Advance Care Planning Updates: Controversy, Complexity, and Practical Tips from the PREPARE For Your Care Program

Rebecca Sudore, MD
Professor of Medicine, Division of Geriatrics, UCSF
Director, Vulnerable Aging Research Core of the NIA-funded Pepper Center
Director, Innovation and Implementation Center of Aging & Palliative Care Research

UCSF

University of California, San Francisco
Division of Geriatrics

Objectives

- The evolving definition of ACP
- Recent controversies in ACP
- Updates in the field
- PREPARE for Your Care: Practical tips

Traditional ACP Definition

- To have patients make treatment decisions in advance of serious illness

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

Evolving Paradigm

"I'm afraid you've had a paradigm shift."

ACADEMIA AND CLINIC | Annals of Internal Medicine

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

Rebecca L. Sudore, MD, and Terri R. Fried, MD

Life sustaining treatments

<u>Preparation</u> for communication & decision making

Fried, Sudore. *Ann Intern Med.* 2010 Aug

PREPARE Goal: Move ACP Upstream

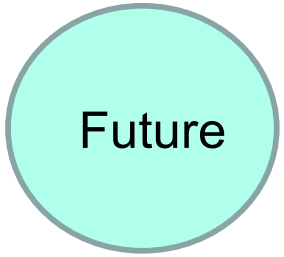
Readiness to Engage

First Steps → **Next Steps** → **Advanced Steps**

Life Course

2017 Published ACP Definition International Delphi Panel

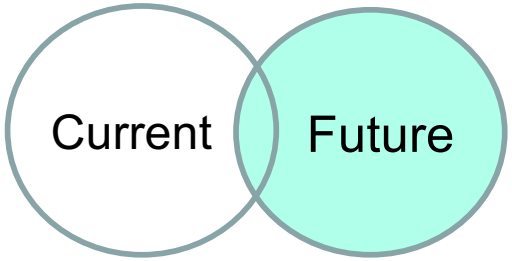
- ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.



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

PREPARE 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 *current* or future medical care & *prepares them for communication & decision making.*



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

Evolving: Possible Name Change?

- *"Advance Serious Illness Preparations and Planning (ASIPP) consists of discrete steps using evidence-based tools to prepare people for future clinical decision-making in the context of shared decision-making and informed consent."*

Heyland, DK. ACP vs. ASIPP. Healthcare. 2020 Jul, 18;8(3):218

Objectives

- The evolving definition of ACP
- **Recent controversies in ACP**
- Updates in the field
- PREPARE for Your Care: Practical tips

Why is ACP Important?

- In some studies…
  - Improves patient satisfaction with care
  - Improves quality of life
  - Improves goal concordant care
  - Improves surrogate-clinician communication
  - Less stress for the surrogate decision maker

Detering KM et al. *BMJ*. 2010; Silveira MJ, et al. *N Engl J Med*. 2010;362(13):1211-1218; Houben CH, et al. *J Am Med Dir Assoc.* 2014; Bischoff et al. *J Am* Geriatr Soc. 2013; Bond WF, et al. *J Palliat Med.* 2018; Teno MJ et al. JAGS 2007

ACP Realities

- ACP rates ~ 33% for the past 10 years
- Lower in racial/ethnic minority pop., ~ 15-20%
- Only 10-20% discussed wishes with clinicians
- ICU decedents, ~ 20% no ACP before death

Silveira et al. *N Engl J Med*. 2010; Yadav et al. Health Aff (Millwood). 2017; Harrison et al. *JAMA Intern Med*, 2016; Block BL, et al. *JAMA Intern Med.* 2020

Mixed Evidence

- Review of 80 systematic reviews with > 1660 studies
  - "Limited, low-quality evidence: ACP benefits = improved EOL communication, documentation, and dying in preferred place. Effective interventions include repeated and interactive discussions, decision aids, interventions targeting multiple stakeholders."
  - "Further studies are needed on the impact of ACP for different populations, settings, and contexts."

Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. J Pain Symptom Manage. 2018;56(3):436-459.e25.

Mixed Evidence

- Review of 80 systematic reviews with > 1660 studies
  - "Limited, low-quality evidence: ACP benefits = improved EOL communication, documentation, and dying in preferred place. Effective interventions include repeated and interactive discussions, decision aids, interventions targeting multiple stakeholders."
  - "Further studies are needed on the impact of ACP for different populations, settings, and contexts."

Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. J Pain Symptom Manage. 2018;56(3):436-459.e25.

Controversy

- *"We now have a wealth of data from 30 years of research that demonstrate that for the vast majority of people, ACP has no measurable or discernable impact on clinical outcomes."*

- *"Given the evidence gaps in our field, is it fair to patients & families to continue to focus our limited research workforce, finite effort, journal space, & scarce research, & clinical operational dollars on ACP while ignoring other needs? Isn't it time to finally acknowledge that advance directives/care planning is "an answer that is clear, simple, and wrong?"*

Morrison; Advance Directives/Care Planning: Clear, Simple, and Wrong, J Palliat Med. J Palliat Med. 2020 Jul;23(7):878-879

The National Academies of SCIENCES ENGINEERING MEDICINE

Controversy

- ACP requires complex knowledge of prognosis & treatment
- Pref when hypothetical not reflect current decision making
- Pt are not ready, or the subject is taboo
- Concerns “written off” with DNR = do not treat
- Serious illness conversations = procedures w/ special skills
- Goal concordant care will not be achieved until healthcare is not driven by profit motives

Morrison; Advance Directives/Care Planning: Clear, Simple, and Wrong, J Palliat Med. J Palliat Med. 2020 Jul;23(7):878-879

Objectives

- The evolving definition of ACP
- Recent controversies in ACP
- **Updates in the field**
- PREPARE for Your Care: Practical tips

Traditional ACP Definition

- To have patients make treatment decisions in advance of serious illness

Focus on Treatment Decisions Only is Flawed

- Prediction
- Adaptation
- Extrapolation

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; **Winter L, et. al**., Int J Aging Hum Dev. 2003; **Ubel PA, et. al.,** Health Psychol. 2005; **Gillick MR**. N Engl J Med. 2004; **Perkins HS**. Ann Intern Med. 2007

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., Can we agree to disagree?** JAMA, 2009

Why Do Anything in Advance?

‘‘ADs/care planning is clear, simple, and wrong?’’

Morrison; Advance Directives/Care Planning: Clear, Simple, and Wrong, J Palliat Med. J Palliat Med. 2020 Jul;23(7):878-879

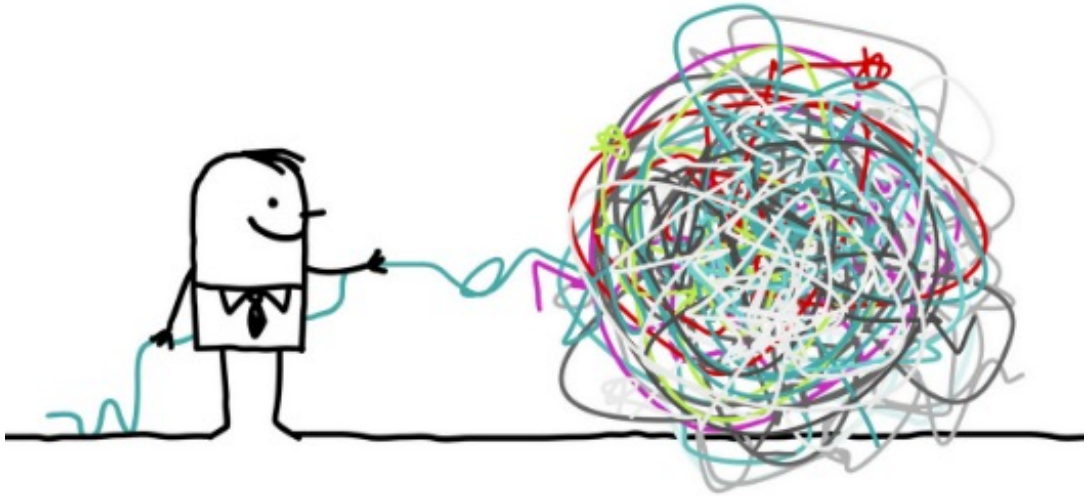
Why Prepare Patients & Surrogates?

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

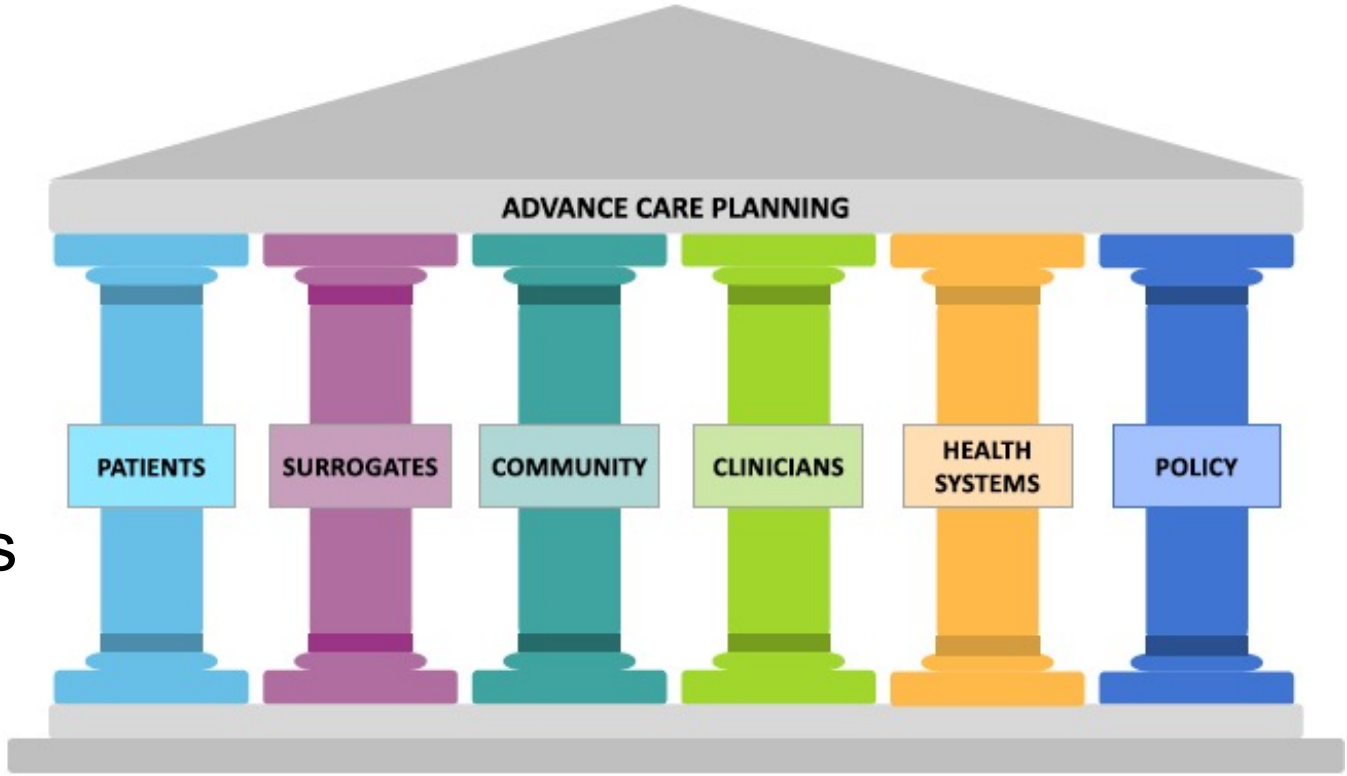
Perkins HS.. Ann Intern Med. 2007; **Torke AM, et. al.,** J Gen Intern Med. 2009

What About the Mixed Evidence?



ACP is Not Simple = Very Complex

- New Definition:
  - Process over time
- Multiple stakeholders



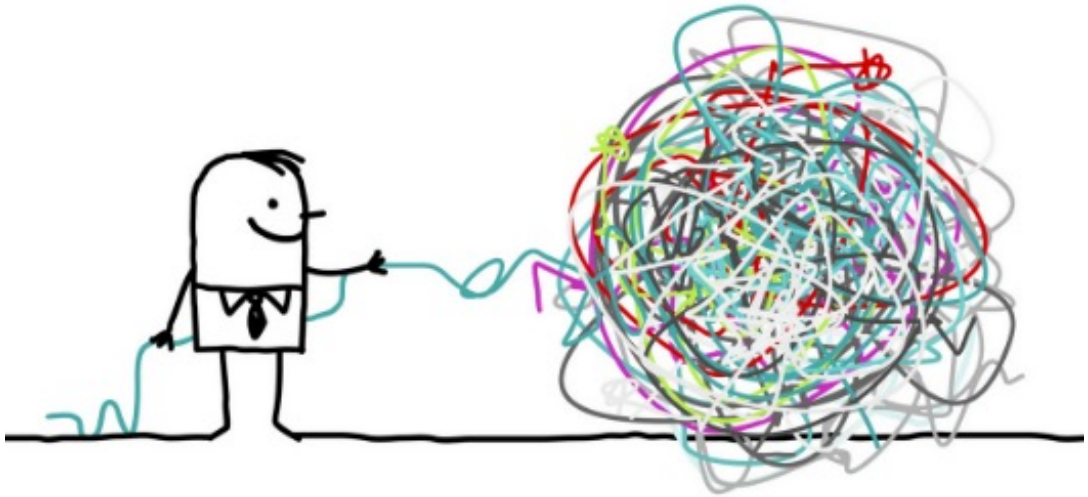
McMahan, Sudore: Deconstructing the Complexities of ACP Outcomes: What Do We Know and Where Do We Go? A Scoping Review, *J Am* Geriatr Soc. Sept. 2020

Complexity of Readiness & Life Course

Readiness to Engage

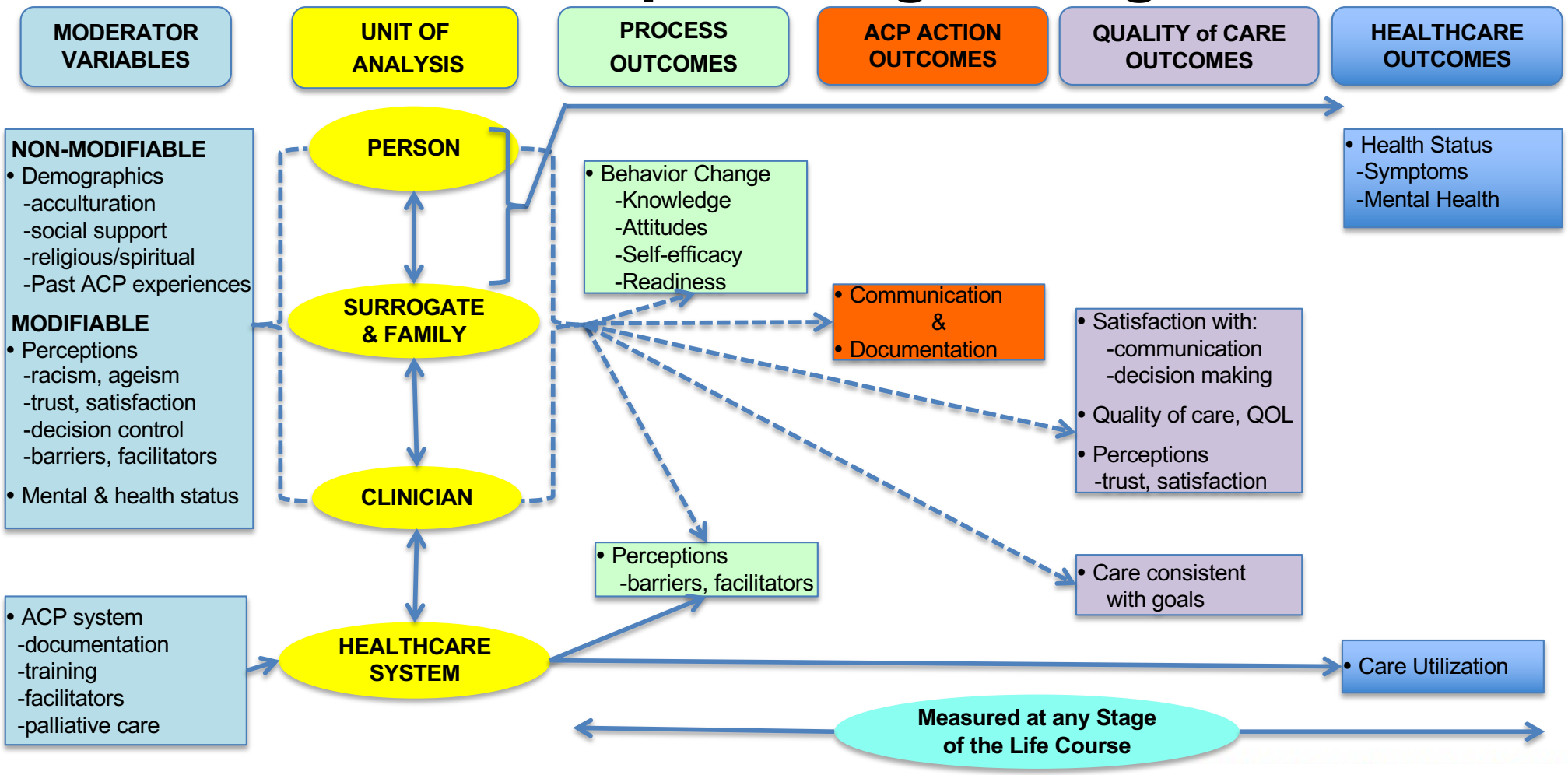
Life Course

Outcomes Are Complex: Organizing Framework



Sudore, et. al. Outcomes that Define Successful ACP. J Pain Symptom Manage. 2018 Feb

Outcomes Are Complex: Organizing Framework



Sudore, et. al. Outcomes that Define Successful ACP. J Pain Symptom Manage. 2018 Feb

Lack of Validated Outcomes

- **Conundrum of Goal Concordant Care (GCC)**

"While this outcome is extremely important, I am not currently aware of an instrument or method to reliably measure this, especially a method that would be amendable to most ACP studies."

"We cannot measure this in a meaningful and consistent way. So you are setting up a dilemma for our field of research, and potentially setting up a policy dilemma as well."

Sudore, et. al. Outcomes that Define Successful ACP. J Pain Symptom Manage. 2018 Feb; Unroe K et al. J Pain Symptom Management 2016; Sudore R et al., J Pain Symptom Management 2018; Halpern S, NEJM 2019

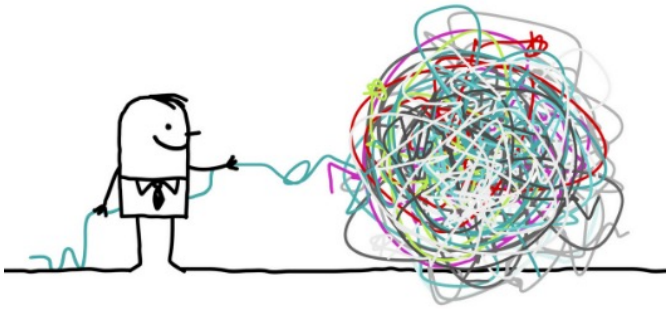
What Do We Know & Where Do We Go?

Journal of the American Geriatrics Society

AGS Geriatrics Healthcare Professionals
Leading Change. Improving Care for Older Adults.

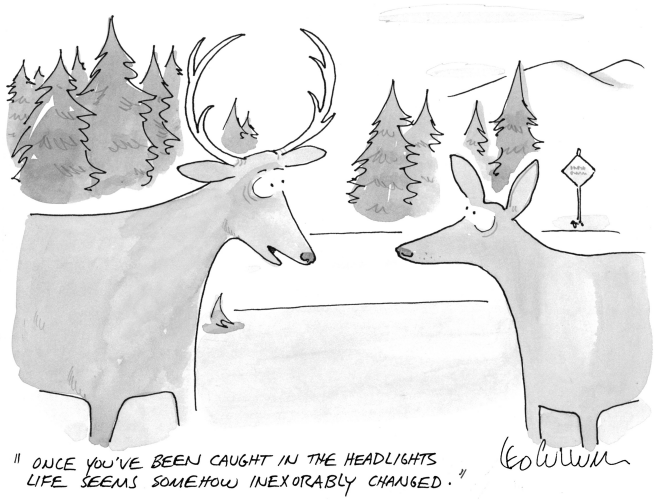
Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review

Ryan D. McMahan, MD, MAS,† Ismael Tellez, BA,*† and Rebecca L. Sudore, MD*†*



Patients, Surrogates, Clinicians want Preparation

- Patients, surrogates, clinicians rate ACP as important
  - especially if they have experience making decisions for serious illness.



McMahan, Sudore et al. *J Am* Geriatr Soc. 2020 Sep 7

Patients, Surrogates, Clinicians want Preparation

- Patients want to talk to clinicians about ACP
- Expect providers to initiate ACP
- Patients view as way to prepare surrogates, decrease decision-making burden, & ensure wishes honored.
- Clinicians view as an important part of job to help patients and families prepare for decision-making.

McMahan, Sudore et al. *J Am* Geriatr Soc. 2020 Sep 7

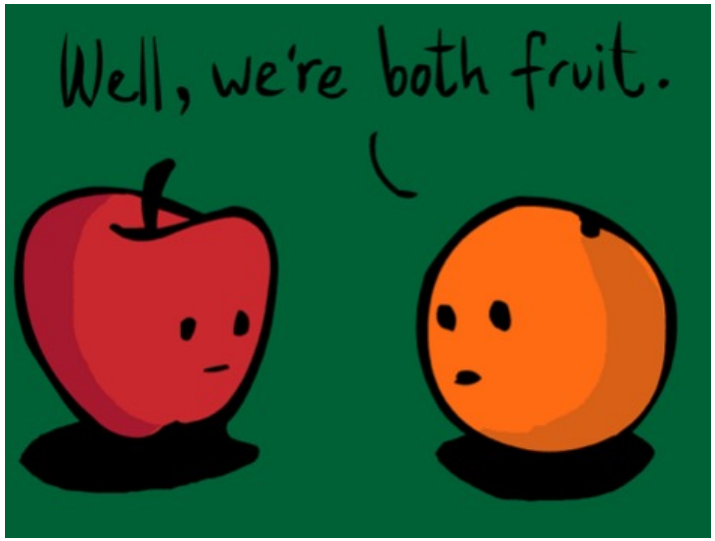
Scoping Review Methods

- ACP RCTs Jan 2010 to Mar 2020
  - 69 met eligibility, 94% high quality
    - None included in prior reviews

- Excluded
  - Pediatrics, pilot RCTs

Results: Wide Heterogeneity

- Definitions
- Populations
- Life trajectory
- Settings
- Intervention modalities
- Follow-up time points
- Outcomes



Intervention Type: Most Studies Positive

- Written only: 75%
- Multimedia programs: 69%
- Facilitated discussions: 67%
- Video only: 59%
- Clinician training: 57%

Process & Action Outcomes Mostly Positive

- **Process (readiness):** 72%

- **Action:** 86%
  - –Communication 78%
  - –Documentation 86%

Congruence & Satisfaction Mostly Positive

- **Congruence** patient/surrogate/clinician: 88%

- **Satisfaction** with:
  - Communication (pt/surrogate/clinician): 100%
  - Surrogate satisfaction with dec making: 67%
  - Surrogate satisfaction with medical care: 75%

Decreased Distress Positive

- Decreased surrogate anxiety/depression, PTSD, complicated grief & CG burden: 100%

- Decreased Clinician distress: 1 of 1

Mostly Negative Outcomes

- Goal Concordant Care: 10% positive
- Health Status of patients: 37% positive
- Healthcare Utilization: 42% positive

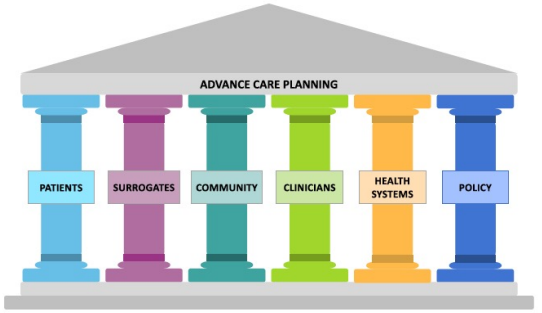
Where Do We Go?

- Pt, surrogates, clinician want ACP
- Most recent RCTs +
- Decrease surrogate burden

- Not all o/comes +
- Hard to measure GCC

- Given pt, surrogate, clinician desire for ACP, especially if previous experience, incumbent on us to make sense of ACP's complexity.

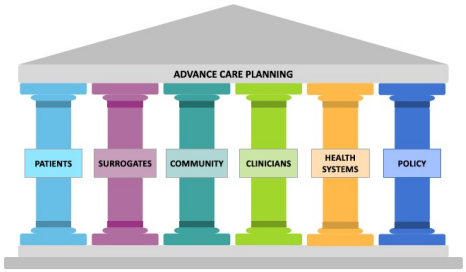
Holistic Approach



- ACP is COMPLEX!
  - –ACP intervention for one pillar would not be expected to positively affect all types of outcomes

- Desired ACP outcomes (goal concordance) may be unattainable w/o standardized validated measures

Holistic Approach



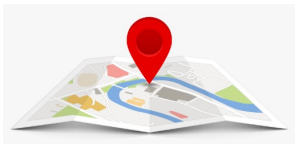
- Clinician and surrogate distress may be more appropriate outcomes
  - ACP is meeting patients' stated goals for ACP—decreasing decision making burden on others.
- Each “pillar” may need its own interventions/ outcomes
- Testing of combined interventions & implementation strategies in real-world contexts.

Is it Reasonable to Expect ACP to Fix All Problems in a Broken HC System?

Serious Illness = Flying down a broken highway

- Destination = Value concordant care
- Road = US healthcare (Insurers, CMS, legislators, providers)

- Car = Access (Cadillac or Pinto)
- Who is driving (pt, surrogate, clinician), who is in the car
- **GPS/Map = ACP**



- Roadside assistance (AAA/OnStar) = Clinician/Pall Care

Susan Hickman, PhD; June Lunney, PhD, RN; Ryan McMahan, MD

We Should Prepare Patients & Surrogates

Objectives

- The evolving definition of ACP
- Recent controversies in ACP
- Updates in the field
- **PREPARE for Your Care: Practical tips**

ACADEMIA AND CLINIC | Annals of Internal Medicine

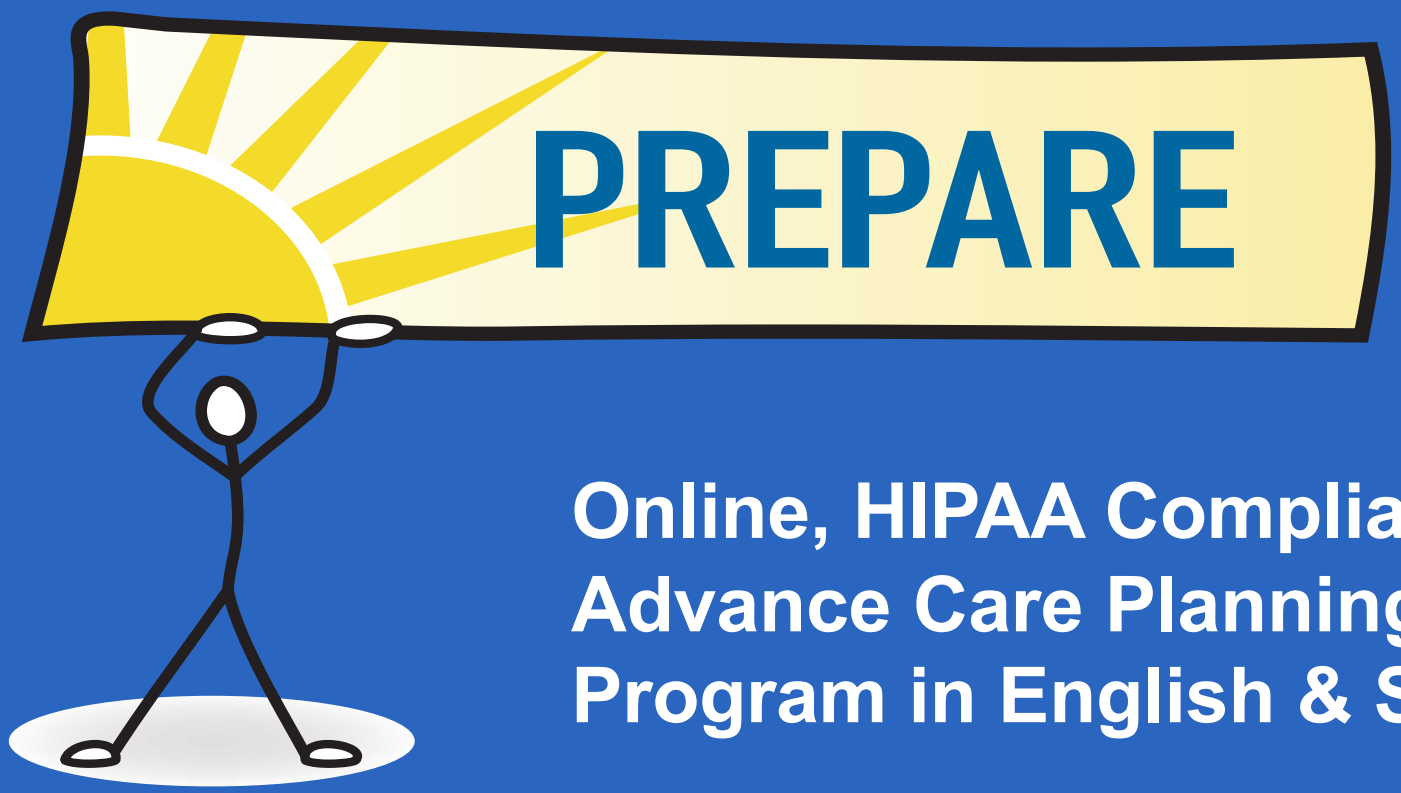
Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

Life sustaining treatments

<u>Preparation</u> for communication & decision making

Fried, Sudore. *Ann Intern Med.* 2010 Aug



Online, HIPAA Compliant Advance Care Planning Program in English & Spanish

www.prepareforyourcare.org

Health Literacy Considerations

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

- Advance directives, >12th grade level

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.

National Adult Literacy Survey: http://nces.ed.gov/naal/;
Ott BB, Hardie TL, Readability of advance directive documents, Image J Nurs Sch 1997

Language Considerations

- 61 million (~20%) speak language other than English at home
  - **40 million Spanish**, 3.4 million Chinese

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 & system is untrustworthy

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

What Matters Most

- 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

Easy-to-Read AD

RCT: English & Spanish

- Doubled completion rates
- Overwhelmingly preferred

regardless of literacy/ language

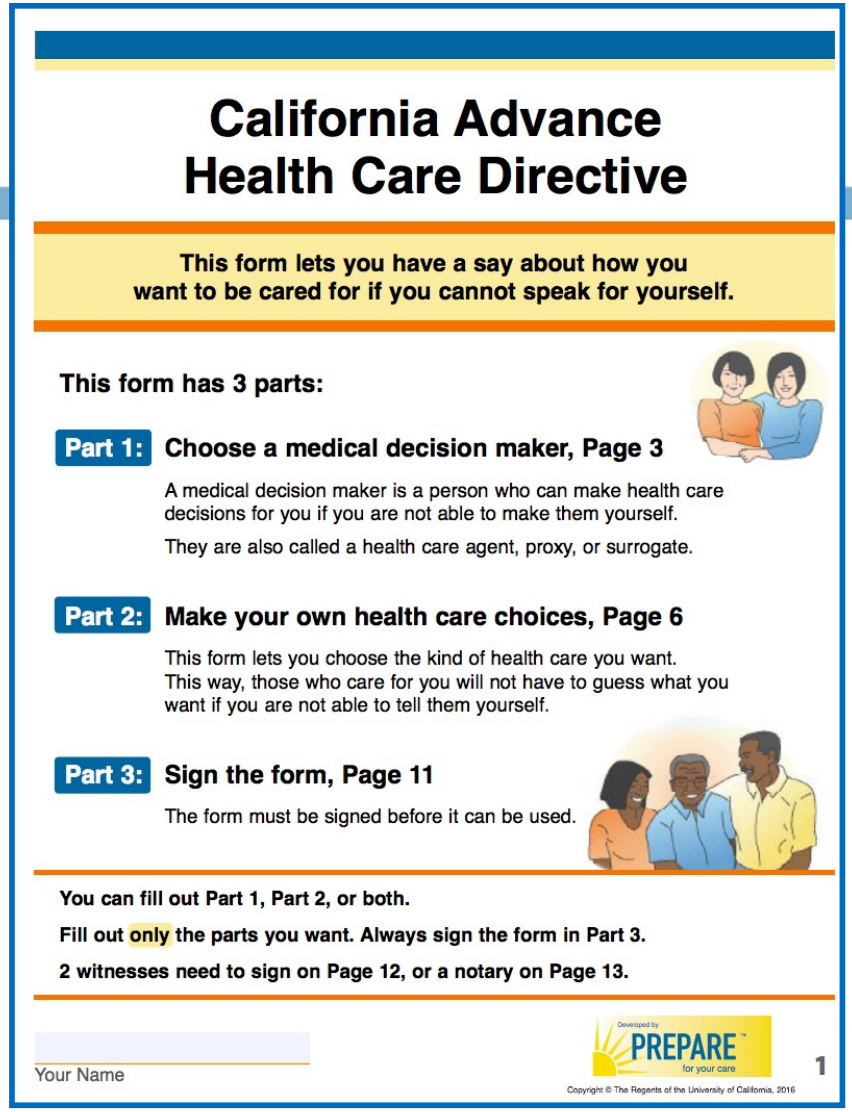
10 languages in CA

All states: English & Spanish

5+ states in Chinese

www.PrepareForYourCare.org

Sudore RL et. al., Patient Educ Couns 2007



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

Values & Space to write “Why” & other specific wishes

Part 2 Make your own health care choices

Fill out only the questions you want.

How do you prefer to make medical decisions?

Some people prefer to make their own medical decisions. Some people prefer input from others (family, friends, and medical providers) before they make a decision. And, some people prefer other people make decisions for them.

Please note: Medical providers cannot make decisions for you. They can only give information to help with decision making.

How do you prefer to make medical decisions?

- ☐ I prefer to make medical decisions on my own without input from others.
- ☐ I prefer to make medical decisions only after input from others.
- ☐ I prefer to have other people make medical decisions for me.

If you want, you can write why you feel this way, and who you want input from.

What matters most in life? Quality of life differs for each person.

What is most important in your life? Check as many as you want.

- ☐ Your family or friends
- ☐ Your pets
- ☐ Hobbies, such as gardening, hiking, and cooking
  - Your hobbies
- ☐ Working or volunteering
- ☐ Caring for yourself and being independent
- ☐ Not being a burden on your family
- ☐ Religion or spirituality: Your religion
- ☐ Something else

What brings your life joy? What are you most looking forward to in life?

Your Name

Quality of life differs for each person at the end of life. What would be most important to you?

AT THE END OF LIFE

Some people are willing to live through a lot for a chance of living longer.

Other people know that certain things would be very hard on their quality of life.

- Those things may make them want to focus on comfort rather than trying to live as long as possible.

At the end of life, which of these things would be very hard on your quality of life?
Check as many as you want.

- ☐ Being in a coma and not able to wake up or talk to my family and friends
- ☐ Not being able to live without being hooked up to machines
- ☐ Not being able to think for myself, such as severe dementia
- ☐ Not being able to feed, bathe, or take care of myself
- ☐ Not being able to live on my own, such as in a nursing home
- ☐ Having constant, severe pain or discomfort
- ☐ Something else

- ☐ **OR**, I am willing to live through all of these things for a chance of living longer.

If you want, you can write why you feel this way.

What experiences have you had with serious illness or with someone close to you who was very sick or dying?

- If you want, you can write down what went well or did not go well, and why.

If you were dying, where would you want to be?

☐ at home ☐ in the hospital ☐ either ☐ I am not sure

What else would be important, such as food, music, pets, or people you want around you?

Your Name

What else should your medical providers and medica decision maker know about you and your choices for medical are?

OPTIONAL: How do you prefer to get medical information?

Some people may want to know all of their medical information. Other people may not.

If you had a serious illness, would you want your doctors and medical providers to tell you how sick you are or how long you may have to live?

- ☐ Yes, I would want to know this information.
- ☐ No, I would not want to know. Please talk with my decision maker instead.

If you want, you can write why you feel this way.

* Talk to your medical providers so they know how you want to get information.

Your Name

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

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

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

www.PrepareForYourCare.org
Interactive, multi-media website

PREPARE™ for your care

Español | No Talking on This Page | Sign in

How to Use | The PREPARE 5 Steps | Summary of My Wishes | Advance Directive | Other Tools

PREPARE is a step-by-step program with video stories to help you:

- Have a voice in YOUR medical care
- Talk with your doctors
- Fill out an advance directive form to put your wishes in writing.

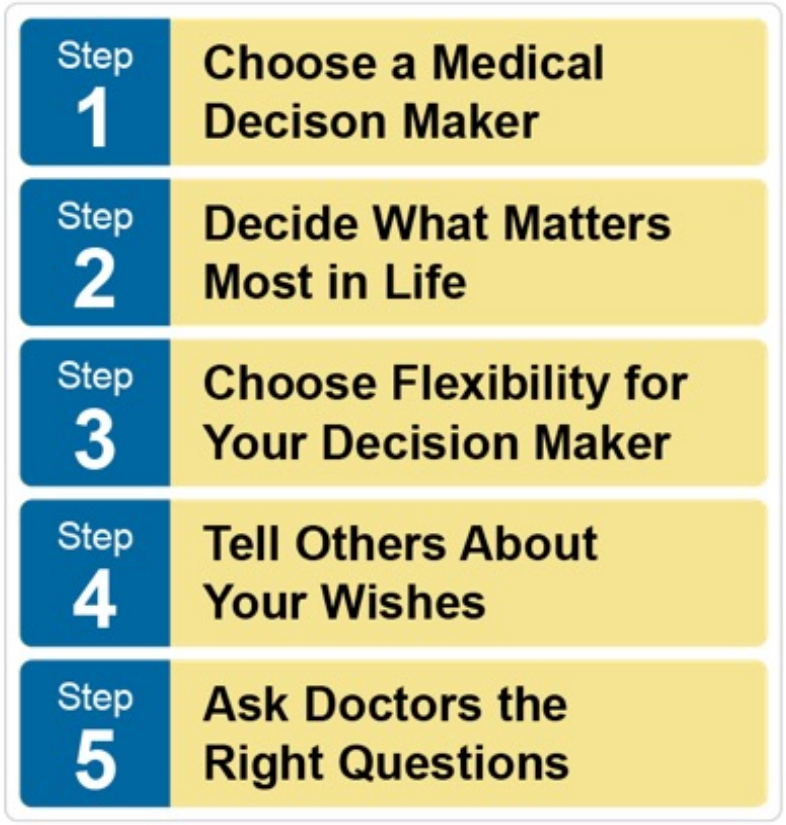
Click the video above to learn more.

Click Here to Start PREPARE

It has video stories and can help you fill out an advance directive.

If you only want to download an advance directive without help from PREPARE, scroll down below.

5-Steps of PREPARE



PrepareForYourCare.org

Creating PREPARE

- Co-created with diverse populations
- Easy to understand: 5th-grade reading level
  - Voice-overs & closed captioning (Eng/Span)
- Range of video stories:
  - Surrogate availability
  - Decision making preferences
- Videos that **model** ACP behavior

*** Sudore RL et. al.,** J Pain & Symptom Manage, 2012

How to Ask a Decision Maker

PREPARE

Show Menu

How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.

How to Talk with Family & Friends

Show Menu

How To Tell Others About Your Wishes

How to Ask Clinicians Questions

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

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

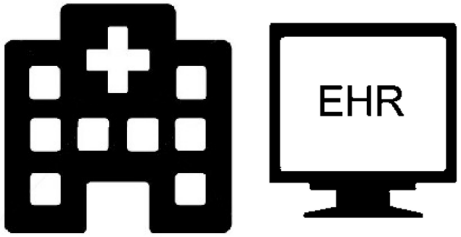
Developed by PREPARE for your care

JAMA Internal Medicine

EVIDENCE:
2 RCTs : 1400 Eng & Span patients

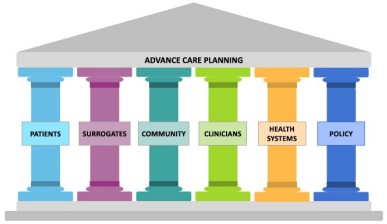
ACP

Clinician or Facilitator



Healthcare System

Patients



JAMA Internal Medicine

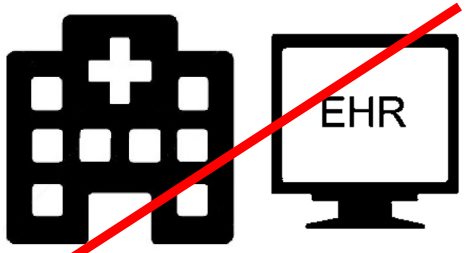
EVIDENCE:
2 RCTs : 1400 Eng & Span patients

ACP

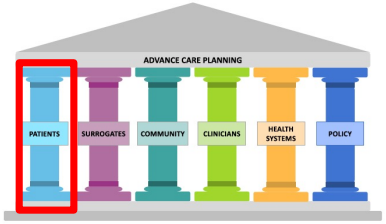
Clinician or Facilitator

The Focus

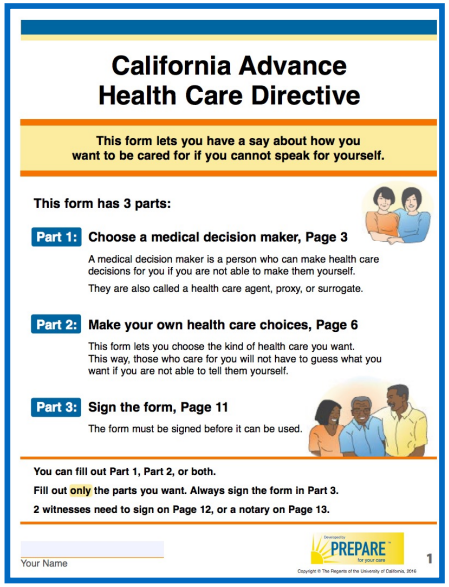
Patients



Healthcare System



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.

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

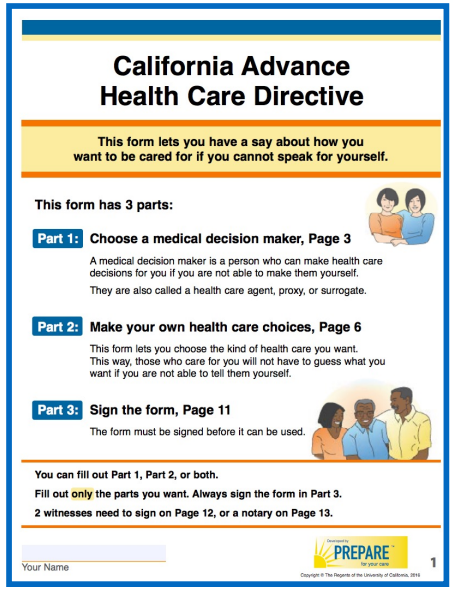
PREPARE

1

Copyright © The Regents of the University of California, 2014

vs.

+



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

Copyright © The Regents of the University of California, 2014

www.PrepareForYourCare.org

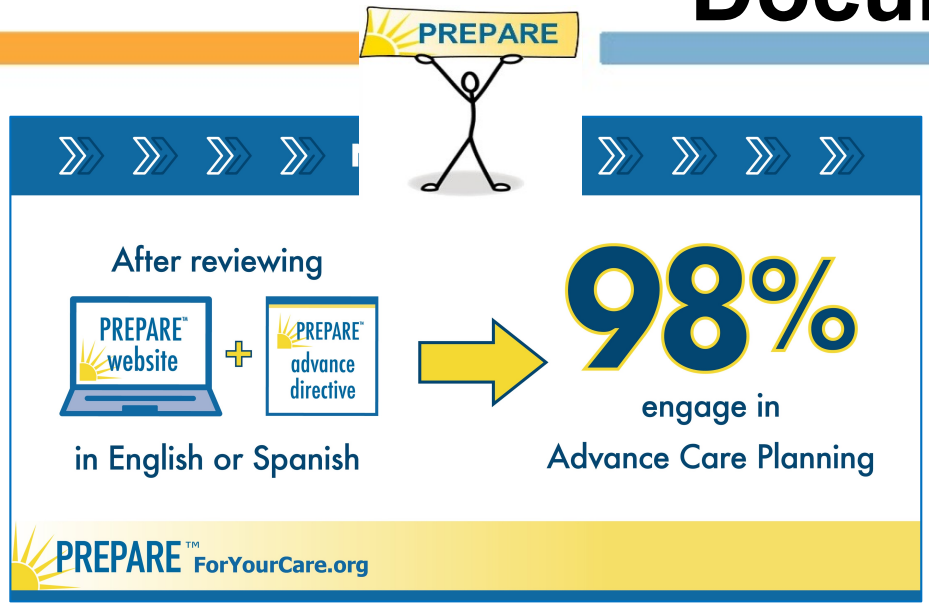
*There were no clinician- or system-level interventions or education. Only patient education was provided.

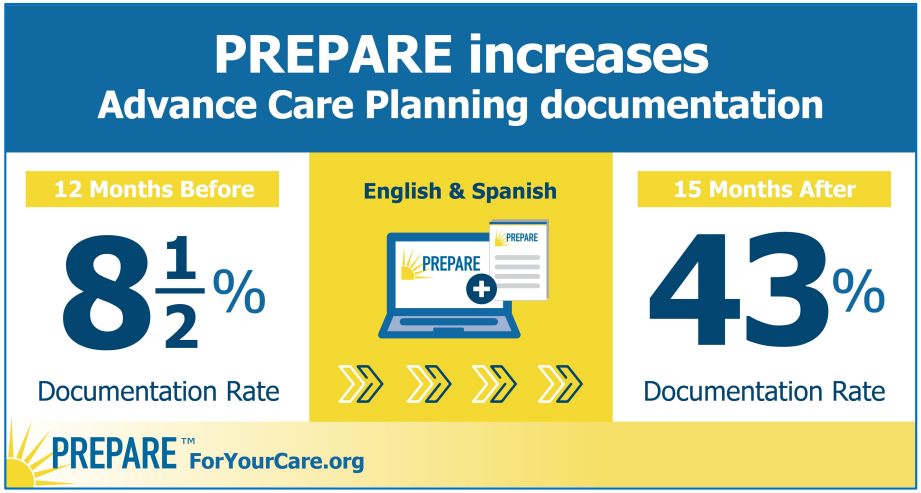
H_o – Patients would be empowered to complete the forms and talk about their wishes with clinicians.

ZUCKERBERG SAN FRANCISCO GENERAL
Hospital and Trauma Center

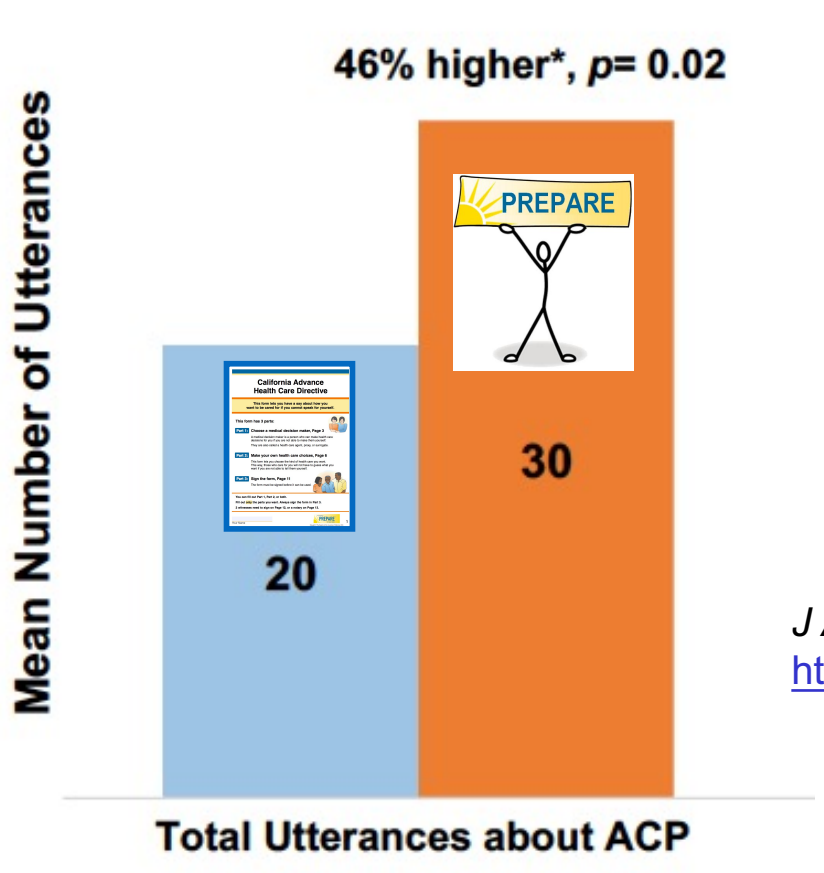
Pt Characteristics, n = 986		
	AD-only n=505	**PREPARE+AD n=481**
Mean Age (SD)	63 (6)	63 (6)
Women	62%	62%
Spanish-speaking	**45%**	**46%**
Racial/Ethnic minority	80%	83%
Fair-to-poor health	49%	53%
Limited health literacy	**40%**	**39%**
Internet access	53%	48%

PREPARE Increases Engagement & Documentation





PREPARE Empowers People to Speak Up



*Adjusted analysis

393 recorded clinic visits

46% Higher Empowerment

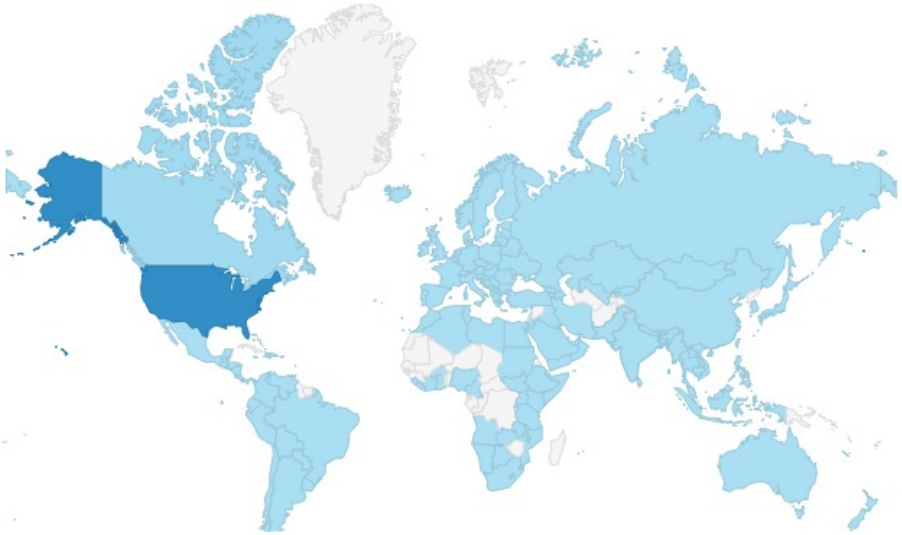
J Am Geriatr Soc. 2020
https://pubmed.ncbi.nlm.nih.gov/32157684/

Dissemination Research

UCSF San Francisco VA Medical Center
Division of Geriatrics

PREPARE Reach to the Community

- ~400,000 unique users, over 115 countries
- COVID-19 = 5x use



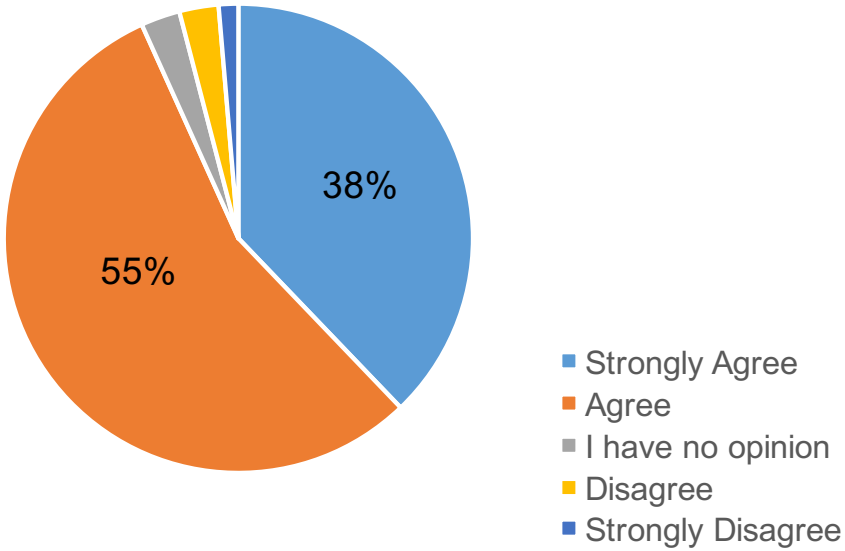
Group Medical Visits w/ PREPARE Movies

- Minimal facilitation: All info in Movies
- Pre-to-post: 1 week, n =22
  - Surrogate designation 48% to 85%, p = 0.01
  - AD form completion 9% to 24%, p =0.21

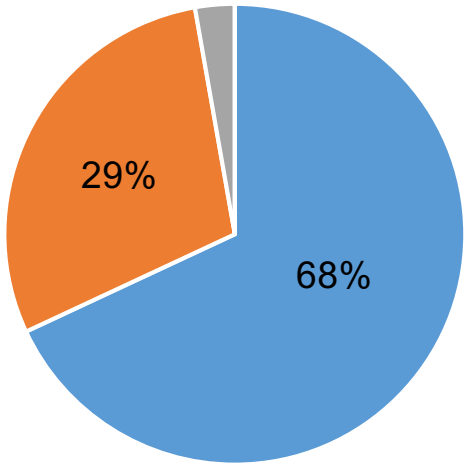
Zapata, et al., Journal of Palliative Medicine, 2018

Movie Toolkit: Senior Centers, n =75
100% rated easy to understand

93% Ready to answer ?s about preferences



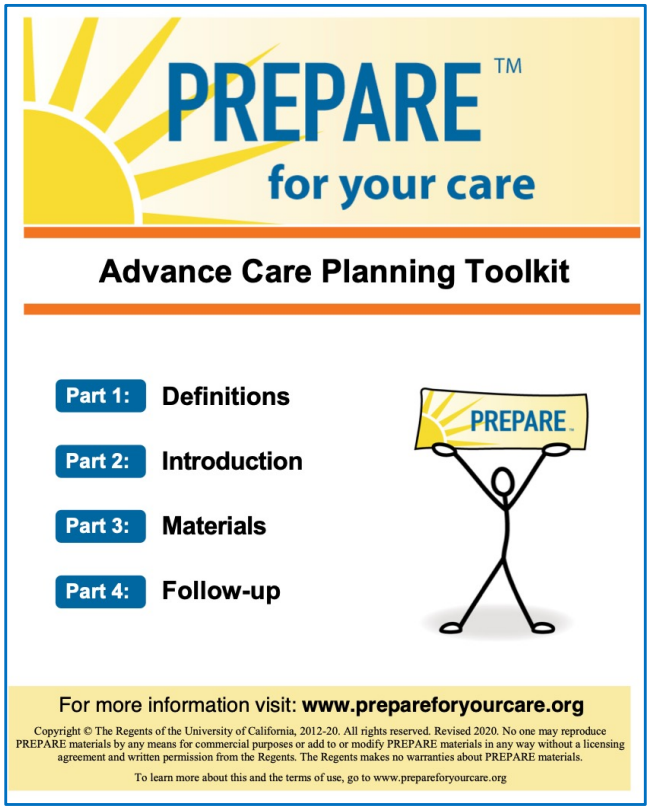
97% Recommend session



UCSF San Francisco VA Medical Center
Division of Geriatrics

Dept Disability & Aging: Toolkits for In Home Supportive Services

- Case Managers:
  - 100% increased confidence
  - 100% reported easy to use & recommend
- Older Clients
  - 100% increased readiness to do ACP
  - 100% easy to understand, 92% recommend



J Palliat Med. 2020 Aug: https://pubmed.ncbi.nlm.nih.gov/32865472/

PCORI: Capacity Building in WA

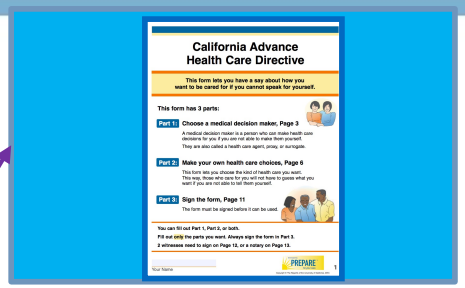
- Honoring Choices Pacific Northwest & PREPARE

Honoring Choices®
PACIFIC NORTHWEST

PREPARE™
for your care

PCORI: Population Health Based ACP

- UCLA, UCSF, UCI
- 50 clinics
- 20,000 patients
- 65 years & older



AD + PREPARE

AD + PREPARE + Navigator

Automated Epic MyChart Messages

Automated Mail Messages

Practical Tips

PREPAREforYourCare.org

UCSF San Francisco VA Medical Center
Division of Geriatrics

Who Can Use PREPARE?

- **Target**: Ethnically-, culturally-, linguistically-diverse older adults

- **Who Delivers**: Anyone

- **Training**: Minimal. All ACP information already included in Toolkits & website

PREPARE™ for your care

Español

No Talking on This Page | Sign in

How to Use | The PREPARE 5 Steps | Summary of My Wishes | Advance Directive | Other Tools

PREPARE is a step-by-step program with video stories to help you:

- Have a voice in YOUR medical care
- Talk with your doctors
- Fill out an advance directive form to put your wishes in writing.

Click the video above to learn more.

Click Here to Start PREPARE

It has video stories and can help you fill out an advance directive.

If you only want to download an advance directive without help from PREPARE, scroll down below.

Free PREPARE Easy-to-read Advance Directives and Other Tools Below.

PREPARE™ for your care

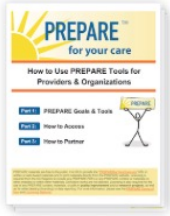
Español

No Talking on This Page | Sign in

How to Use | The PREPARE 5 Steps | Summary of My Wishes | Advance Directive | Other Tools

PREPARE Tools for Providers & Organizations

PREPARE materials are free to the public. It is OK to provide the "PREPAREforYourCare.org" URL in written or web-based materials and to print materials directly from the PREPARE website. Licensing is required from the UC Regents to include any PREPARE PDFs or any PREPARE content or materials on other websites or within other materials. Derivative works are not allowed. Licensing is also required for the use of any PREPARE content, materials, or pdfs in **quality improvement** and/or **research projects**, as well as for white labeling (branding) or data reporting. For more information, please see the **PREPARE Terms of Use** and **Licensing Options.**



How to Use PREPARE Tools for Providers & Organizations

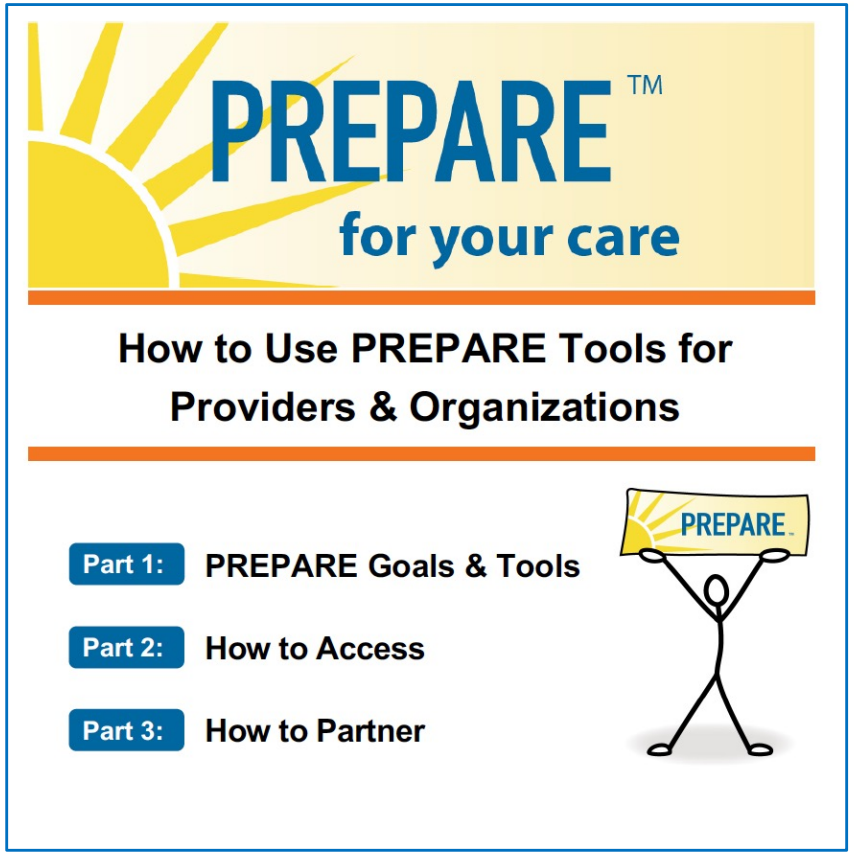
A brief summary of the PREPARE tools and how to use them.

PREPARE Quick Start Guide

This handout includes pictures and instructions to help users get into and start using the online program.

PREPARE Tools For Providers

1. How to use PREPARE Tools
2. PREPARE Quick Start Guide
3. PREPARE Advance Directives
4. PREPARE Pamphlets
5. PREPARE Easy-to-use ACP Scripts
6. PREPARE ACP Toolkit
7. PREPARE Movie Event Toolkit
8. 4-item ACP Engagement Survey



Quick Start Guide

PREPARE™ for your care — QUICK START GUIDE

Welcome to PREPARE! Learn helpful information in as little as 10 minutes.

PREPARE is a step-by-step program with video stories to help you:

- Have a voice in YOUR medical care
- Talk with your doctors
- Fill out an advance directive form to put your wishes in writing

Type in this address into your internet browser: prepareforyourcare.org

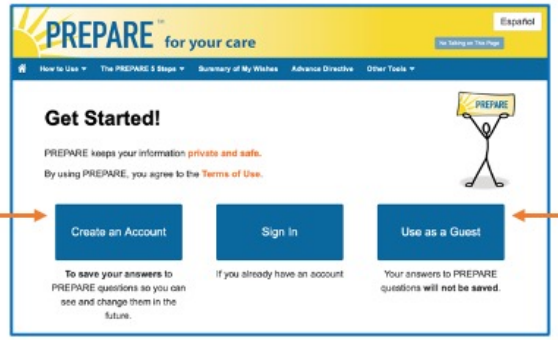
This will bring you to the PREPARE home page.

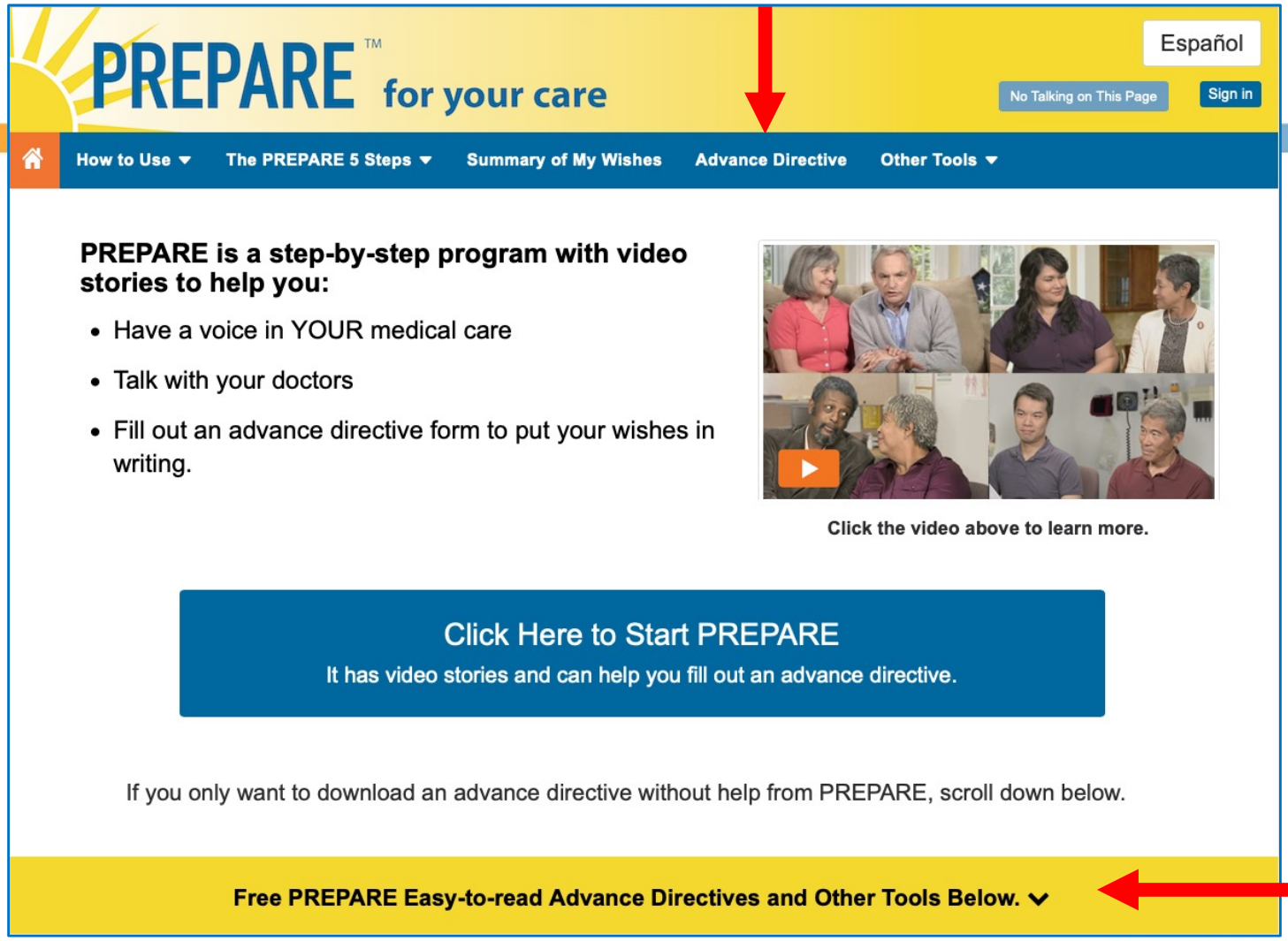
Click here to Start

You can click on this 1-minute video to learn more about PREPARE

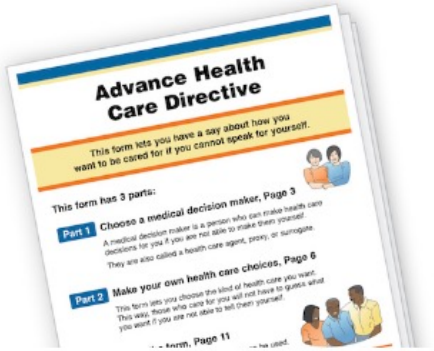
You will then come to this login page.

To save your information, click on Create an Account. Or, use PREPARE as a guest.




PREPARE™ for your care
Español
No Talking on This Page
Sign in
How to Use
The PREPARE 5 Steps
Summary of My Wishes
Advance Directive
Other Tools
PREPARE is a step-by-step program with video stories to help you:
• Have a voice in YOUR medical care
• Talk with your doctors
• Fill out an advance directive form to put your wishes in writing.
Click the video above to learn more.
Click Here to Start PREPARE
It has video stories and can help you fill out an advance directive.
If you only want to download an advance directive without help from PREPARE, scroll down below.
Free PREPARE Easy-to-read Advance Directives and Other Tools Below.

Free PREPARE Easy-to-read Advance Directives and Other Tools Below. ⌄



PREPARE Easy-to-Read Advance Directives:

Free to fill out and print for all states.

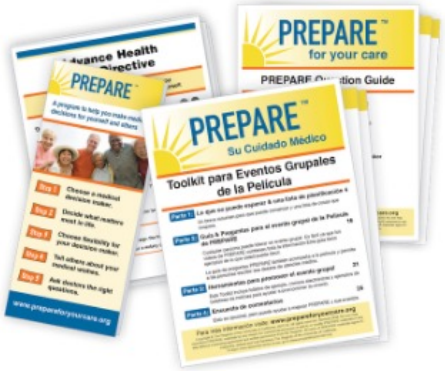
Get the PREPARE Advance Directive

Other PREPARE Tools for Providers and Organizations ⌄

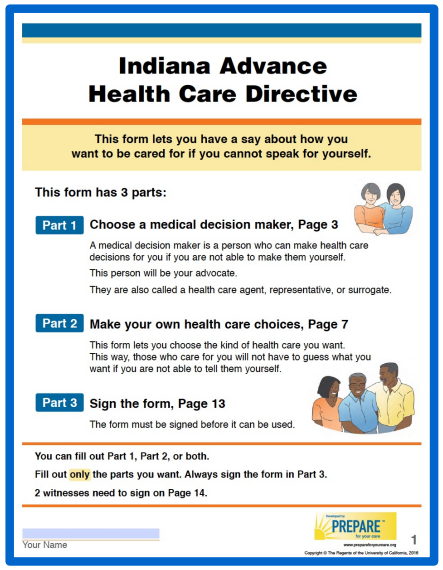
For Providers and Organizations:

- PREPARE Pamphlets
- Tools for Group Movie Events
  - PREPARE Toolkit for Group Movie Events
  - PREPARE Movies
  - PREPARE Question Guide

Get Other PREPARE Tools



Easy-to-read ADs for all US States in English & Spanish (5+ Chinese)



Indiana 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.

This person will be your advocate.

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

Part 2 **Make your own health care choices, Page 7**

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 13**

The form must be signed before it can be used.

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

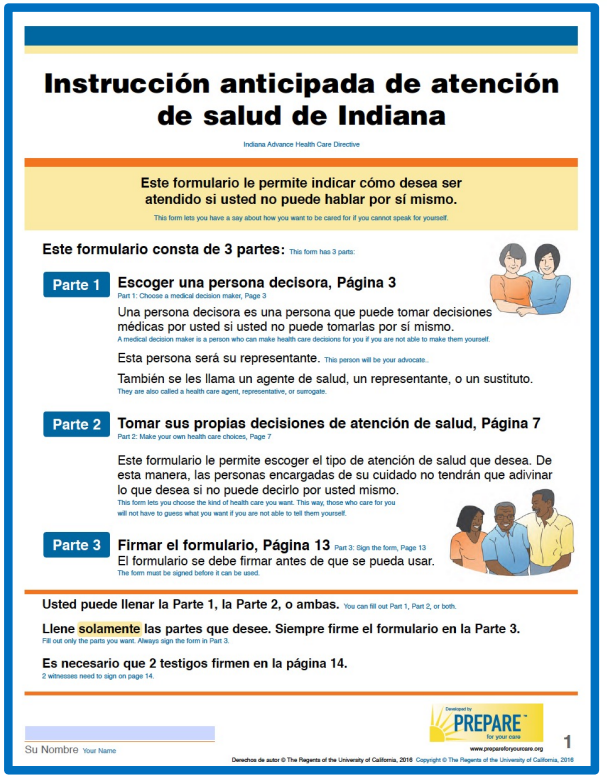
Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on Page 14.

Your Name

PREPARE

1



Instrucción anticipada de atención de salud de Indiana

Indiana Advance Health Care Directive

Este formulario le permite indicar cómo desea ser atendido si usted no puede hablar por sí mismo.

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

Este formulario consta de 3 partes: This form has 3 parts:

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

Part 1: Choose a medical decision maker, Page 3

Una persona decisora es una persona que puede tomar decisiones médicas por usted si usted no puede tomarlas por sí mismo.

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

Esta persona será su representante. This person will be your advocate..

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

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

Parte 2 **Tomar sus propias decisiones de atención de salud, Página 7**

Part 2: Make your own health care choices, Page 7

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 no puede decirlo por usted mismo.

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.

Parte 3 **Firmar el formulario, Página 13** Part 3: Sign the form, Page 13

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

The form must be signed before it can be used.

Usted puede llenar la Parte 1, la Parte 2, o ambas. You can fill out Part 1, Part 2, or both.

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

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

Es necesario que 2 testigos firmen en la página 14.

2 witnesses need to sign on page 14.

Su Nombre Your Name

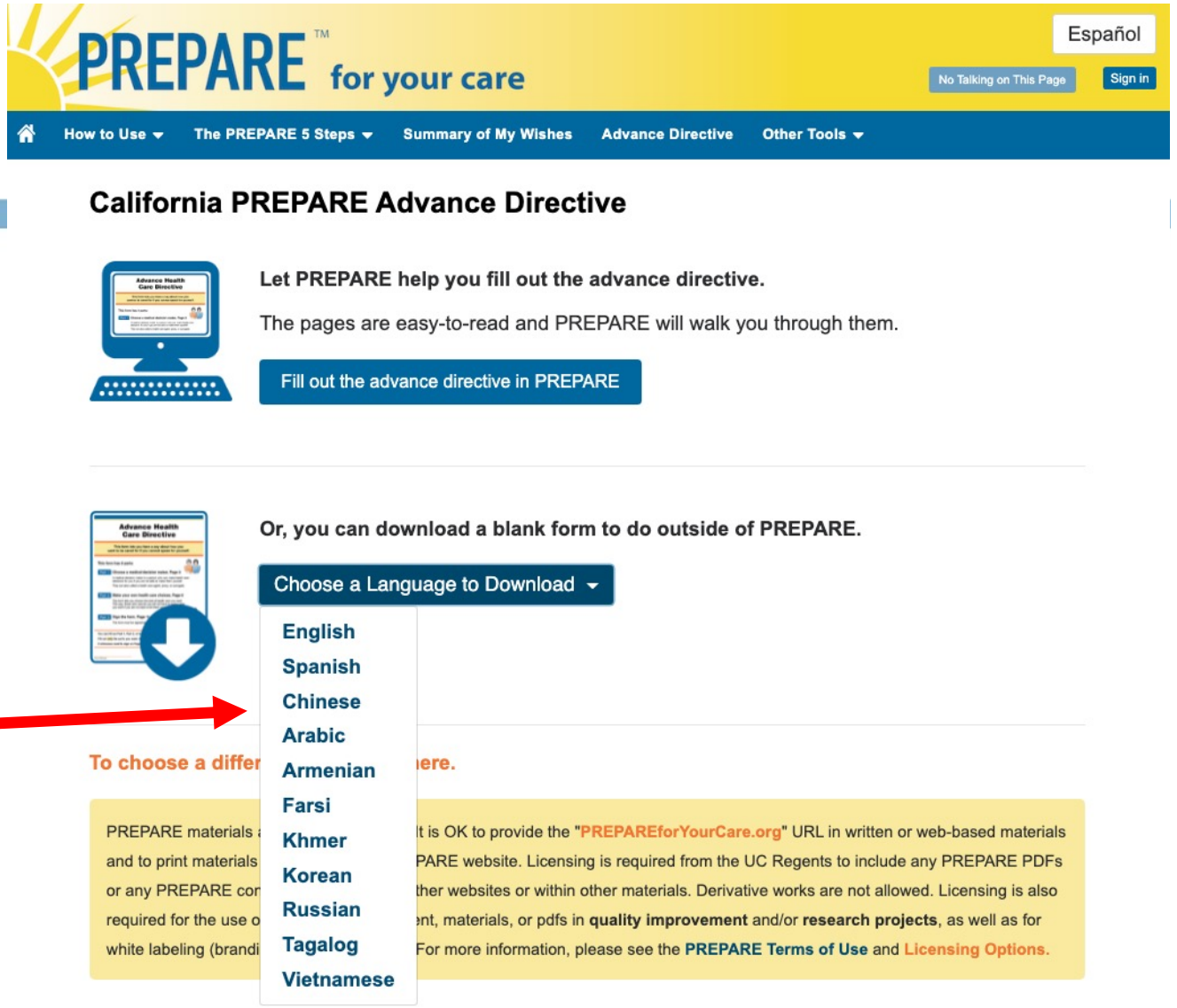
PREPARE

www.prepareforyourcare.org

1

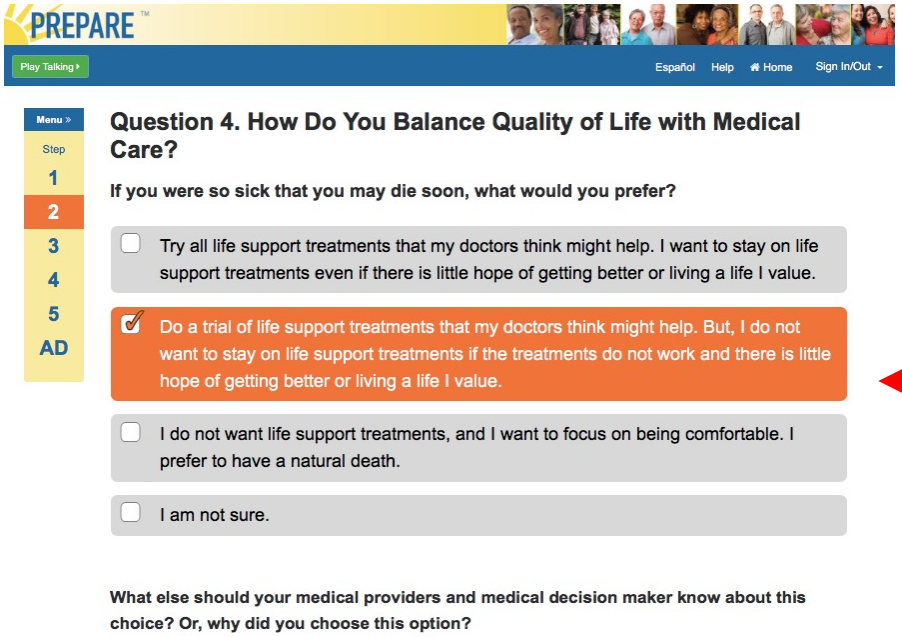
Derechos de autor © The Regents of the University of California, 2016 Copyright © The Regents of the University of California, 2016

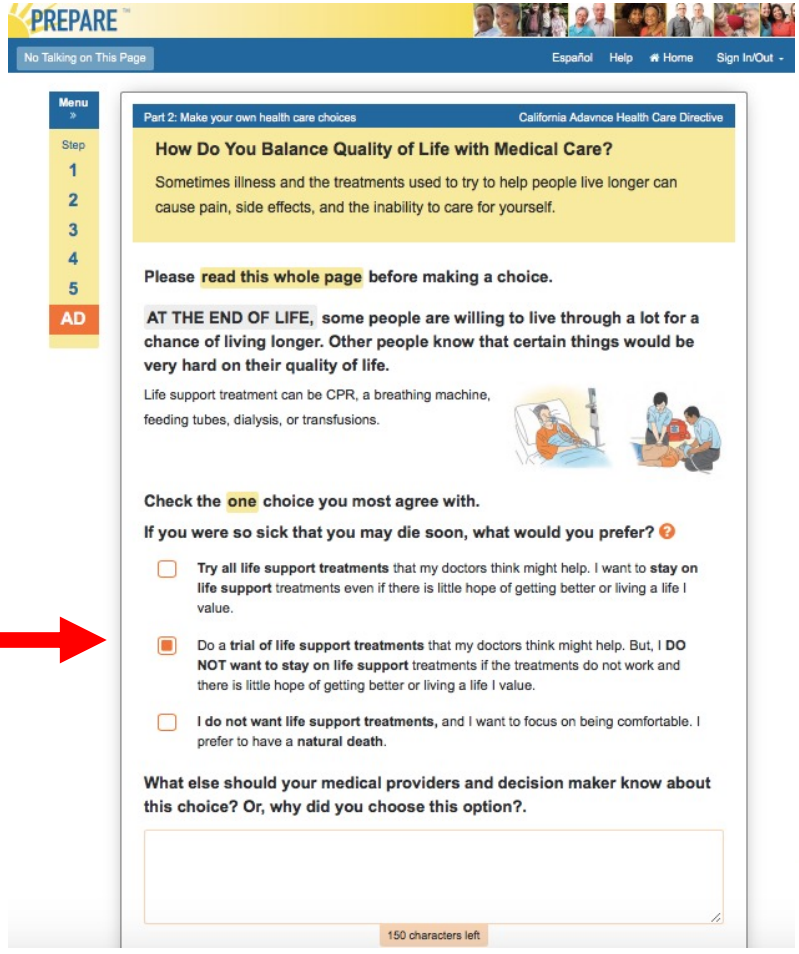
11 Languages in CA



PREPARE Steps Pre-populates AD (Eng/Sp)

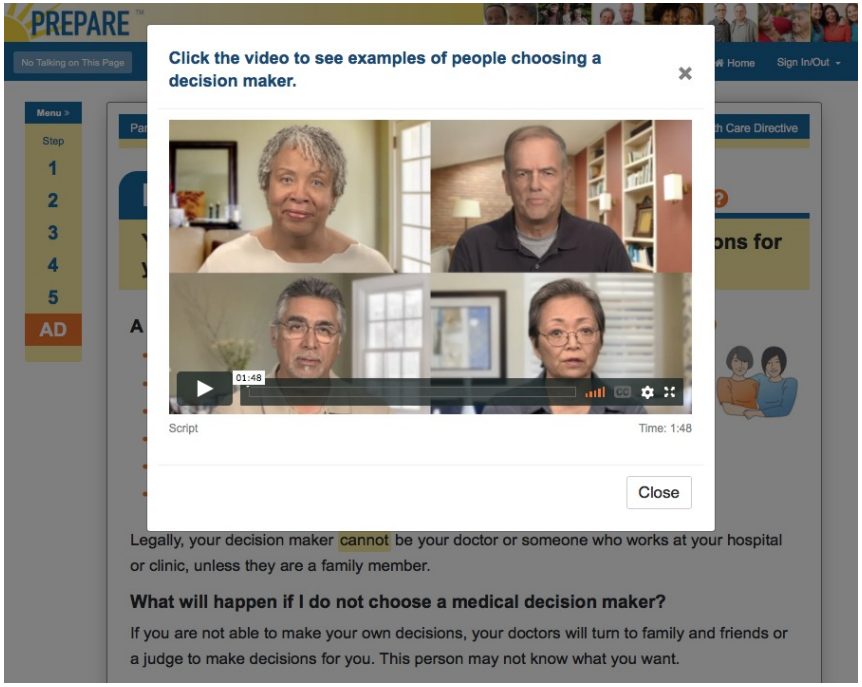
- Tailored answer automation





Guided AD Step (Info & videos in Eng/Sp)

- Additional information and videos available if needed



PREPARE Pamphlet

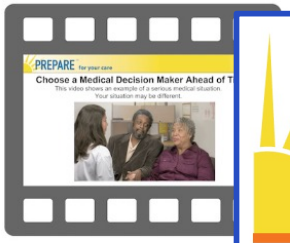
Trifold
English, Spanish, Chinese

Group Movie Events

The PREPARE Movie

You can watch one part of the PREPARE Movie or the full movie by clicking a button below.

- **Welcome**
- **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 Wishes
- **Step 5:** Ask Doctors the Right Questions
- **Your Next Steps**
- **Watch the full movie**



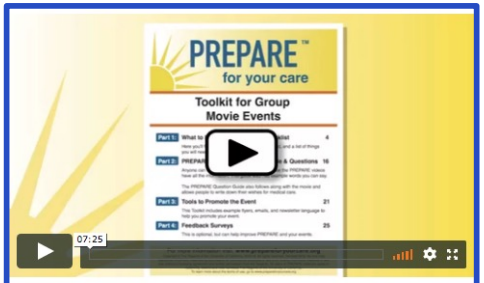
For group movie events, please see our Toolkit.

Get the PREPARE Toolkit

PREPARE™ for your care

Toolkit for Group Movie Events

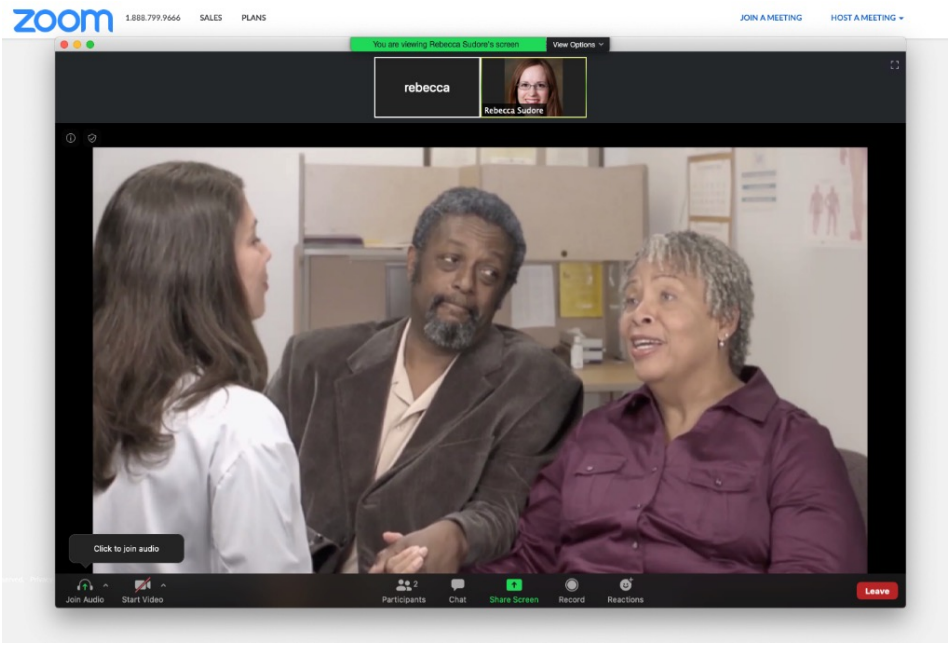
For more information visit: **www.prepareforyourcare.org**



How to Put on a PREPARE Movie Event

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

Group visits through Video



Simple Scripts

Anyone & any discipline

1. Ask about a surrogate
2. Ask about prior ADs
3. Give basic ACP info

Block, Smith, Sudore. *J Am* Geriatr Soc. May, 2020
Sudore, Fried. *Annals of Intern Med, 2010*

Due to COVID-19, Advance Care Planning is Imperative: We All Need to Pitch In

Regardless of healthcare profession, please address basic ACP during phone, video, or in person visits. Any ACP done now may save patients, families, and other providers from uncertainty and stress later on.

What You Can Say:

STEP 1: Ask About a Surrogate Decision Maker

"I wanted to take a moment to talk to you about advance care planning. This involves choosing an emergency contact and the medical care that is important to you."

"First, I would like to ask if there is someone you trust to help make medical decisions for you if there ever came a time you could not speak for yourself?"

If yes: "That's great. If not already, now is a good time to reach out and tell them that you chose them for this role and what is important to you. That way they can be the best advocate and speak up for you if needed."

"I will make sure I put this in your medical record. It is also important to keep their name and phone number on hand, both on your phone and also written down in your purse or wallet."

If no: "It is OK if you cannot think of someone right now. If someone comes to mind in the future, please let your medical providers know so we can put the information in your medical record."

STEP 2: Ask about Advance Directives

"Have you ever completed an advance directive? This is a legal form that lets you write down the name of your medical decision maker and your wishes for medical care." What about a POLST form?

If yes: "That's great. Do you remember what you wrote down? Do you still feel the same way? Do you know where this form is?"

"The most important part is to now share the information in this form with your family and friends. It is also important to bring a copy of the form with you if you need to come to the clinic or hospital. That way your family, friends, and medical providers will know what is most important to you."

If no: "This is OK. *[Example, use local preference]* A good place to start is a website called PREPAREforYourCare.org. It has simple information and advance directive forms for free and COVID-19 specific information and resources. You can get the website on a smartphone, a tablet, or a computer. You can even do this with your family and friends. That website again is PREPAREforYourCare.org. You can download the form to fill out on your computer or print to out."

[Optional due to social distancing]: "The forms sometimes need extra witnessing or a notary to be legal. While we are practicing social distancing, if you fill out the form it is OK for now to just sign and date it. And, it is really important to share the information with your family and friends and medical providers. These conversations are the most important part. Bring a copy of the form with you if you need to come to the clinic or hospital."]

nter

PREPARE™

for your care

Advance Care Planning Toolkit

Part 1: Definitions

Part 2: Introduction

Part 3: Materials

Part 4: Follow-up

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

Scripts to start conversations & discuss PREPARE tools

PREPARE: Free to the Public

- **FREE:**
  - Link to (use) the PREPARE url for online or print materials
    - How to Use PREPARE Guide: Has standardized descriptions
  - Forward link instead of PDFs to colleagues/patients
  - Print materials from the PREPARE website

- **UCSF Licenses Available:** https://prepareforyourcare.org/partner
  - PREPARE materials/PDFs on other online platforms, EHRs, or print material
  - Branding, data reporting, research

Questions?

www.PrepareForYourCare.org

: rebecca.sudore@ucsf.edu

: @prepareforcare

UCSF San Francisco VA Medical Center
Division of Geriatrics