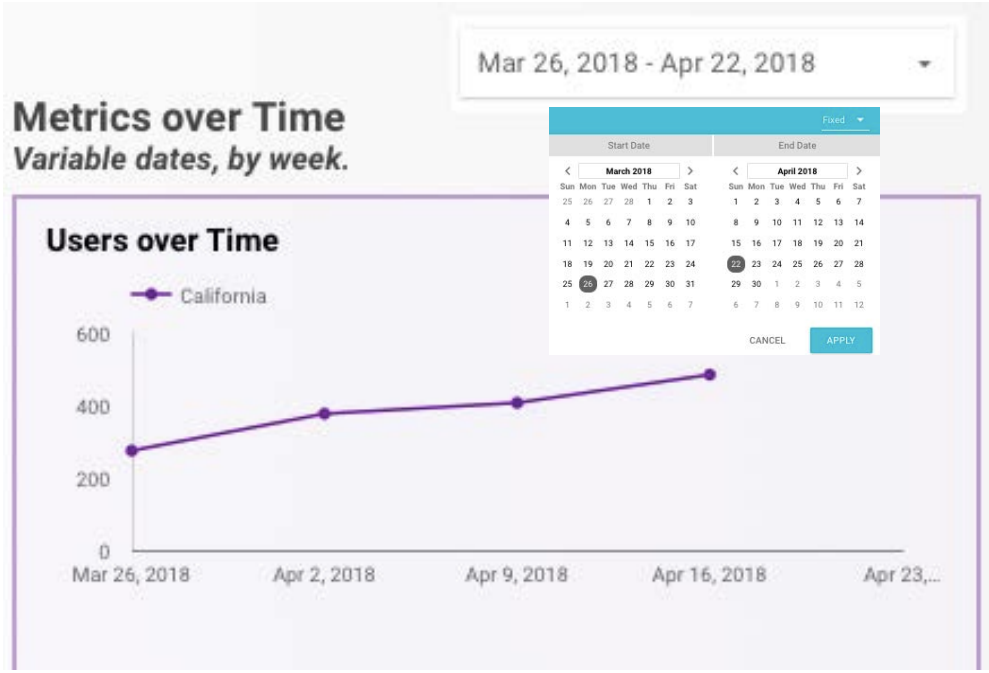
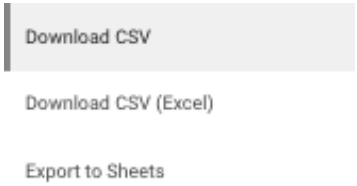
Data Reporting

- **Custom urls and interactive analytics dashboards**

- **Reporting**
  - **users**
  - sessions
  - page views
  - downloads
  - step completions
  - returning users





PCORI Engagement Award

- PREPARE + Honoring Choices PNW

- Capacity building in WA
  - Conduct stakeholder needs assessments
  - Develop analytics infrastructure to track PREPARE dissemination

Honoring Choices®
PACIFIC NORTHWEST

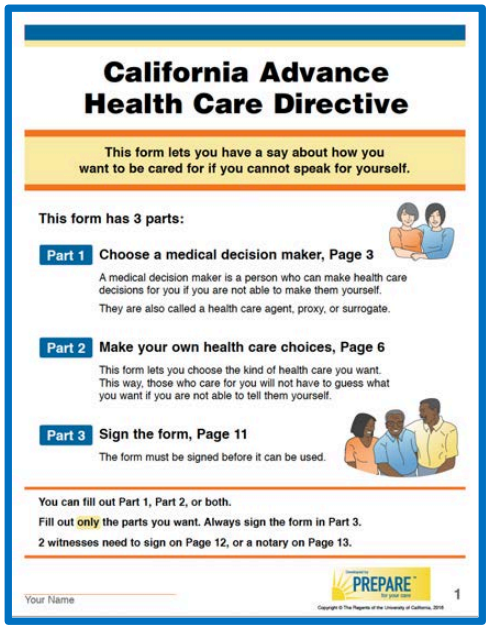
PREPARE™
for your care

Thank You!

PrepareForYourCare.org

info@prepareforyourcare.org

@prepareforcare



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1 Choose a medical decision maker, Page 3

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

They are also called a health care agent, proxy, or surrogate.

Part 2 Make your own health care choices, Page 6

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3 Sign the form, Page 11

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 12, or a notary on Page 13.

Your Name

PREPARE

1