



Program in Advance Care Planning

Rebecca L. Sudore, MD
Associate Professor of Medicine, UCSF

Outline

- Background
- Theories
- Conceptual Model
 - PREPARE Program
 - Survey Development



My Research Goal

- To improve advance care planning and medical decision making by designing, testing, and implementing easy-to-understand, patient-centered decision support tools.



California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

● This form has 3 parts. It lets you:

Part 1: Choose a health care agent.
A health care agent is a person who can make medical decisions for you if you are too sick to make them yourself.

Part 2: Make your own health care choices.
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 too sick to tell them yourself.

Part 3: Sign the form.
It 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 10 or a notary public on page 11.

YOUR NAME: _____

Go to the next page  **1**

2 Major Deficits

- Patients are not empowered



- Lack of guidance



UNPREPARED Patients & families

- Uninformed choices
- Care inconsistent w/ goals
- ↑ expenditures



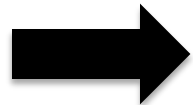
Sudore RL, Fried TR, Annals of Intern Med, 2010

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



Preparation for
communication &
decision making

Solution: Interactive, multi-media website



Welcome

View the PREPARE Pamphlet

- 1 Choose a Medical Decision Maker**
- 2 Decide What Matters Most In Life**
- 3 Choose Flexibility for Your Decision Maker**
- 4 Tell Others About Your Wishes**
- 5 Ask Doctors the Right Questions**

Your Action Plan

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 >



Objective



- Develop a patient-centered advance care planning (ACP) website based on preparing patients for communication & decision making.
- Target population
 - Any adult with chronic or serious illness
 - Goal is to start the process early
- Where do you start & how can theories help?

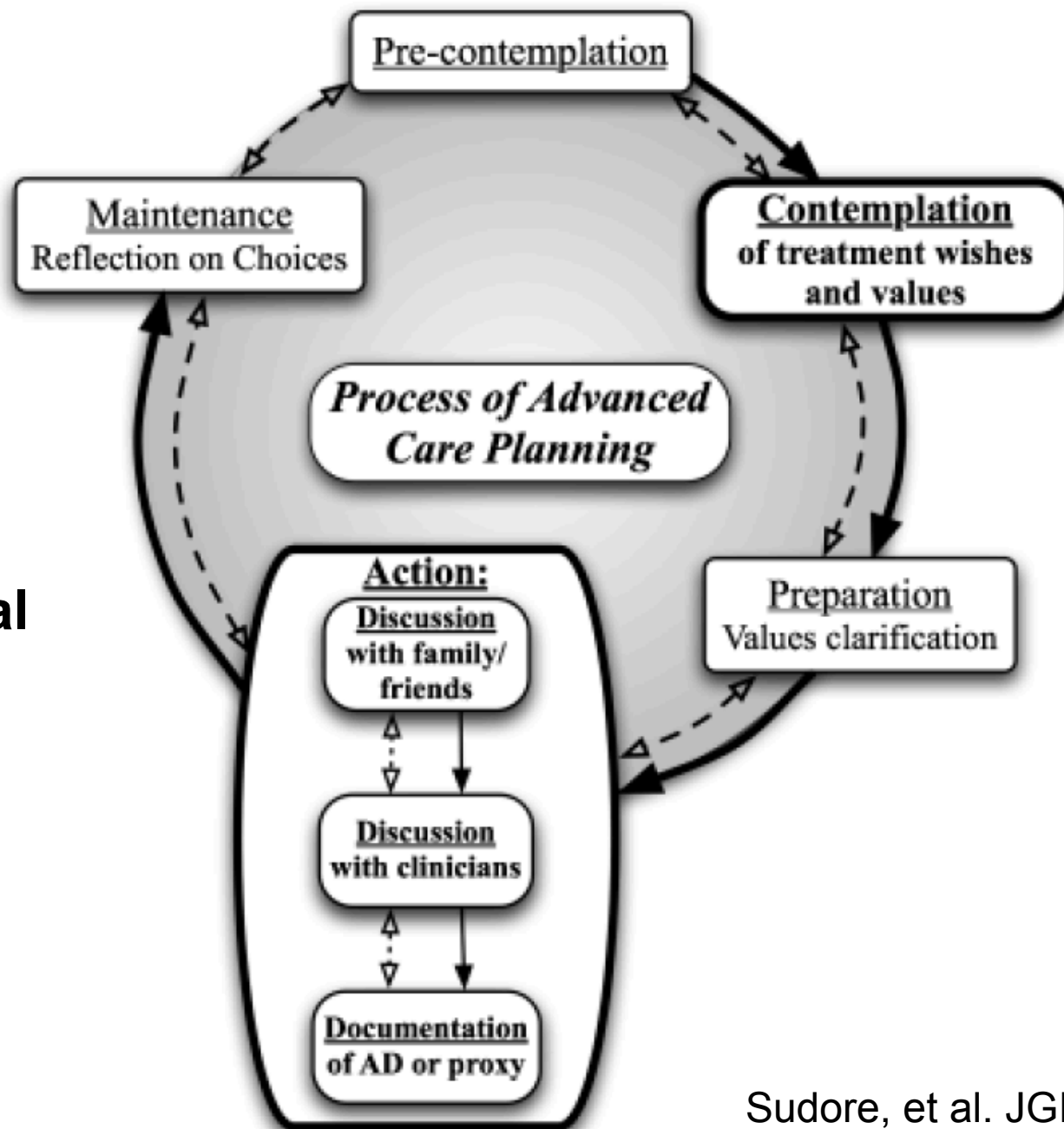
Creating PREPARE



First Studies

- 173 English/Spanish speakers from SFGH
 - 73% non-white, 1/3 < HS education
- **Results:**
 - 61% contemplated ACP
 - 56% discussed with family/friends
 - 22% discussed with clinicians
 - 13% documented wishes
 - > discuss w/ clinician or document if first talked with family/friends.

My first
conceptual
model



Sudore, et al. JGIM 2008

Focus Groups



- Semi-structured interviews
 - Patients' and surrogates' experiences with decision making for serious illness
 - Past experiences with discussions @ death
 - “**Advice**” about what best prepared them

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

Interactive, multi-media website



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PREPARE Website

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Your Action Plan

What makes behavior interventions successful? Theory-based

- Glanz K, Annu Rev Public Health, 2010:
- Theory at a Glance: A guide for health Promotion Practice, NCI 2005
 - Health promotion more effective if based on social and behavioral scientific theories
 - Theories can be combined
 - 33 theories combined in Theoretical Domains Framework, Michie et al., 2005

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

Social Cognitive Theory

Table 5. Social Cognitive Theory

<i>Concept</i>	<i>Definition</i>	<i>Potential Change Strategies</i>
Reciprocal determinism	The dynamic interaction of the person, behavior, and the environment in which the behavior is performed	Consider multiple ways to promote behavior change, including making adjustments to the environment or influencing personal attitudes
Behavioral capability	Knowledge and skill to perform a given behavior	Promote mastery learning through skills training
Expectations	Anticipated outcomes of a behavior	Model positive outcomes of healthful behavior
Self-efficacy	Confidence in one's ability to take action and overcome barriers	Approach behavior change in small steps to ensure success; be specific about the desired change
Observational learning (modeling)	Behavioral acquisition that occurs by watching the actions and outcomes of others' behavior	Offer credible role models who perform the targeted behavior
Reinforcements	Responses to a person's behavior that increase or decrease the likelihood of reoccurrence	Promote self-initiated rewards and incentives

Health Belief Model

Table 2. Health Belief Model

<i>Concept</i>	<i>Definition</i>	<i>Potential Change Strategies</i>
Perceived susceptibility	Beliefs about the chances of getting a condition	• Define what populations(s) are at risk and their levels of risk • Tailor risk information based on an individual's characteristics or behaviors • Help the individual develop an accurate perception of his or her own risk
Perceived severity	Beliefs about the seriousness of a condition and its consequences	• Specify the consequences of a condition and recommended action
Perceived benefits	Beliefs about the effectiveness of taking action to reduce risk or seriousness	• Explain how, where, and when to take action and what the potential positive results will be
Perceived barriers	Beliefs about the material and psychological costs of taking action	• Offer reassurance, incentives, and assistance; correct misinformation
Cues to action	Factors that activate "readiness to change"	• Provide "how to" information, promote awareness, and employ reminder systems
Self-efficacy	Confidence in one's ability to take action	• Provide training and guidance in performing action • Use progressive goal setting • Give verbal reinforcement • Demonstrate desired behaviors

Theory of Planned Behavior

Table 4. Theory of Planned Behavior

<i>Concept</i>	<i>Definition</i>	<i>Measurement Approach</i>
Behavioral intention	Perceived likelihood of performing behavior	Are you likely or unlikely to (perform the behavior)?
Attitude	Personal evaluation of the behavior	Do you see (the behavior) as good, neutral, or bad?
Subjective norm	Beliefs about whether key people approve or disapprove of the behavior; motivation to behave in a way that gains their approval	Do you agree or disagree that most people approve of/disapprove of (the behavior)?
Perceived behavioral control	Belief that one has, and can exercise, control over performing the behavior	Do you believe (performing the behavior) is up to you, or not up to you?

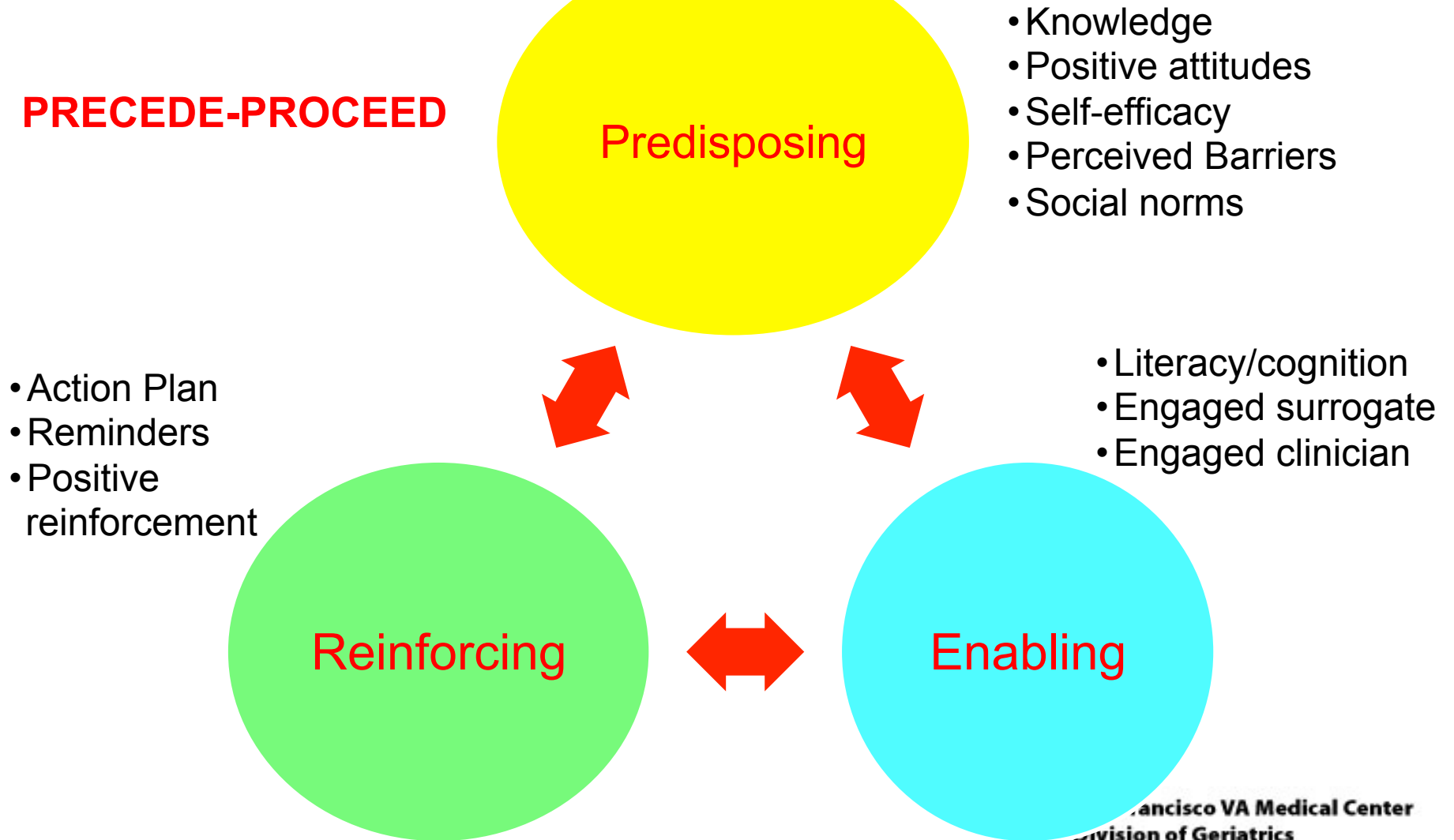
Stages of Change

Table 3. Stages of Change Model

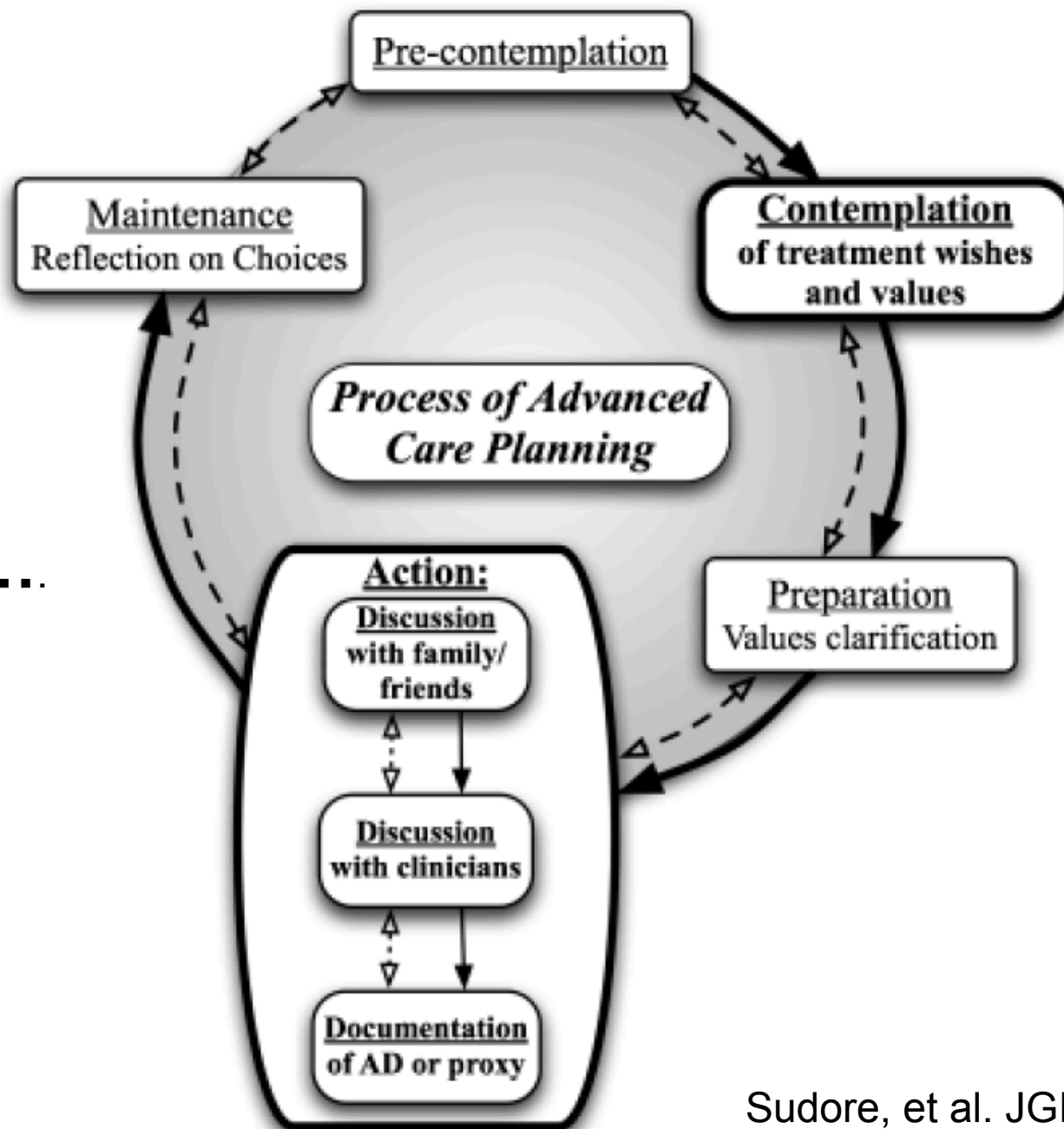
<i>Stage</i>	<i>Definition</i>	<i>Potential Change Strategies</i>
Precontemplation	Has no intention of taking action within the next six months	Increase awareness of need for change; personalize information about risks and benefits
Contemplation	Intends to take action in the next six months	Motivate; encourage making specific plans
Preparation	Intends to take action within the next thirty days and has taken some behavioral steps in this direction	Assist with developing and implementing concrete action plans; help set gradual goals
Action	Has changed behavior for less than six months	Assist with feedback, problem solving, social support, and reinforcement
Maintenance	Has changed behavior for more than six months	Assist with coping, reminders, finding alternatives, avoiding slips/relapses (as applicable)

Implementation Considerations

PRECEDE-PROCEED

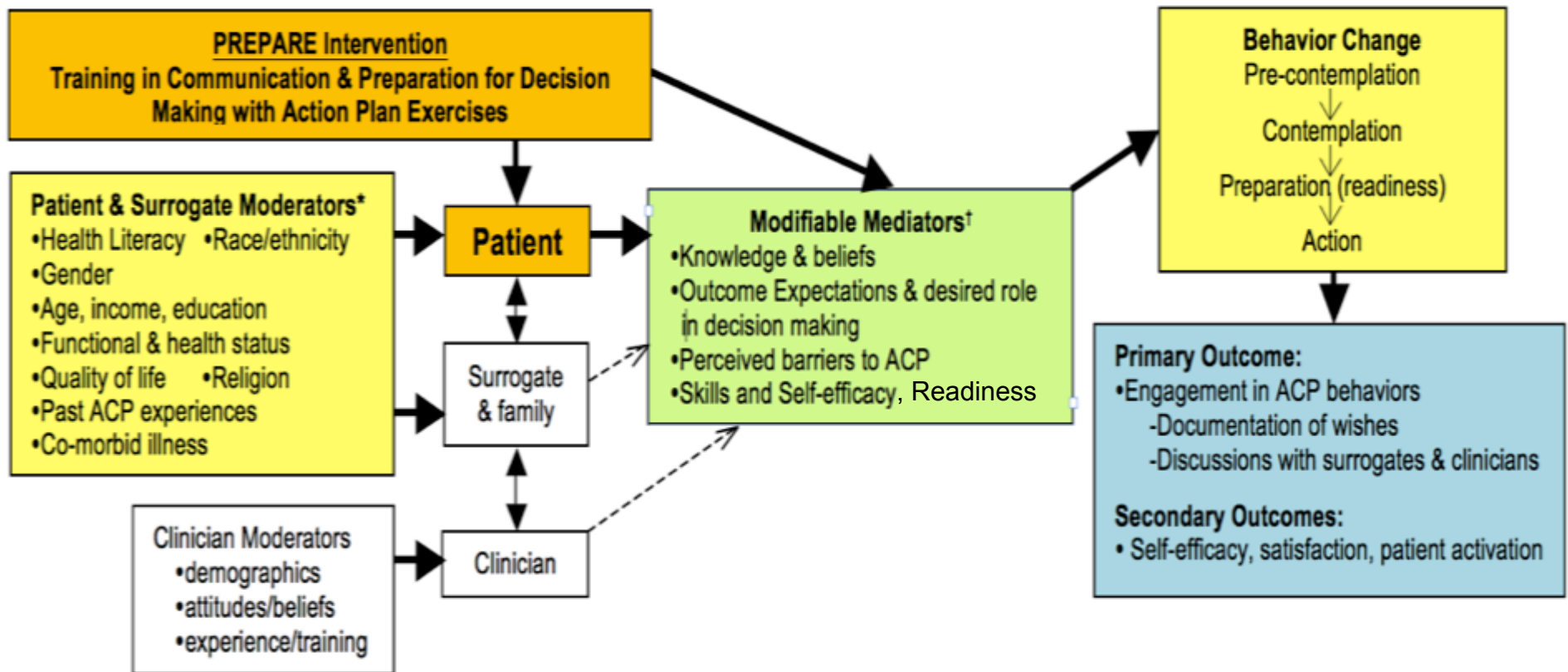


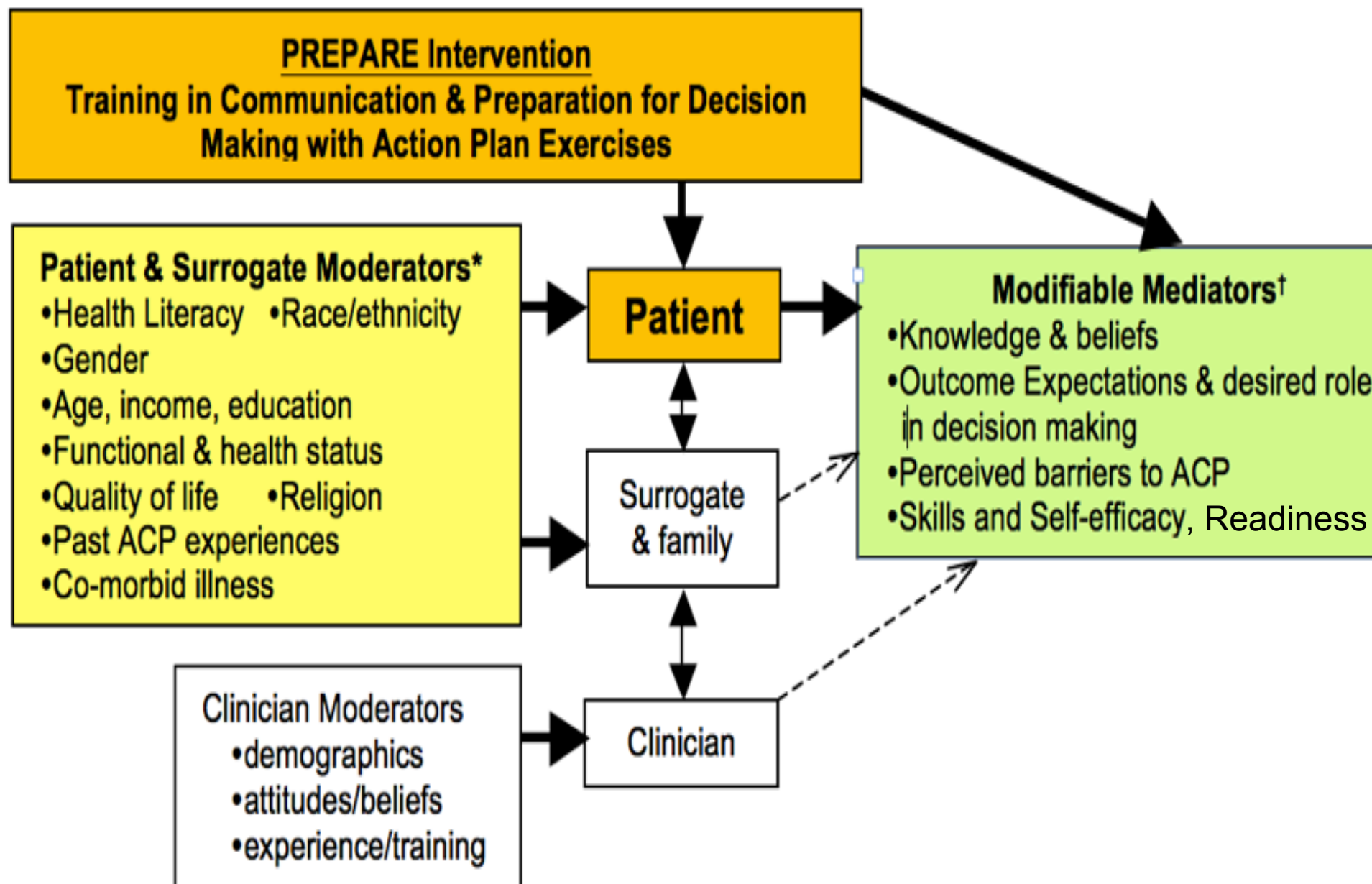
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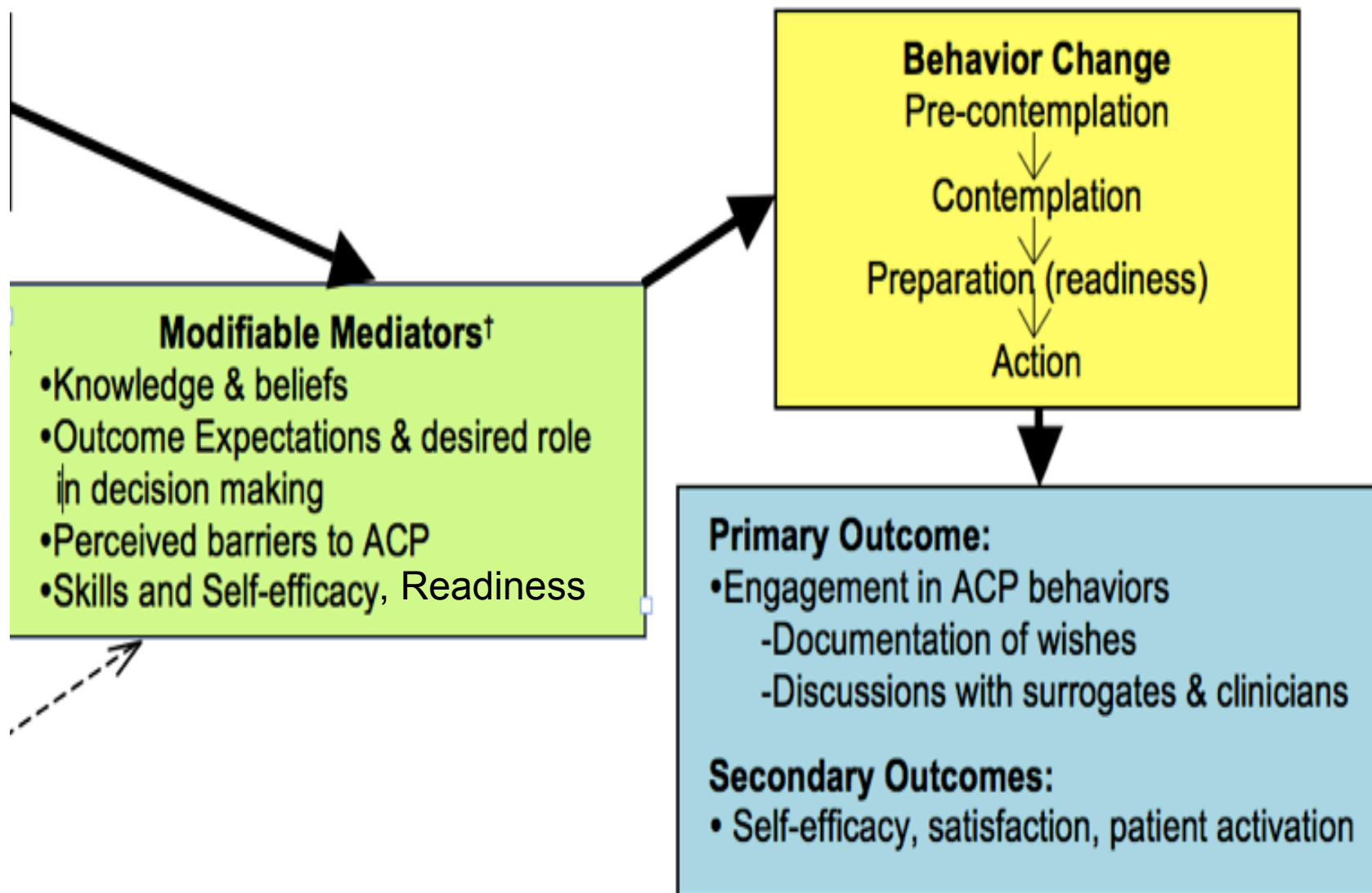


Sudore, et al. JGIM 2008

Conceptual Framework







Creating PREPARE

- Expert panel
 - Health Literacy
 - Geriatrics & Palliative Care
 - Behavior change
- 13 focus groups
 - Patients & surrogates
- Cognitive interviews



Creating PREPARE

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



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 vs. no surrogate (15-20%)
 - Want to be involved in dec making vs. not (18%)





Welcome

Hide Menu

1 Choose a Medical Decision Maker

- A. Why this is important
- B. What you need to do
- C. How to do it - how to say it

2 Decide What Matters Most In Life

3 Choose Flexibility for Your Decision Maker

4 Tell Others About Your Wishes

5 Ask Doctors the Right Questions

Your Action Plan

Step 1: Choose a Medical Decision Maker



Step 2

Step 3

Step 4

Step 5

Action Plan

Click the NEXT button to move on.

< GO BACK

NEXT >



PREPARE



Show Menu

Choose a Medical Decision Maker Ahead of Time



Click the pictures to see who these people chose as their decision maker.



Cynthia chose her husband

[Click to P](#)



Jorge chose his family

[Click to P](#)



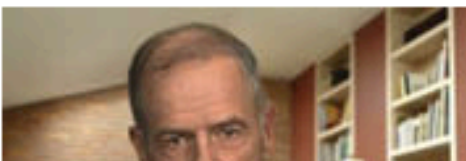
Helen may choose her neighbor

[Click to P](#)



John chose his son to make ALL his decisions

[Click to P](#)



Ken has no one to chose



Show Menu

How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.





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.

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NEXT 



Show Menu

Do any of these reasons make it hard for you to choose a medical decision maker? Click on as many as you want.



I am afraid to think about being really sick.



I would rather leave my health to God and to prayer.



I do not want to burden my friends and family members.



Or, something else is making this hard to do.

Click the NEXT button to move on.



GO BACK

NEXT



PREPARE



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

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PREPARE Website

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View the PREPARE Pamphlet

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Your Action Plan

PREPARE



Show Menu

What is an Action Plan?

An action plan is a contract you make with yourself to do something.



We want you to do one of the 5 Steps.

[<](#) GO BACK

NEXT [>](#)

Name: RebeccaS



My Action Plan

Talk to your doctor about your medical wishes.

You will do this by July 30.

Summary of All Steps

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 have close family and friends who may have strong opinions about your medical care.
- 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.
- When making decisions with your family and friends, you want your family and friends to make all medical decisions for you.
- You **WOULD** want your doctor to tell you how sick you are or how long you have to live.

FOR THE DOCTOR

Goals of Care Information: This document reflects preferences your patient chose on the advance care planning website called PREPARE (www.prepareforyourcare.org). This is not a legal document.



SURROGATE DECISION MAKER

Who is the surrogate:

John Doe (your spouse/partner)

When surrogate is to make decisions:

When do you want someone (the surrogate) to make medical decisions for you?



I ONLY want someone to make medical decisions for me if I become too sick to make my own decisions.

Research Objective



- To assess the efficacy of PREPARE to improve behavior change in multiple advance care planning behaviors.
 - e.g., choosing surrogate, defining goals, communicating with family and doctors

Need New Outcomes to Measure Successful ACP



- **Old paradigm:** Complete advance directives
- **New paradigm:** Multiple ACP behaviors
 - Choosing and talking to a surrogate
 - Identifying and communicating goals with family and doctors
- Detect movement along behavioral change pathway from pre-contemplation to action for multiple ACP behaviors

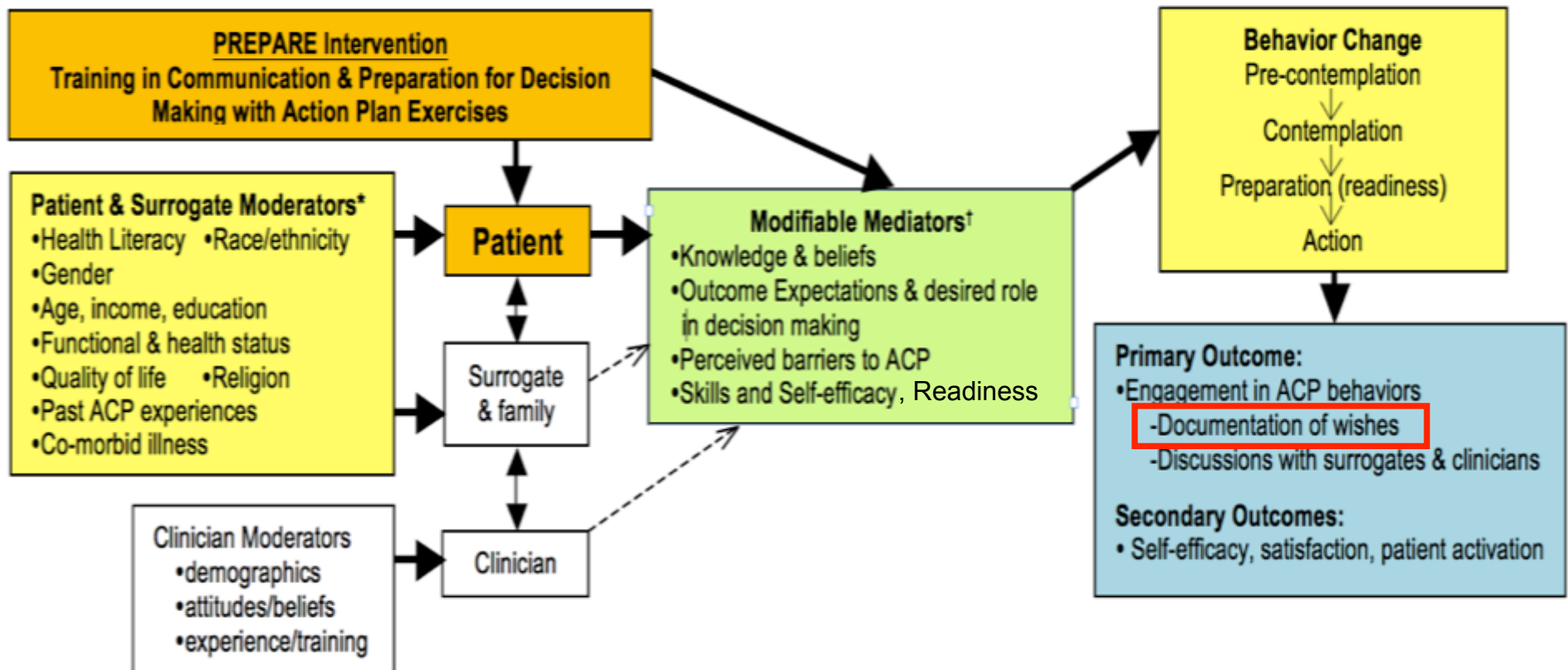
How to Measure the ACP Process?



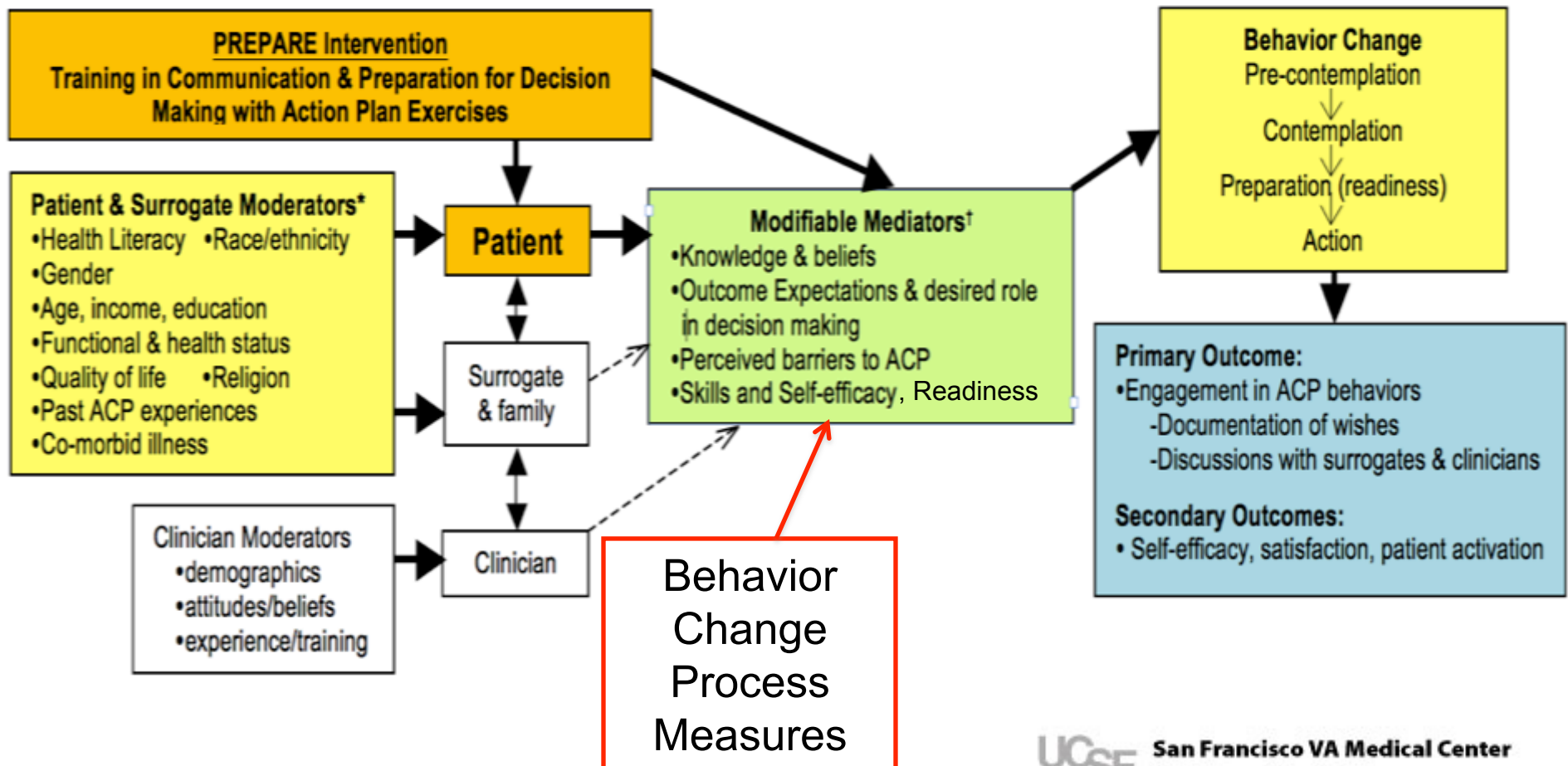
- Complex with multiple components
- People may be in varying stages of behavior change for EACH individual advance care planning behavior

Pearlman, Patient Educ Couns, 1995; Sudore, JGIM 2008; Fried, JAGS 2010,

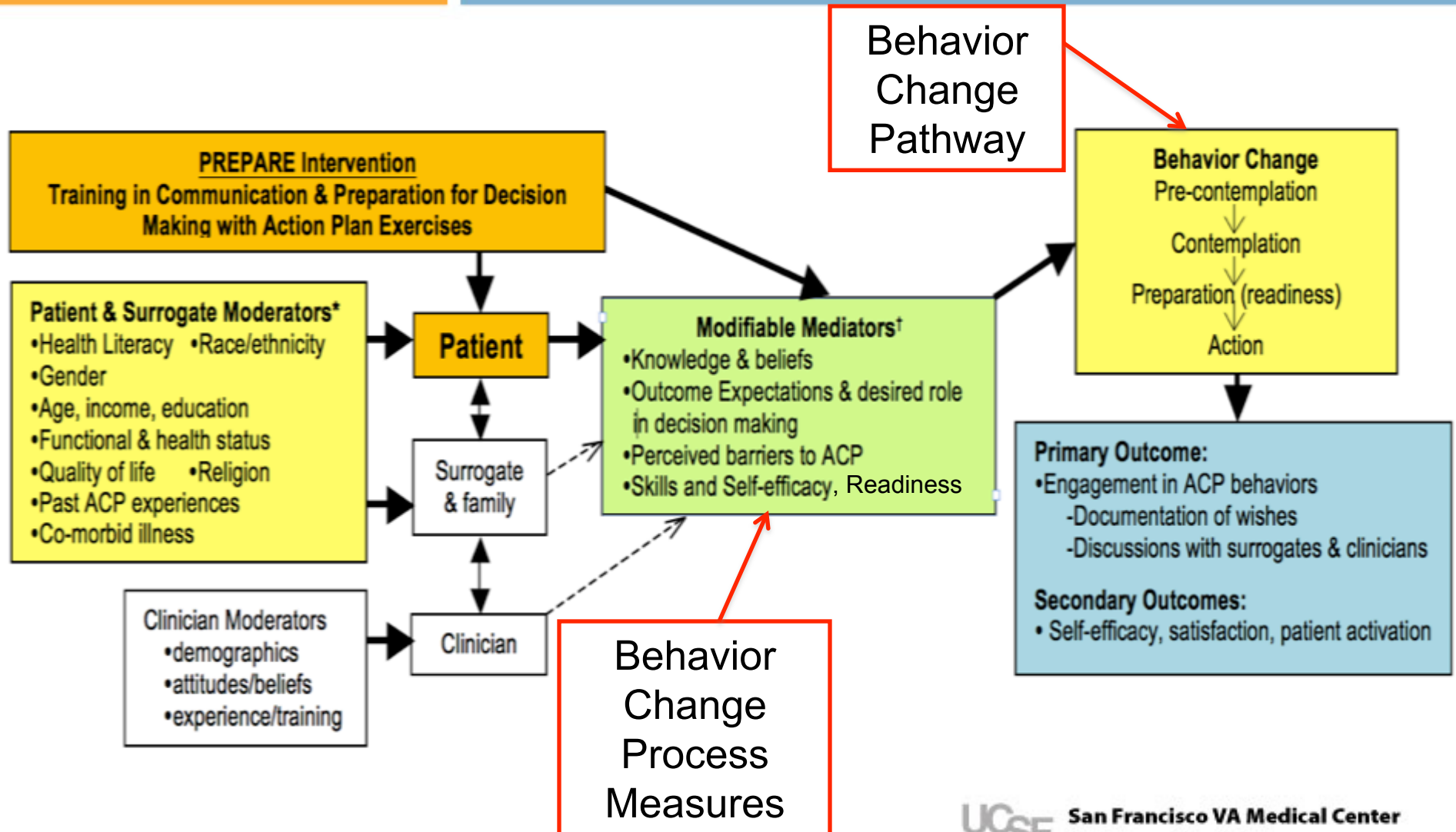
New Surveys to Measure the Process of ACP



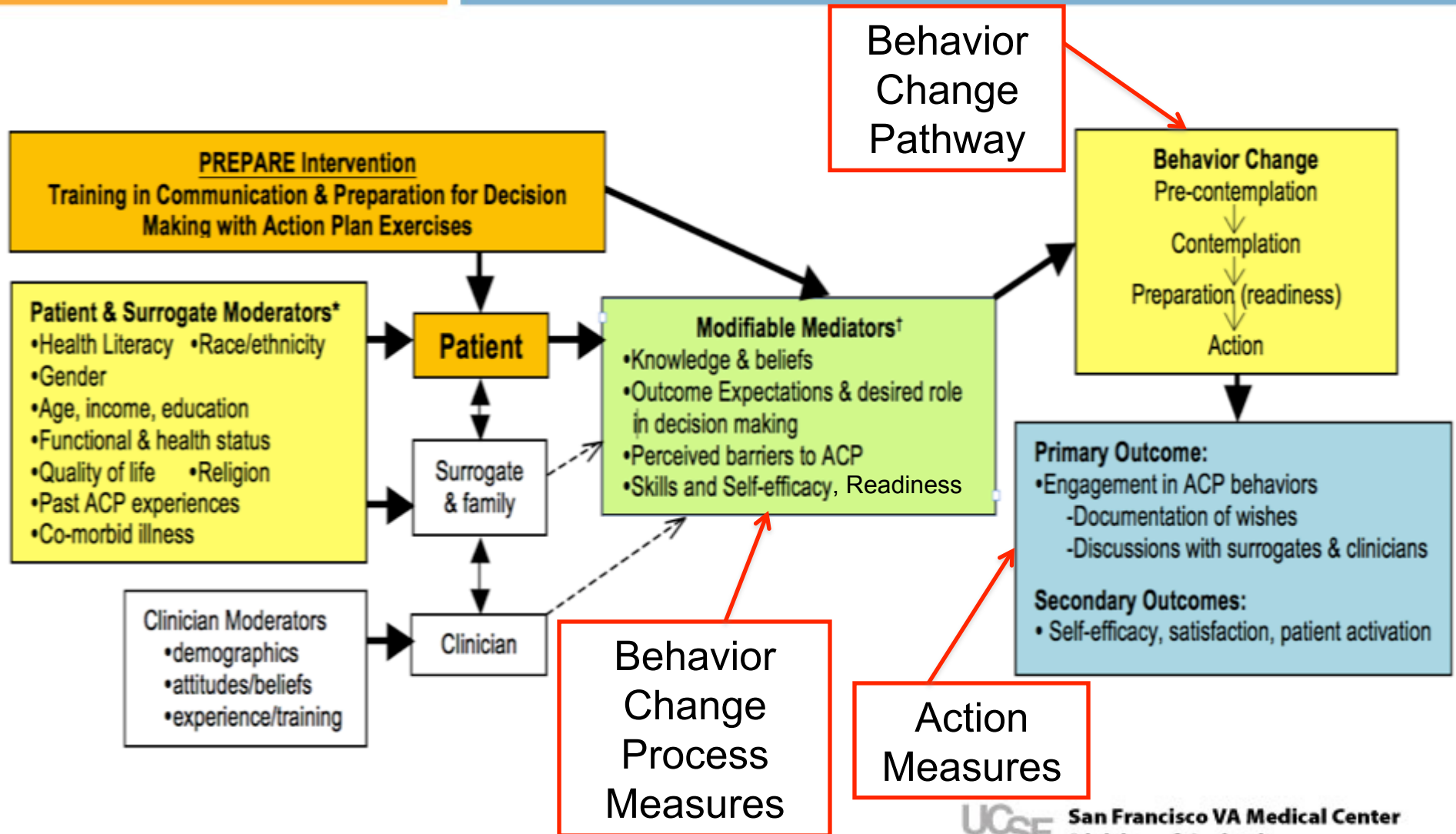
New Surveys to Measure the Process of ACP



New Surveys to Measure the Process of ACP



New Surveys to Measure the Process of ACP



Survey Validation, n=50



- Mean age 69.3 ($\pm$ 10.5), 42% non-White, 38% women, 28% had limited health literacy
- Good internal consistency
 - Process Measures Cronbach alpha, 0.94
- Good test-retest reliability intraclass correlation
 - Process Measures, 0.70
 - Action Measures, 0.87



Can PREPARE Improve the Process of ACP?

Pilot Study

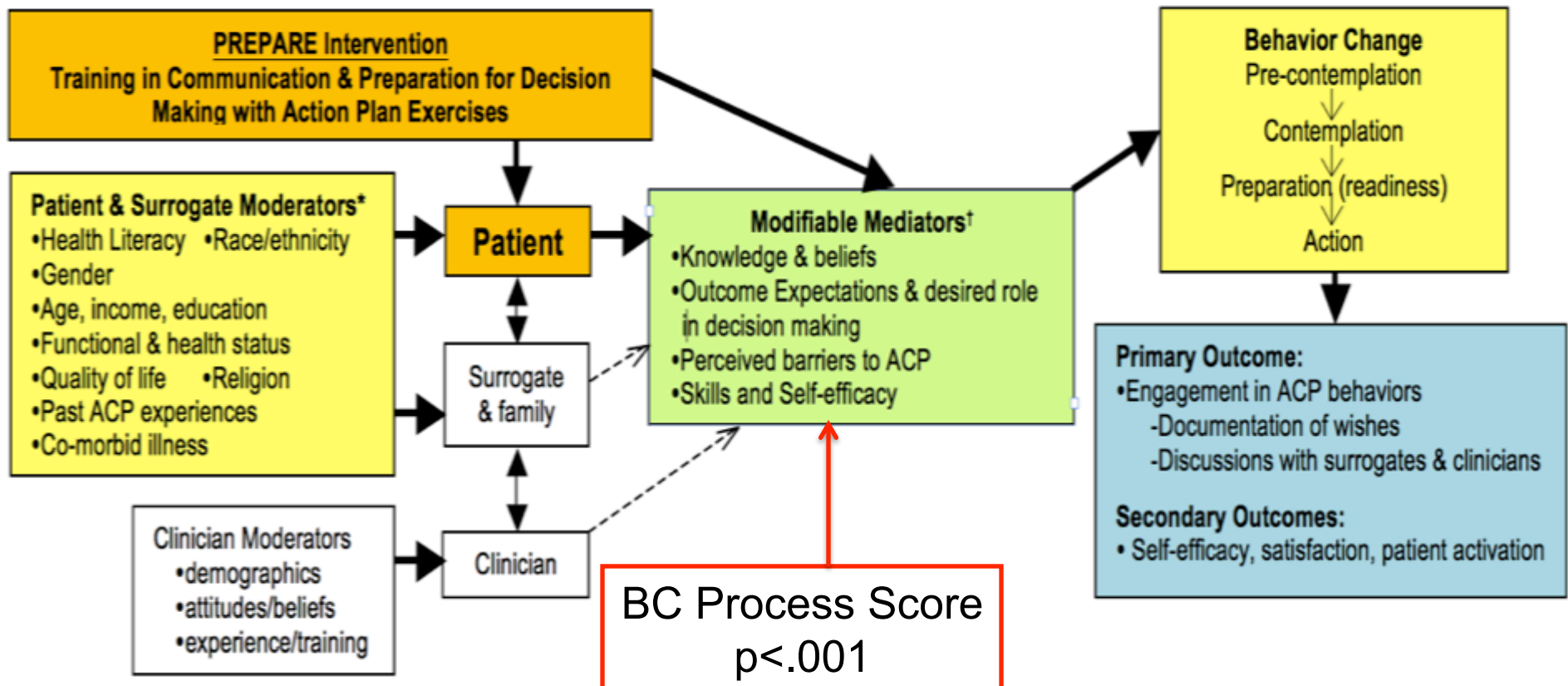


- Pre-to-post (1 week) pilot study of 43 diverse, older adults
 - Low income senior centers in San Francisco
 - ≥ 60 years of age
 - ≥ 2 chronic health conditions

Pilot Participants

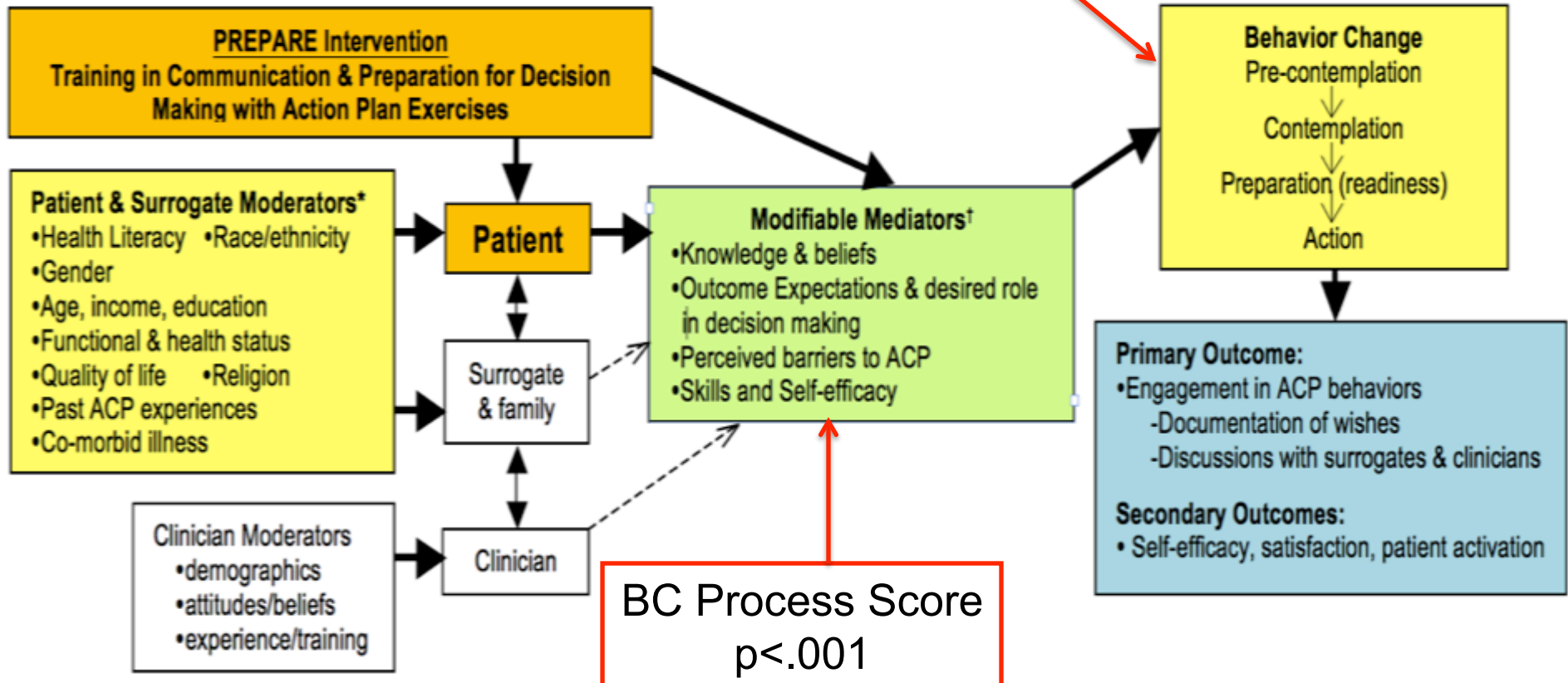
Characteristics	n = 43
Mean Age $\pm$ SD	68 $\pm$ 7
Women	51%
Race/ethnicity	
African American	44%
White	35%
Latino/Non-white Hispanic	9%
Asian/Pacific Islander	7%
Limited Literacy	33%
Limited Computer Literacy	> 90%

PREPARE Improves Engagement in Advance Care Planning



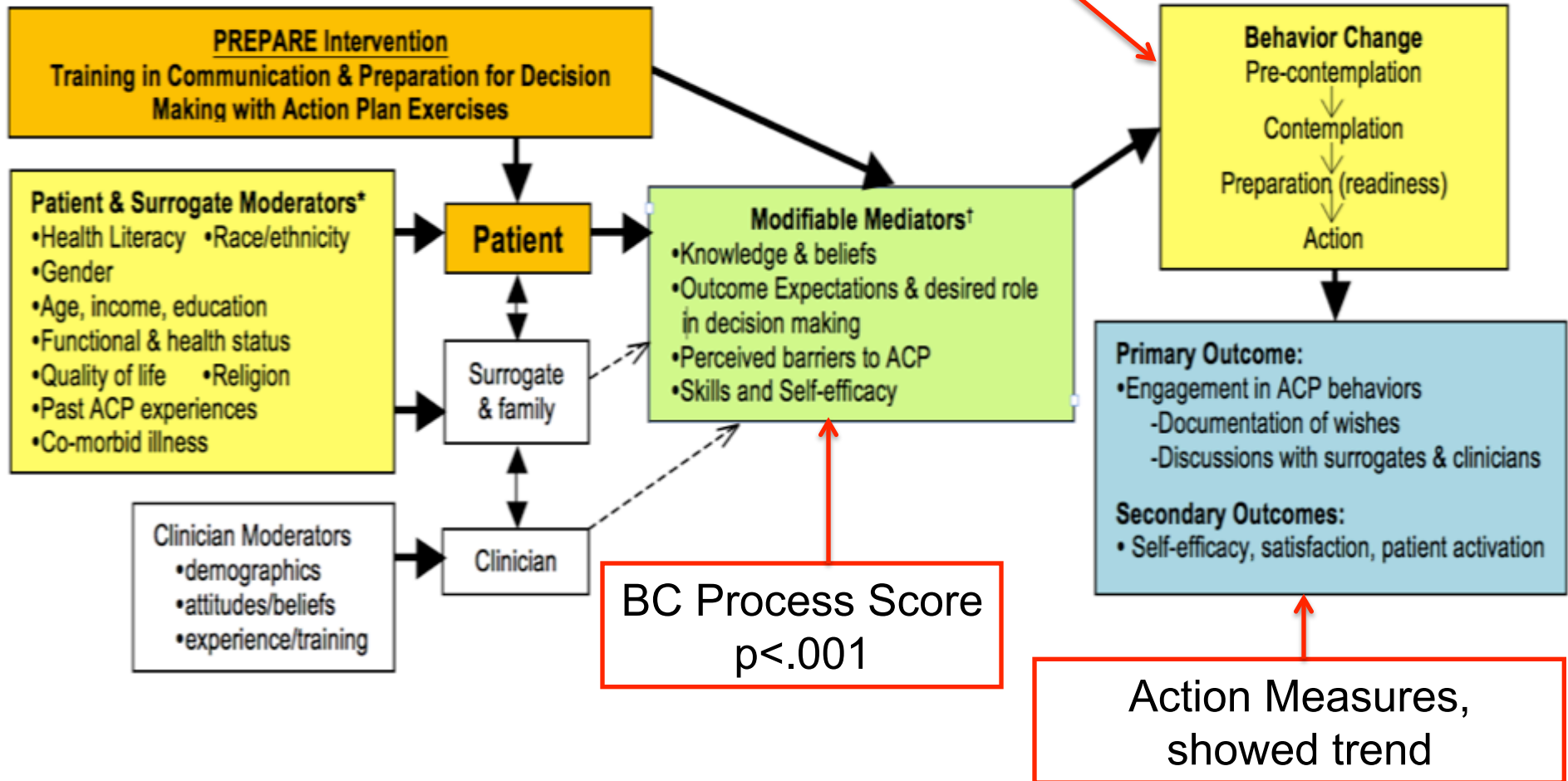
PREPARE Improves Engagement in Advance Care Planning

Behavior Change Pathway: $p < .001$
• Moved out of pre-contemplation for all actions



PREPARE Improves Engagement in Advance Care Planning

Behavior Change Pathway: $p < .001$
• Moved out of pre-contemplation for all actions



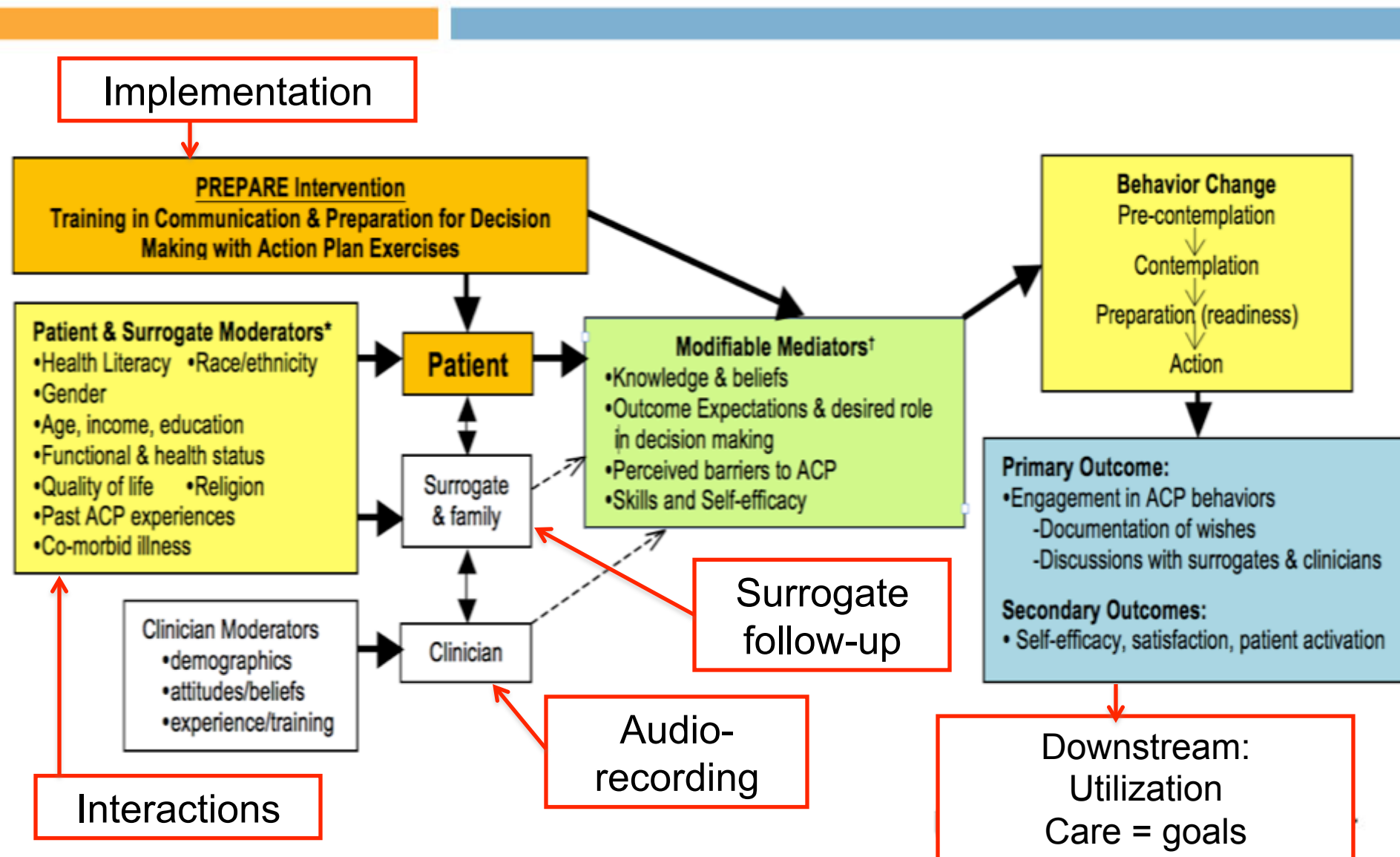
PREPARE Rated Easy to Use

- PREPARE website rated a 9 out of 10 for ease-of-use



The screenshot displays the PREPARE website interface. At the top, there is a yellow banner with a sun icon and the word "PREPARE" in blue. Below this, a row of six small photographs shows diverse groups of people. The main content area features a video player with the title "How to Ask Someone to Be Your Decision Maker" and a yellow subtitle bar that reads "You can watch this video with your friends and family." The video player shows an elderly couple sitting on a couch, engaged in conversation. A "Show Menu" button is visible on the left side of the video player. At the bottom right, the text "Medical Center" is partially visible.

Assessing Other Outcomes



Thank You!

- PREPARE: www.prepareforyourcare.org



- rebecca.sudore@ucsf.edu