

Improving Advance Care Planning for Seriously Ill Primary Care Patients

UC Health Care Planning Study

Rebecca Sudore, UCSF & Anne M. Walling, UCLA

No conflicts of interest

UCSF Program



Objectives

- The Evolving ACP Definition & Research
- Lessons for an ACP PCORI Pragmatic RCT
 - Identifying the cohort with validated algorithms
 - Constructing the ACP EMR Intervention Infrastructure
 - Healthcare navigator arm
 - Trial outcomes: NLP
 - Implementation Lessons

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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?



Problems with Only Advance Directives

- Forms not always available when needed
- Do not improve knowledge of patients' preferences
...without a discussion
 - clinical contexts change, patient's goals change
- Forms alone do not prevent surrogate stress/conflict
 - Not prepared, use own hopes/desires --> anxiety & PTSD

Updated Definitions

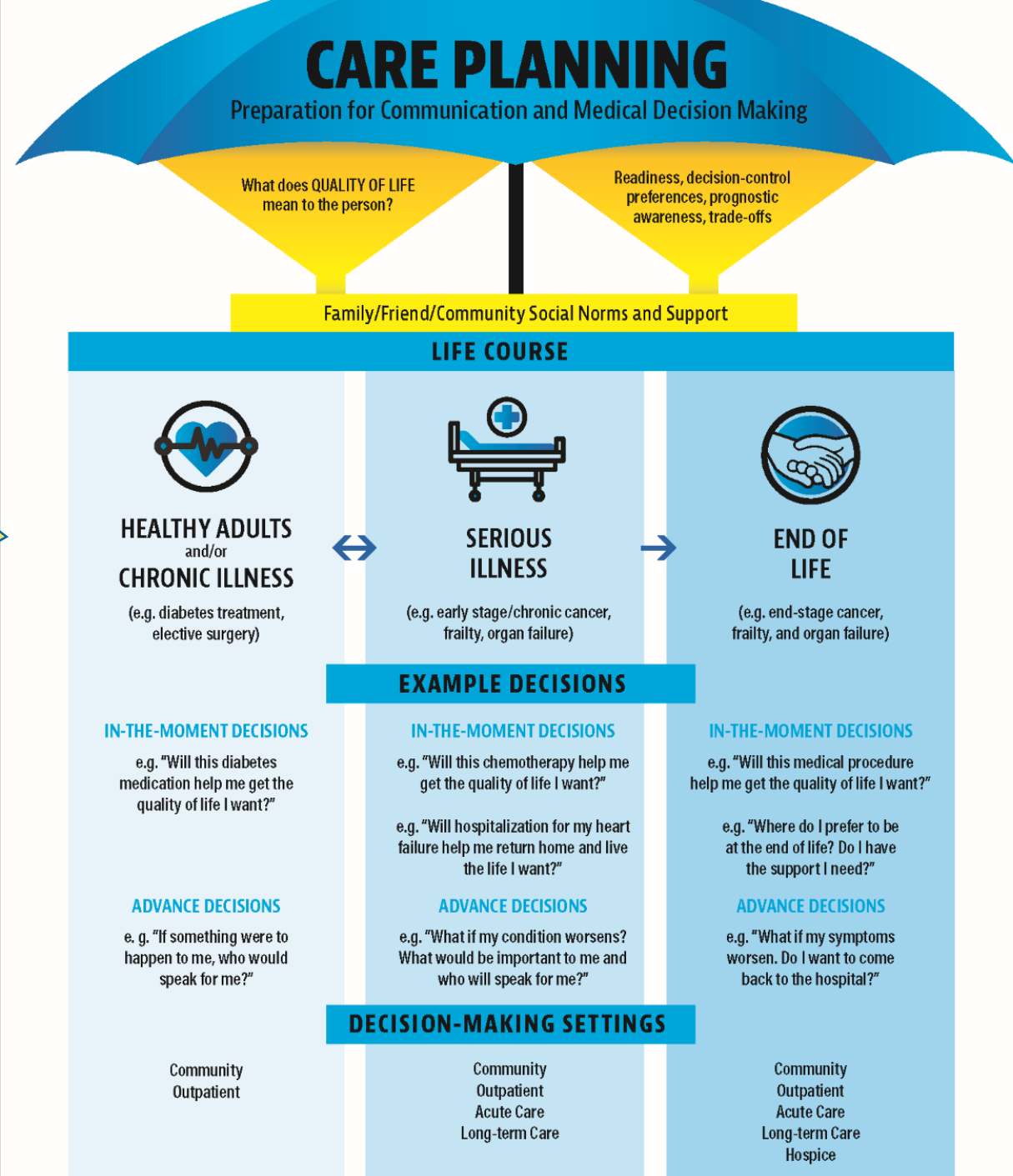


The care planning umbrella: The evolution of advance care planning

Susan E. Hickman PhD^{1,2} | Hillary D. Lum MD, PhD³ |
Anne M. Walling MD^{4,9} | April Savoy PhD^{2,5,6,7} | Rebecca L. Sudore MD⁸

“A NEW framework reflects the updated focus on preparation for communication and medical decision-making and conceptualizes ACP as part of the continuum of care planning across the life course.”

Expect updates over time



Is There Mixed Evidence?



Journal of the
American Geriatrics Society

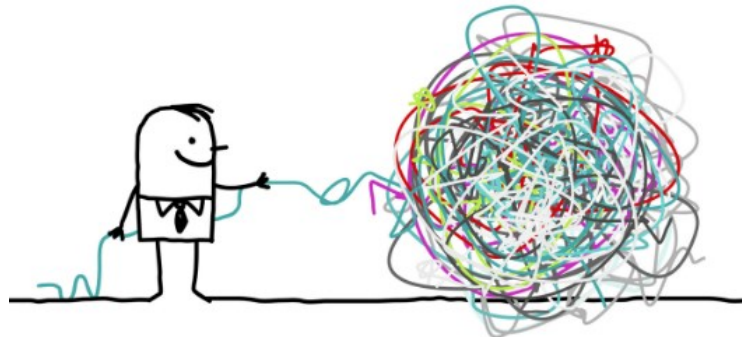
AGS Geriatrics
Healthcare
Professionals
Leading Change. Improving Outcomes.

The National
Academies of

SCIENCES
ENGINEERING
MEDICINE

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*[†]



69 high quality
RCTs: 2010-2020

Results: People Want ACP

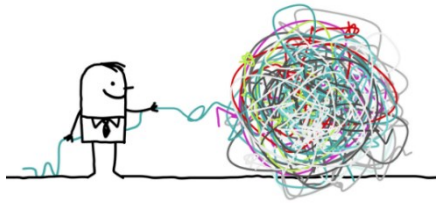
- Patients, surrogates, clinicians want ACP ~*especially if experience making decisions for serious illness*
- Goal for patients is to **prepare surrogates & decrease decision-making burden on others**

Results: Positive Outcomes

- **Intervention types**
 - Written, multimedia, facilitated discussions ~ 70%
 - Clinician training ~ 57%
- **Patient, Caregiver, Clinician Outcomes:**
 - Patient/caregiver satisfaction w/ communication ~ 100%
 - Patient engagement in care planning communication ~ 86%
 - Congruence (pt/surrogate/clinician) ~88%
 - Decreased **surrogate** anxiety/depression, PTSD, complicated grief & caregiver burden: **100%**
 - Decreased Clinician distress: 1 of 1

Results: Mixed Outcomes

- Goal Concordant Care: 10% positive
 - Non-validated, old ACP model
 - Updated studies (real-time GCC, VA, POLST → ++)
- Healthcare Utilization: 42% positive
 - Not patient centered
 - Not focused on holistic workflows



Where Do We Go?

- Move away from checkboxes → PROCESS over time
 - **Preparation for communication and decision making** for patients & surrogates (foster more discussions)
- ACP is not a panacea, but is incredibly meaningful
 - **Preparing people decreases suffering**

Online, Secure ACP Program with Videos and Easy-to-Read Advance Directives



Español

No Talking on This Page
Sign in

How to Use The PREPARE 5 Steps Summary of My Wishes Advance Directive Tools for Providers

PREPARE has 2 programs with video stories to help you:

1. Have a voice in **YOUR OWN** medical care
2. Help **OTHER PEOPLE** with their medical planning and decisions

for YOUR care

Have a Voice In Your Medical Care

This step-by-step program makes it easy with video examples

Click here to do [YOUR OWN](#) medical planning

for THEIR care

Help Other People

Click here to learn how to help [OTHER PEOPLE](#) with their medical planning and decisions

New!

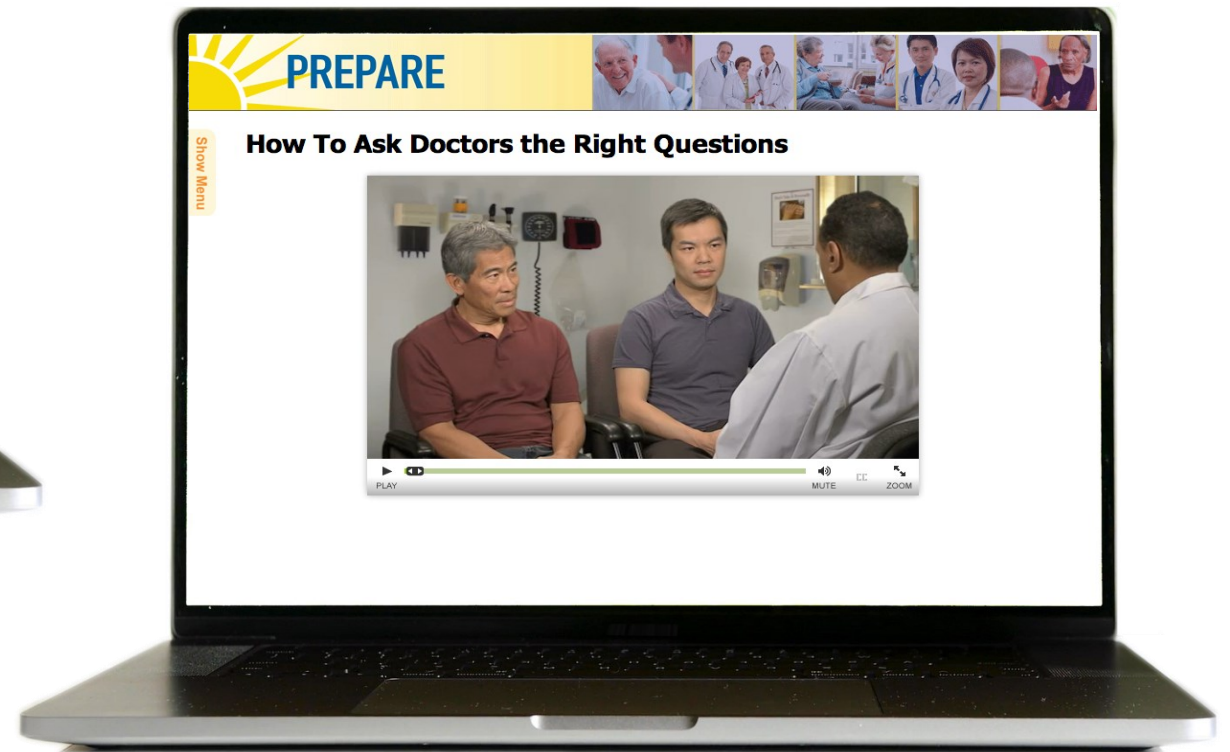
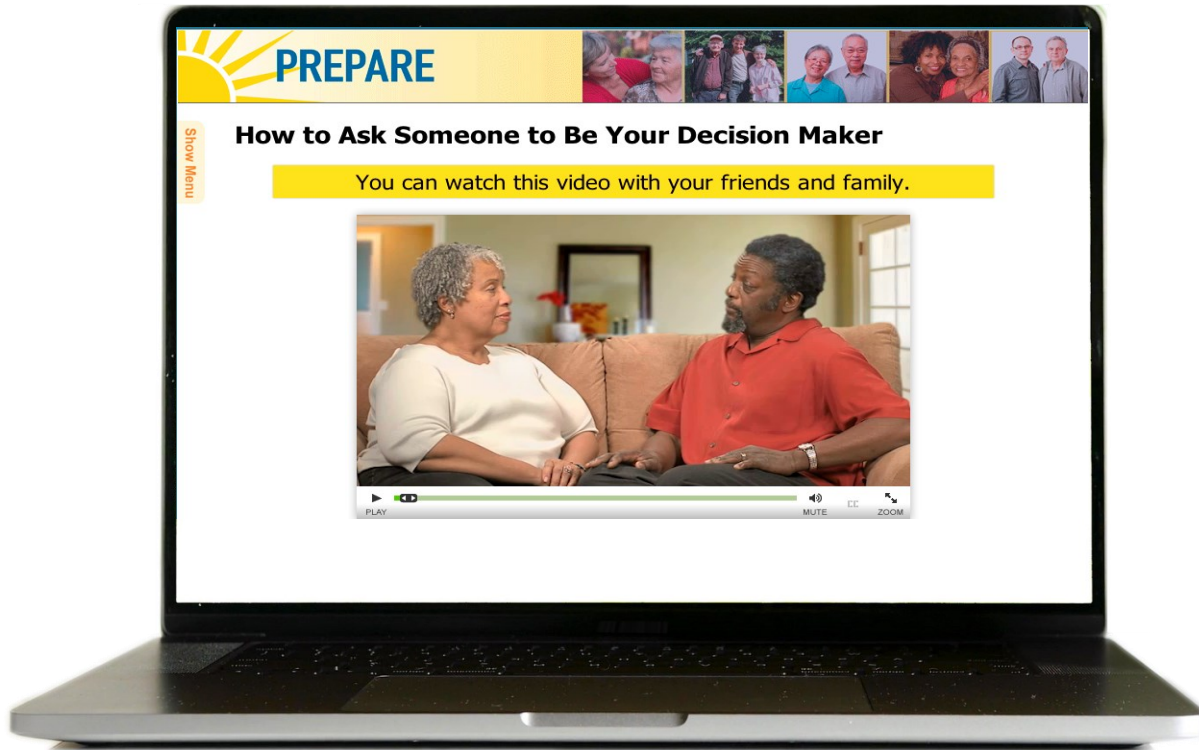
PREPARE Tools for Providers & Organizations

Free PREPARE Easy-to-Read Advance Directives Below

The collage shows three versions of the California Advance Health Care Directive form:

- English:** "California Advance Health Care Directive" with instructions: "This form lets you have a say about how you want to be cared for if you cannot speak for yourself." It lists three parts: 1. Choose a medical decision maker, 2. Make your choices, 3. Sign the form.
- Spanish:** "Paunang Direktiba Pangkalusugan" with instructions: "Ang form na ito ay nagpapahintu paano mo nais na maalagaar...". It lists three parts: 1. Pumili ng tagapagpasiya, 2. Pumili ng tagapagpasiya, 3. Pormal na ito ay may 3 bahagi.
- Chinese:** "加州醫療照護事前指示書" with instructions: "在您無法表達意見時，這份指示書可讓您表達您希望得到的醫療照護。" It lists three parts: 1. 選擇一位醫療代理人，2. 選擇您的醫療照護，3. 簽署指示書。

Shows “How to” Videos



5th grade reading level
Narration & closed captioning

Integrates Easy-to-read Legal ADs for all US states in English & Spanish and 13+ in Chinese



11 languages in CA

UCSF-UC Law

CONSORTIUM ON
LAW, SCIENCE &
HEALTH POLICY

New York 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, proxy, 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 _____

 1
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Instrucción anticipada de atención de salud de Nueva York

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:

Parte 1 Escoger una persona decisora, página 3

Una persona decisora es una persona que puede tomar decisiones médicas por usted si usted no puede tomarlas por sí mismo. Esta persona será su representante. También se les llama un agente de salud, un representante, o un sustituto. They are also called a health care agent, proxy, or surrogate.

Parte 2 Tomar sus propias decisiones de atención de salud, página 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.

Parte 3 Firmar el formulario, página 13

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 14.

Su Nombre "Your Name" _____

 1
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紐約州醫療照護事前指示書

在您無法表達意見時，這份指示書可讓您表達您希望得到的醫療照護。

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

指示書分為三部分：

第一部分 選擇一位醫療代理人，第3頁

在您無法自己做決定時，您的醫療代理人會幫您做出醫療決定。這個人將是您的權益代言人。她/他也被稱為醫療代理人、委託人、決策者或代理者。

第二部分 選擇您的醫療照護，第7頁

指示書讓您選擇自己想要的醫療照護。這樣，若您無法表達意見時，照護您的人就不需要揣測您的想法。

第三部分 在指示書上簽名，第13頁

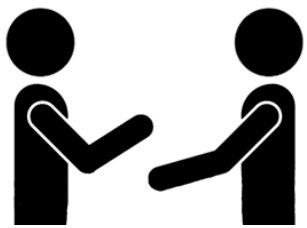
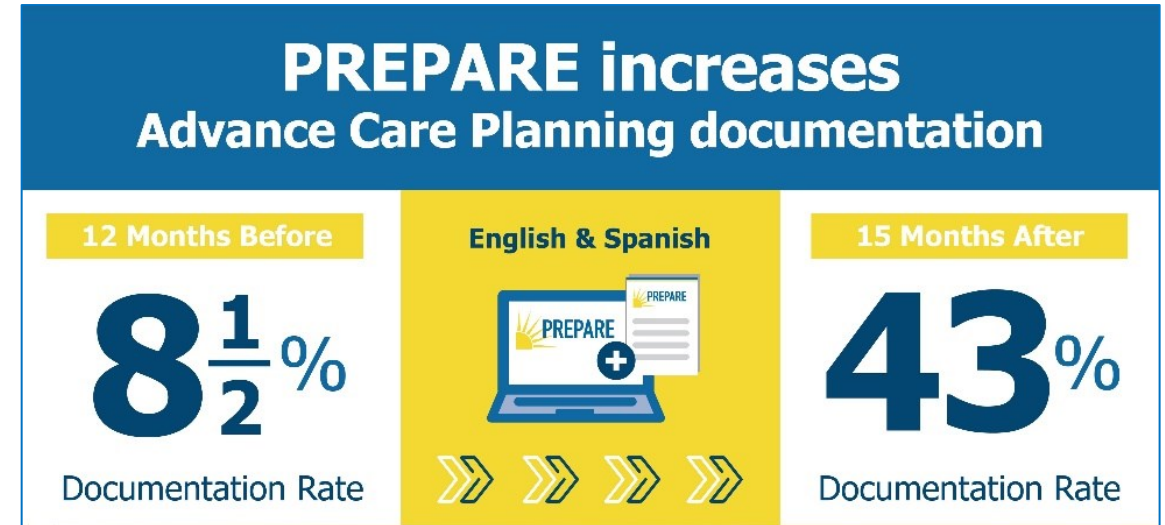
這份指示書必須簽名才可以生效。

您可以填寫第一部分或第二部分，或兩部分都填寫。
只填寫您想要的部分。但是一定要在指示書的第三部分簽名。
兩位見證人必須在第14頁簽名。

您的姓名 "Your Name" _____

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Efficacy RCTs: 1400 English/Spanish-speaking Older Adults: Patient-facing → **Primes Patients, Decreases Disparities**



Directly observed visits:

~50% greater patient empowerment, clinician responsiveness

~50% increased real-time goal concordant care: 33% → 59%

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UC Health Care Planning Study

- **Why we did this study:**

- Institute of Medicine critiqued ACP interventions for aiming at one-time forms rather than incorporating the process into routine care.
- Prior efficacy trials were resource intensive (e.g., 1:1 clinicians), no prior purely pragmatic population-based intervention generated through the EHR
- **A critical gap is** whether and how ACP interventions can be implemented at a healthcare system level.

Population-Based Pragmatic Trial of Advance Care Planning in Primary Care in the University of California Health System

Anne M. Walling, MD, PhD,^{1,2} Rebecca L. Sudore, MD,^{3,4} Doug Bell, MD, PhD,¹
Chi-Hong Tseng, PhD,¹ Christine Ritchie, MD, MSPH,³ Ron D. Hays, PhD,¹ Lisa Gibbs, MD,⁵
Maryam Rahimi, MD,⁵ Javier Sanz, BS,¹ and Neil S. Wenger, MD, MPH¹

- Test, implement, and disseminate real-world, scalable ACP interventions in primary care clinics
- Evaluate the effect of ACP interventions on a population-based cohort of patients with serious illness in primary care clinics
- Enroll a research cohort of patients at these clinics to assess ACP engagement and goal-concordant care

UC Health Care Planning Study Team

- Neil S. Wenger
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Patient/Caregiver Advisory Group

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- Irene Conway
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- Arnold Porath
- Jason Kogan
- Wanda Reynolds
- Tom Reynolds
- Imelda Aguilera
- Nabi Khorrami
- Naz Khorrami

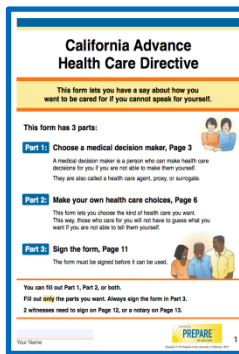
Population-based, Cluster Randomized trial

Intervention: Automated EHR Messages
50 Clinics at **UCLA, UCSF, UCI** Randomly Allocated

24-month study period

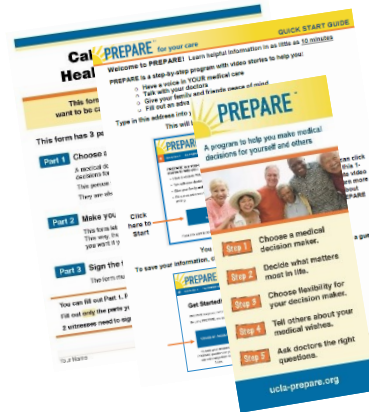
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PREPARE ADs
(or UCLA AD)



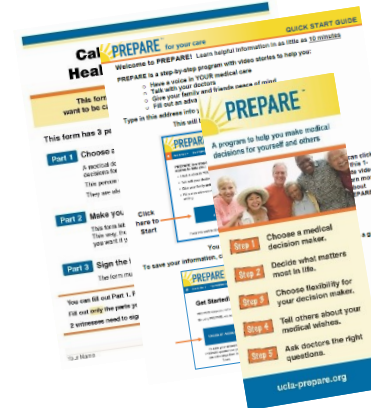
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PREPARE ADs
+ Website



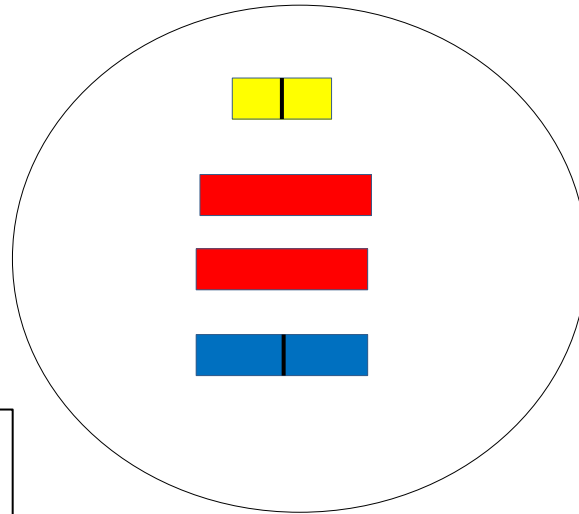
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ADs +
PREPARE +
Navigator

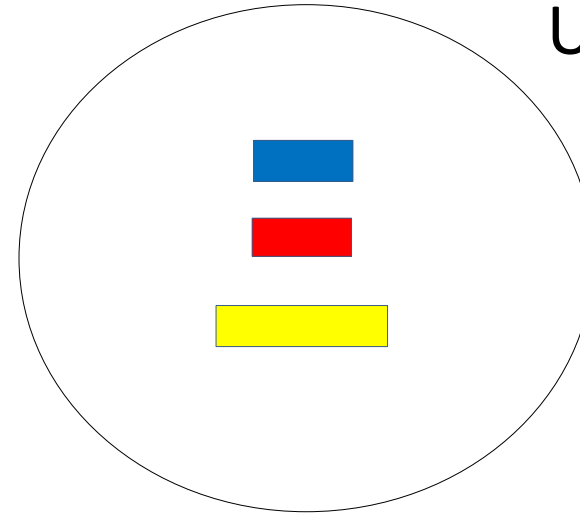


Intervention Across Clinics

UCI

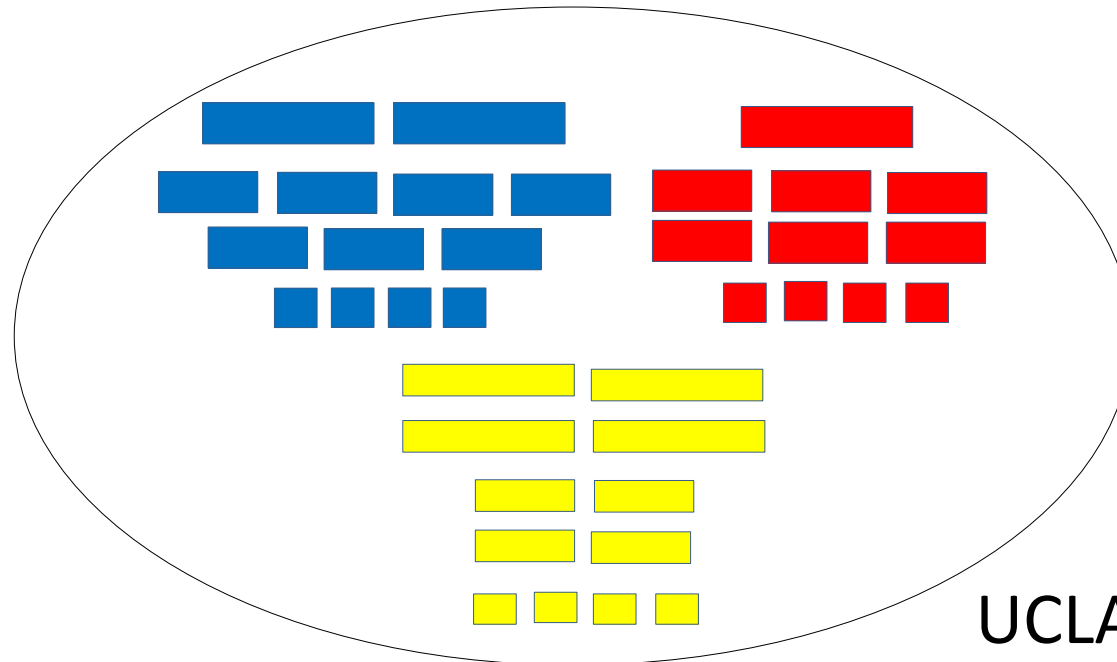


UCSF



Intervention

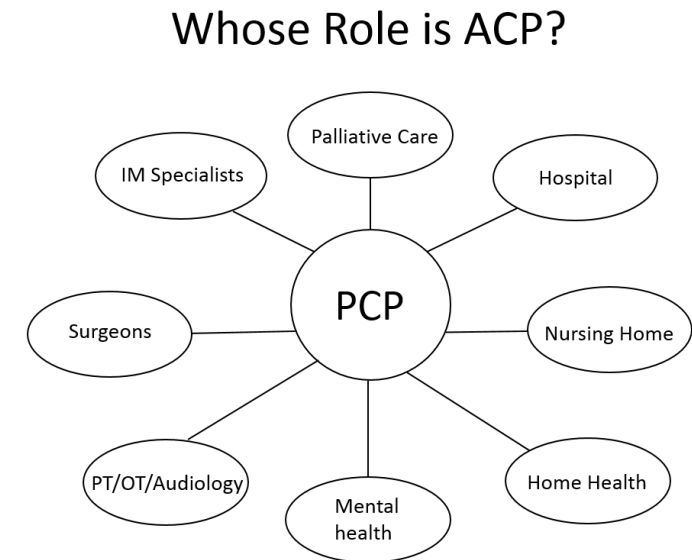
- Arm 1
- Arm 2
- Arm 3



UCLA

Primary Care Physician Training

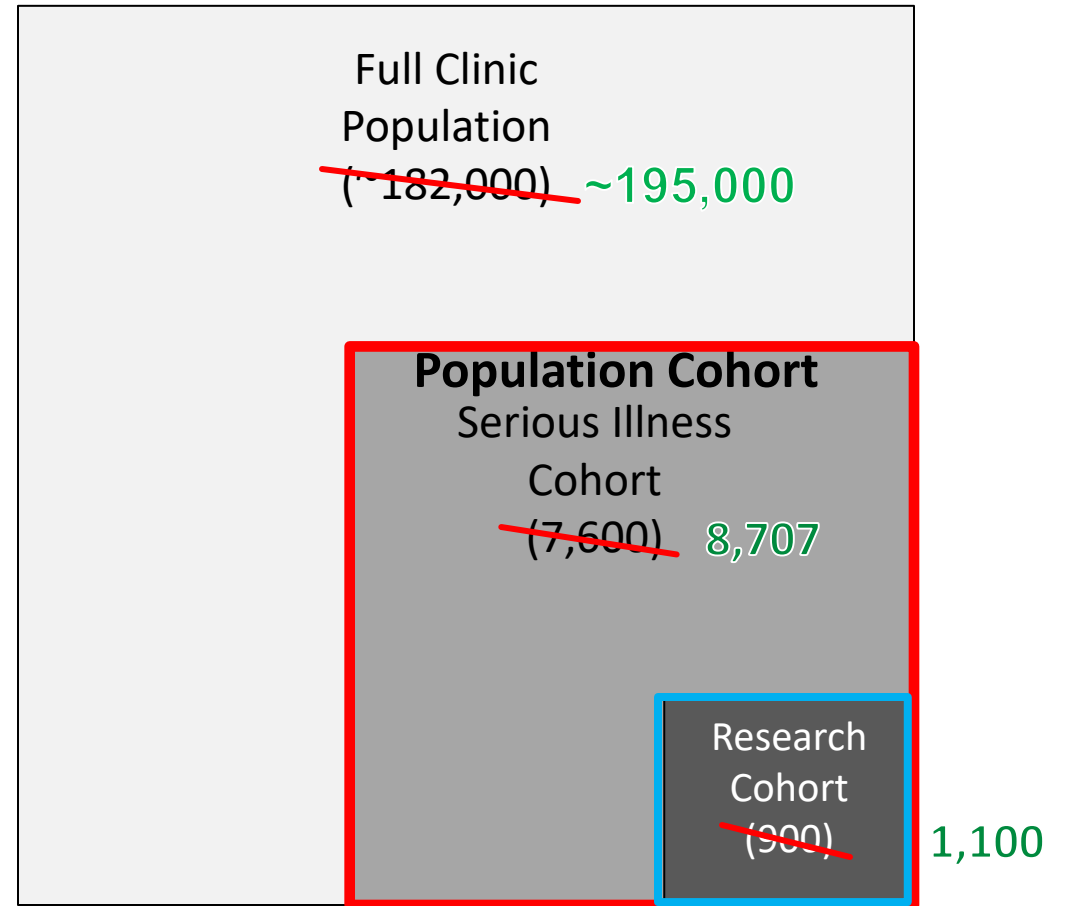
- Brief, 1-time, case-based raising of awareness of PCP's role in ACP
- Fundamentals of ACP tools
 - How ACP fits into HER
- How ACP fits into workflow
- Billing for ACP
- Intervention-specific introduction to project



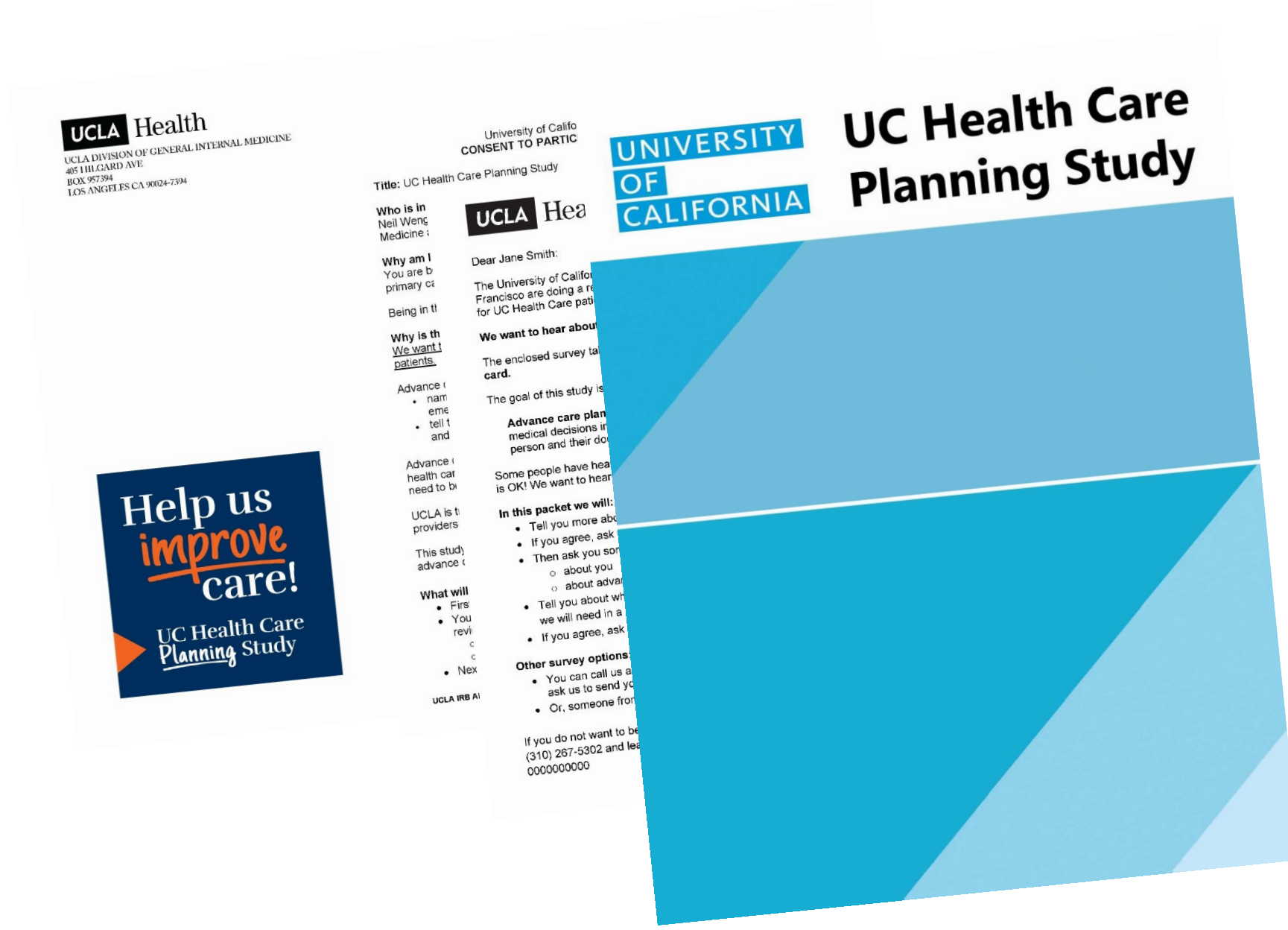
Patient Population

- **Population Cohort** identified automatically from the EMR
 - Age 18 or older
 - ≥ 2 outpatient visits with primary care in last 12 mo
 - Serious Illness

***Automated ACP messages in EMR**
- **Research Cohort Subset**
 - Surveys for PROs



Research Cohort: Recruitment Survey Mailed Packet



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Identifying Seriously Ill Patients

- Most algorithms focus on high utilizing patients
 - Many of these patients do not have serious illness
 - Regression to the mean
- Palliative care registries focus on a sick patient population
 - Late for early discussions and conditioning for shared decision making
- Needs to be automated, consistent across all 3 health systems, and available in real time

Defining Serious Illness

- Age ≥ 18 years, ≥ 2 primary care visits in 12 months
- Has a Serious Illness
 - Advanced cancer
 - Advanced COPD
 - Dialysis-dependent chronic renal failure
 - Advanced heart failure
 - End-stage liver disease
 - ALS
- ACP Priority Criteria
 - Poor short term survival prognosis (1-2 years) OR
 - Developing incapacity OR
 - Worsening functional status OR
 - High burden of disease (conditions causing excessive healthcare utilization or suffering)

Development of the Serious Illness Algorithm

- Began w/ published EMR data elements
 - Designed to align w/ Public Hospital Redesign & Incentives in Medi-Cal (PRIME)
 - Billing codes, encounter codes, Problem list elements, utilization, lab values, diagnostic tests
 - ICD-10 codes alone do not adequately identify a seriously ill population
 - E.g., COPD ICD codes that are stable and only on albuterol
- Data elements must be available across 3 UC health systems using Epic
- Iterative chart abstraction identified elements c/w serious illness
 - Use internal gold standards (example of PFT's)
 - Problem lists better than encounter codes

Example Advanced Illness Definitions and Identification Criteria

Advanced Illness Group	Advance illness Group Definition	Identification Criteria
Advanced COPD	COPD that substantially affects the patient's function ([shortness of breath with exertion or cannot do activities and not due to another cause] or GOLD class 3 or 4) and FEV1 < 50% predicted OR O ₂ -dependent at home (all the time or for exertion but not just at night)	Problem List ICD code for COPD AND [(V or Z code for home oxygen) OR (At least 1 hospital admission with an ICD code for COPD in the last year)]
Advanced Heart Failure (HF)	Diagnosed heart failure- heart failure substantially affects the patient's function {{{(Shortness of breath or weakness or chest pain or ectopy with exertion or edema affecting function or cannot do activities) and not due to another cause} or class 3 or 4} last known LVEF < 31%	(Problem List or Ambulatory encounter billing ICD-10 code for HF in the past year <u>AND</u> any left ventricular ejection fraction over the last 3 years <31%) <u>OR</u> (Problem List for HF <u>AND</u> at least 1 hospital admission with an ICD-10 code for HF)

Validation of the Serious Illness Algorithm

- Charts reviewed across 3 UC Health systems to ensure that patients met one or more of the ACP Priority criteria.
- Chart abstraction found that 301/306 (98%) met at least one ACP Priority criterion.
- Checked the consistency of the population across the health systems by checking the percentage of patients who meet the serious illness definition among all primary care patients.

Seriously Ill Primary Care Patients at 3 UCs

Condition	N (%)
Advanced cancer	1722 (20%)
Advanced heart failure	1989 (23%)
Advanced COPD	951 (11%)
End stage renal disease	1394 (16%)
End stage liver disease	539 (6%)
ALS	26 (0.3%)
Age 75 and a condition	2988 (34%)

Mortality	N (%)
Death by 12 months	1075 (12.3%)
Death by 24 months	1799 (20.7%)

- Seriously ill : 4%-7% of PC population in each system
- Proportion related to whether the PC practice is hospital adjacent
- “Seriously ill” and a “utilization-based high-risk” PC population overlap by 50%
- About 20% of seriously ill patients are captured by a Palliative care algorithm

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Constructing the ACP Intervention Infrastructure across 3 UC Systems

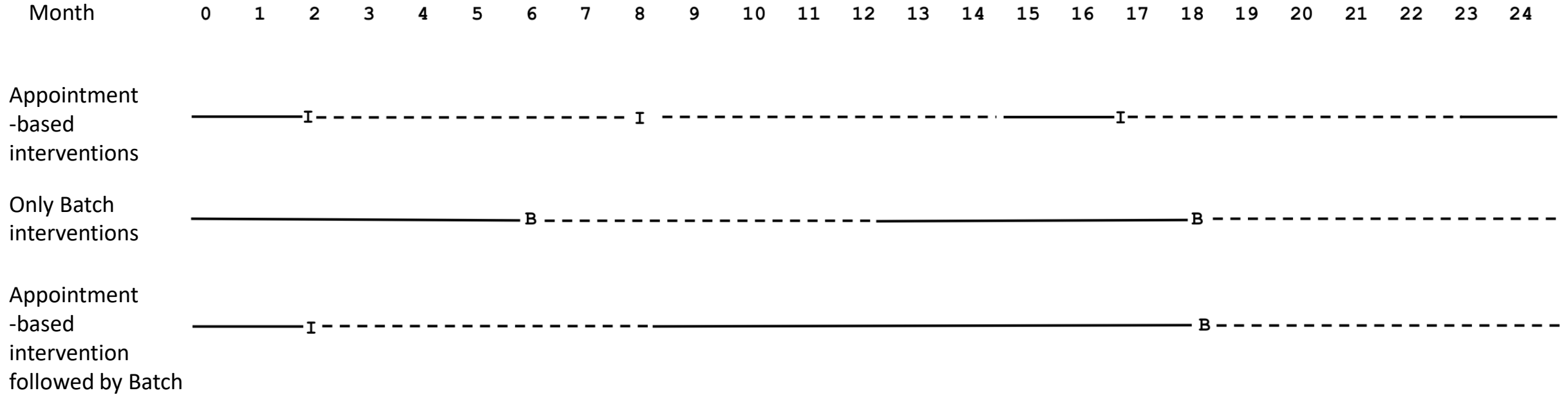
- Identify seriously ill PC patients w/o AD or POLST in the last 3yrs
 - Time-intensive effort to ensure fidelity of intervention across sites
 - weekly meetings with EPIC build and data teams across sites
 - Builds are “genotypically” different, but “phenotypically” the same

Category	UCLA	UCI	UCSF
Meet all business and research requirements			
Automation: find patients and other relevant information			
Automation: integrate with EHR			
Automation: deliver the interventions			
Minimal Epic maintenance			
Flexibility: researchers can quickly update logic			

Intervention Patterns for Patients

- Goal was to time intervention prior to PCP visits
- If the patient did not have a PCP visit after 6 months, they would receive a “batch” intervention (not timed to a visit)
- Once a patient received an intervention, there was a 6-month lock-out before they became eligible to receive an intervention (if they had not completed ACP)

Intervention Patterns for Patients



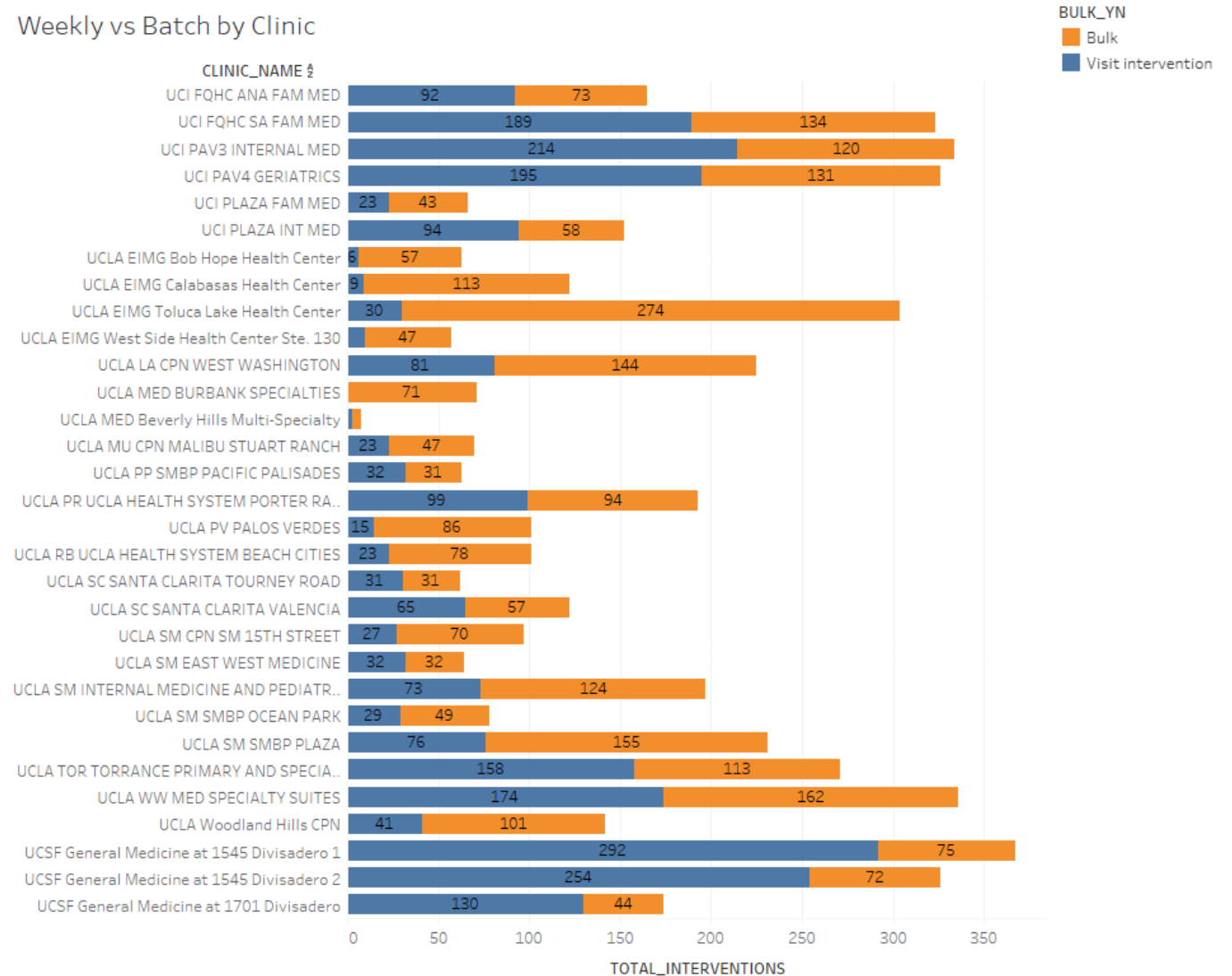
I = Appointment-based intervention
B = Batch intervention

Solid line = eligible to receive intervention
Dotted line = locked out – not eligible to receive intervention

Appointment-based versus “Batch” Interventions

- After 24 months:
 - 43% had received an appointment-based intervention
 - 55% had received at least one batch intervention

Weekly vs Batch by Clinic



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Healthcare Navigator Training



Documentation: HCN SmartForm

- Training videos
- Monthly meetings

UCSF University of California San Francisco

UCSF HEALTH CARE NAVIGATOR ADVANCE CARE PLANNING MANUAL

- 50+ page Manual
 - Scripts to respond
 - Updated over time

Care Mgmt

DOCUMENTATION ACP Outreach

Advanced Care Planning Screening Outreach (Enc)

Reached Status (Required Field)
PLEASE UPDATE REACHED STATUS EACH TIME YOU ARE IN A PATIENT CASE

Select...

- Patient Not Reached After 1st Attempt - Try in a Few Days
- Patient Not Reached After 2nd Attempt - Try in a Few Days
- Patient Not Reached After 3rd Attempt - Close Case
- Patient Reached after 1st Attempt - All Actions Complete (close case, remove from dash)
- Patient Reached after 2nd Attempt - All Actions Complete (close case, remove from dash)
- Patient Reached after 3rd Attempt - All Actions Complete (close case, remove from dash)
- Patient Reached - Further Follow-Up Needed

Advanced Care Plan

AD < 3 years old in chart (HCN to review and ensure that AD field has document linked) Yes No

POLST < 3 years old in chart (HCN to review and ensure that POLST field has document linked) Yes No

AD < 3 years old at home completed (elicit information on HCA to enter into CC)

No AD at Home Will mail in Will fax in Will bring to clinic

Other

AD > 3 years old on file still valid (HCN reviewed and discussed with patient) Yes No

Introduce ACP and AD completion with patient Yes No

Patient refuses to engage in advance care planning Opt out

Encourage patient to use "Prepare For Your Care" website

HCN encouraged/instructed to use materials HCN helped with access

HCN to send materials Patient declined

Encourage patient to complete AD

HCN encouraged/instructed HCN helped with access to AD, Mailed

HCN helped with access to AD, MyChart Patient not ready for ACP

Patient in process but needs follow up Patient will complete using PREPARE

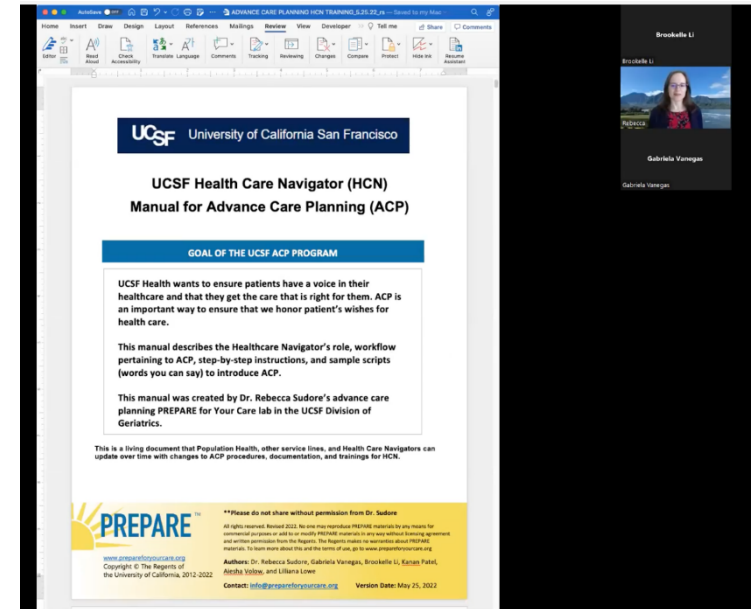
Patient will complete AD and submit via:

Mail Fax Bring to clinic Other (see com)

Too soon to specify

POLST may be appropriate (Patient DNR at hospital discharge and no POLST on file indicating DNR)

Message sent to physician for consideration at next appointment



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Population Cohort EHR Data

- Demographics
 - Age, sex, race and ethnicity, insurance, social vulnerability index (SVI)
- Advance directive and POLST in the EHR
- Hospitalization, ICU visits, ER visits
- Death
- Site, Clinic, and Randomized arm
- Number of ACP interventions
 - Appointment-based or Batch

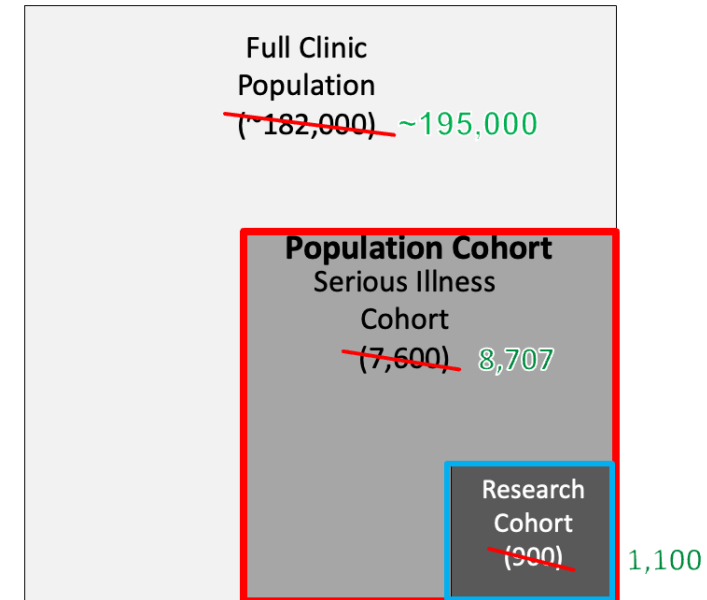
Trial Outcomes

Primary Outcomes

- **Population cohort:** Advance directive completion at 12 mo, 24 mo
- **Research cohort:** Goal concordant care among decedents

Secondary Outcomes

- **Population cohort:**
 - New advance directive completion at 12 mo, 24 mo
 - Healthcare utilization among decedents
 - ACP documented conversations in the EHR
- **Research cohort**
 - Self-reported Advance Care Planning Engagement at baseline, 12 mo, 24 mo
 - Self-reported goal concordant care
 - Medical record chart review for goal concordant care of decedents



Documented Goals of Care Discussions

Goals of Care (GoC) documentation using computer assisted abstraction

- Clinical Regex (Lindvall Lab) uses Regular Expressions Natural Language Processing (NLP)
 - » Started with previously published NLP Library (Lindvall, JPSM 2022)
- Manual abstraction served as a gold standard to optimize an NLP Library
 - » Manual abstraction had kappa > 0.8 across UCLA, UCSF, UCI in capturing GoC discussions
 - » Clinical Regex able to capture 100% of manually abstracted GoC Discussions from within the health system, but could not capture PDFs from CareEverywhere (in some cases Clinical Regex captured notes missed in manual review)

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Cross-platform desktop app for searching and annotating clinical texts.

 [Download v1.0.3](#)

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Image used with permission from Dr. Charlotta Lindvall

Sample

Advance care planning (ACP) is associated with improved health outcomes for patients with cancer, and its absence is associated with unfavourable outcomes for patients and their caregivers. However, older adults do not complete ACP at expected rates due to patient and clinician barriers. We present the original design, methods and rationale for a trial aimed at improving ACP for older patients with advanced cancer and the modified protocol in response to changes brought by the COVID-19 pandemic.

Source: PubMed

Objectives

- The Evolving ACP Definition & Research
- **Lessons for an ACP PCORI Pragmatic RCT**
 - Identifying the cohort with validated algorithms
 - Constructing the ACP EMR Intervention Infrastructure
 - Healthcare navigator arm
 - Trial outcomes: NLP
 - **Implementation Lessons**

Implementation Lessons

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Special Series: Population-based approaches to palliative care

Implementation Challenges for a Multisite Advance Care Planning Pragmatic Trial: Lessons Learned



Rebecca L. Sudore, MD[#], Anne M. Walling, MD, PhD[#], Lisa Gibbs, MD, Maryam Rahimi, MD, and Neil S. Wenger, MD, MPH, and the UC Health Care Planning Study Team

Department of Medicine (R.L.S.), University of California, San Francisco, California; San Francisco VA Medical Center (R.L.S.), San Francisco, California; Department of Medicine (A.M.W., N.S.W.), University of California, Los Angeles, California; VA Greater Los Angeles Health System (A.M.W.), Los Angeles, California; Division of Geriatric Medicine and Gerontology (L.G.), Department of Family Medicine, University of California, Irvine, California; Division of General Internal Medicine and Primary Care (M.R.), Department of Medicine, University of California, Irvine, California

Objectives

- **Implementation Lessons**

- Advisory Boards
- Secular Trends
- RE-AIM and Fidelity
- Recruitment Efforts and HIPAA forms
- Key Lessons

Key Patient, Caregiver, & Clinician Informants



- Study Advisory Group
 - Community Advisory Groups
 - Patients, families, clinicians, clinic staff
 - EHR advisory groups
 - Hospital administration
 - Population health
 - Health plans
- Intervention materials, logos
 - Timing of intervention
 - Messaging & iterations
 - Survey instruments
 - Goal concordant care
 - Physician education
 - Facilitator intervention
 - Dissemination of results

Monthly Advisory Board Newsletter

- Study updates
- ACP in the news
- CAB Member Spotlight
- Study Team Spotlight

NOVEMBER 2021, ISSUE 23

UC Health Care Planning Study

Monthly Newsletter

Project Overview

The UC Health Care Planning Study will use the electronic health record (EHR) to identify primary care patients with advanced illness who do not have an advance directive (AD) by comparing the effectiveness of three interventions:

1. Distribution of an introduction and an AD
2. Engagement with the PREPARE for Your Care website + AD
3. A structured care coordinator advance care planning (ACP) intervention + PREPARE + AD

Data from the EHR will be used to measure AD completion and health care utilization at the end of life. In addition, patients will be invited to participate in a research cohort (900 total) who will provide informed consent for a survey at baseline, 12 months, and 24 months, and medical record review. Caregivers will complete the surveys if the patient is unable. Outcomes include receipt of goal-concordant treatment, ACP engagement, and caregiver outcomes.

ACP Fact of the Month

An anti-advance care planning viewpoint article authored by two members of our Study Advisory Board stakeholders was published in the peer-reviewed medical journal *JAMA* (The Journal of the American Medical Association) in early October. The study's site investigators are preparing a response to the article. You may read the viewpoint at: <https://jamanetwork.com/journals/jama/fullarticle/2785148>.

Announcements

Thank you for your feedback on the caregiver condolence card. We have made many great changes based on your comments and will share the final version before submitting to the IRB for approval.

Our winter Study Advisory Group (SAG) meeting is coming up soon! We are looking at dates in early December and will keep you posted.

Study Updates

Research Cohort Updates

12 Men Surveys Received

Site	Surveys Received	Withdrawn	Passed Away
UCLA	101	29	77
UCSF	107	6	5
UCI	160	7	15

UCI completed 12-month survey recruitment and is on standby until April 2022. UCLA 12-month phone calls are still ongoing. UCSF sent out 24-month surveys mid-October and will begin phone call follow-up this month.

As of 10/27/21, we received 819/1,101 surveys (74.4%). Deceased patients were removed from the total count to calculate response rates. Here is the breakdown by site:

- UCLA: 590/710 (83.1%) Note: 29 withdrew from study, 77 passed away
- UCSF: 91/107 (85.0%) Note: 6 withdrew from study, 5 passed away
- UCI: 138/160 (86.3%) Note: 7 withdrew from study, 15 passed away

UC Health Care Planning Study

Intervention Updates

UCSF has completed their intervention. UCI and UCLA's intervention period will end in mid-April and late June 2022, respectively. An early look at the overall change in the percentage of ADs in the medical record at UCSF's three primary care clinics shows a 12.3% increase since October 2019. All sites are refining their databases in preparation for analysis of the comparative effectiveness of the three intervention arms. Preliminary talks about how to continue this intervention beyond this study are beginning to occur at both the local and institutional levels.

Staff Member Spotlight

Staff Member of the Month

Brookelle Li, Program Coordinator at UCSF

Brookelle is a Program Coordinator in the Division of Geriatrics at UCSF. She earned her degree in psychology from the University of San Francisco, where she first began working with Dr. Rebecca Sudore. After graduating in 2014, she became part of Dr. Sudore's staff.

Aside from the UC Health Care Planning Study, Brookelle is working on other exciting and innovative ACP initiatives, including: 1) a new program aimed at surrogate decision makers, 2) tailoring ACP materials for unhoused community members (who may be without a primary care physician or trusted family members), and 3) teaching older adults with Type II diabetes about deprescribing from insulin using the PREPARE for Your Care model.

Brookelle enjoys working on this study because she is proud to see the evolution of the PREPARE for Your Care program, which she has been a part of shortly after it began. She also loves learning about the research and testing of educational medical materials, due to her interest in public health.

In her free time, Brookelle likes staying active by doing yoga, working out, and visiting the beach near her home in San Francisco. She is actually a registered yoga teacher! She also loves to cook and do DIY skincare and haircare. A fun fact about her is that she is distantly related to the famous martial artist Bruce Lee! Her grandfather lived in the same village in China that Bruce Lee's family is from.

Core Staff Roster

<p>UCLA</p> <ul style="list-style-type: none"> Dr. Neil Wenger Dr. Anne Walling Javier Sanz Victor Gonzalez Katherine Santos Anno Dickey Carlos Antonio Shawny Smith 	<p>UCSF</p> <ul style="list-style-type: none"> Dr. Rebecca Sudore Kanan Patel Brookelle Li Lilliana Lowe Axel Herera Gaby Vanegas
<p>UCI</p> <ul style="list-style-type: none"> Dr. Maryam Rahimi Dr. Lisa Gibbs Aaron Chau Bryan Robles Megan Whalen Lindsay Paguyo 	<p>CCCC</p> <ul style="list-style-type: none"> Judy Thomas Erin Dorn

Objectives

- **Implementation Lessons**

- Advisory Boards
- **Secular Trends**
- RE-AIM and Fidelity
- Recruitment Efforts and HIPAA forms
- Key Lessons

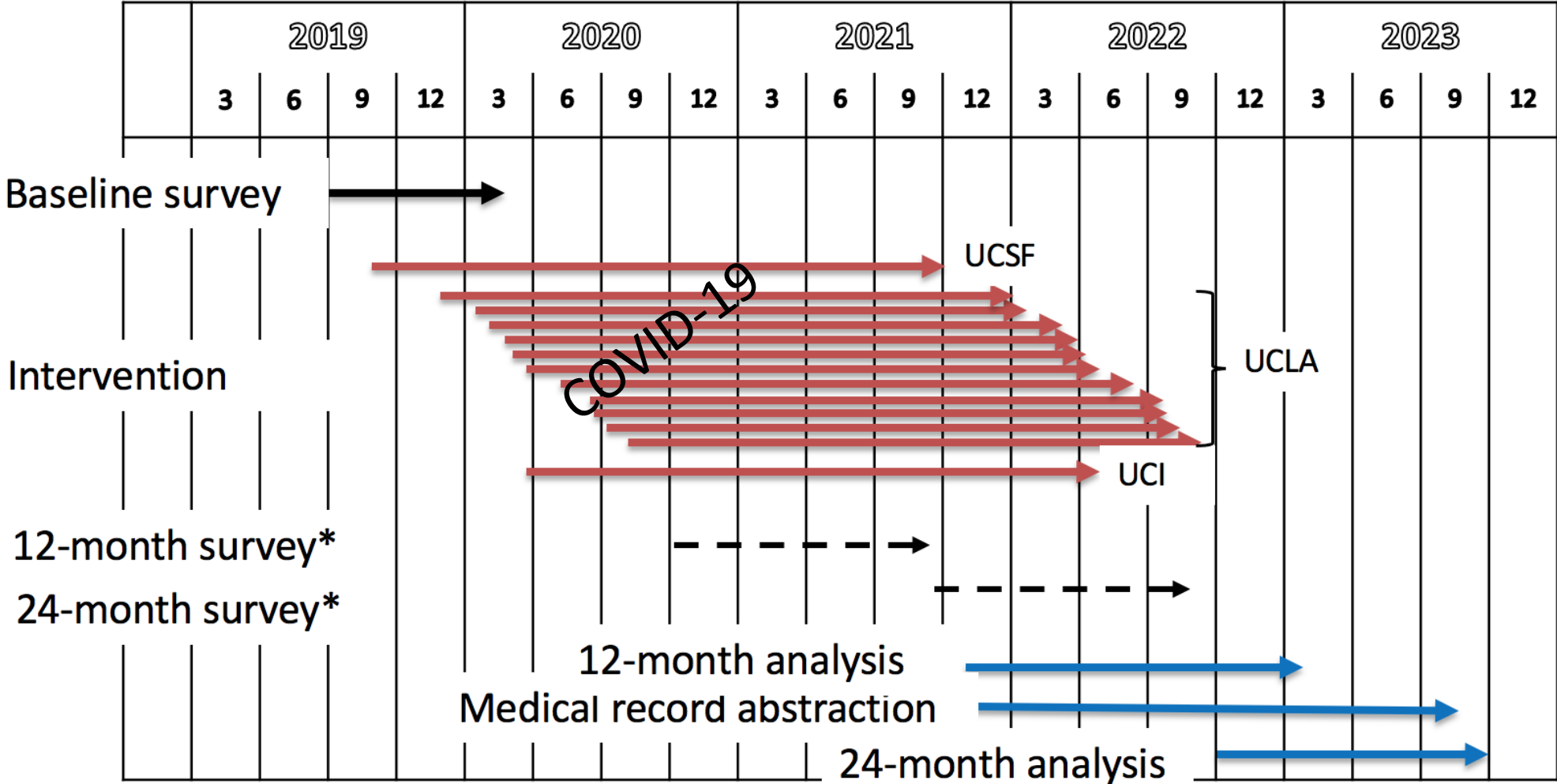
Secular Trend Monitoring

- COVID
- EHR Updates
- QI ACP programs

Secular Trends During This Multisite Advance Care Planning Pragmatic Trial			
Secular Trend	UCLA	UC Irvine	UCSF
External changes			
COVID pandemic, clinics shut down with shift to telehealth	3/2020	3/2020	3/2020
EHR related updates			
EHR ACP activity rolled out to all patients	Started 10/2018	Started 7/2020	Started 1/2019
Fillable AD pdf available for UCLA health AD	Started 7/2020		
AD's added to health maintenance module	Started 10/2020	Started 7/2021	Started 6/2021
EHR patient portal AD reminders instituted for the health system	Started 1/2021	Started 2/2022	Started 10/2021
Ability to upload AD through patient portal and reviewed by health Information Services	Started 4/2021		
Quality improvement programs			
ACP intervention sent to primary care patients 65 and older without serious illness in study clinics	4/2020 (Arm 1 intervention only to health system quality improvement effort)		Started 10/19 (PCORI intervention sent to all patients 65 and older without serious illness)
ACP quality metrics provided to oncologists as part of another QI effort	Started 10/2018		
Population defined "meaningful ACP" from HER elements and created EHR dashboard as part of another QI effort			Started 1/2019
Annual wellness visit push for ACP	Started 4/2021 (nurse practitioners involved in preparing patients for the visits)	Started 7/2022	Started 7/2019
Inpatient ACP intervention	Started 7/2020 (A "surprise" question added to documentation)		Started 7/2019 (education, dashboards, clinician training, incentives)
Separate QI projects use PCORI intervention and study materials in non-PCORI clinics	2/2021 (several primary care clinics)	10/2021 (primary care)	Started 10/2019 (primary care and surgery)
ACP integrated into cancer center materials	Started 6/2022		Started 1/2020
Clinician education and initiatives			
Medicine resident ACP training	Annually	Annually	Annually
Clinician and staff outreach about ACP EMR changes and billing	2/2018	9/2021	Started 1/2019
Additional health system ACP clinician training	4/2019 oncologists and social workers 7/2021 Bone Marrow Transplant nurse practitioners	7/2019 Primary care	4/2019 (4 hours offered to all primary care providers in study clinics)
Patient-focused interventions			
ACP group meetings/events for patients	Started 1/2019	Started 1/2019	Started 4/2019
Notaries in clinic			4/2019, shut down 3/2020 with COVID and staff transitions
Systemwide healthcare decisions day outreach	Started 4/2019		Started 4/2019
Law student home visits for ACP			Started 4/2019 UCSF/UC Hastings Consortium on Law, Science and Health policy
Social workers allowed to complete ACP visits			Started 7/2019

EHR = electronic health record, AD = advance directive, ACP = advance care planning.

UC Health Care Planning Study Timeline



Making a Medical Plan During COVID-19

We are all in this together. You can do your part by making a medical plan. This plan can help you, your family, friends, and your medical providers

**If you need help with other needs, such as food or housing call: 415-355-6700

Plan for Medications:

- Make a list of your medications and keep it on hand
- Look ahead and call your clinic or hospital if you need a refill
- Call your pharmacy to see if your medicines can be sent to your home

Plan for Your Medical Wishes: Keep this information on hand

1. Choose a medical decision maker

- This person will speak for you if you cannot speak for yourself
 - They can make sure your doctors know about the care you want
 - Keep their phone number on hand
 - If able, choose a back-up medical decision maker
- A good medical decision maker is someone who:
 - Can talk to the doctors for you in person or by phone
 - You trust to follow your wishes and what is best for you
- Let your medical decision maker know they were chosen
 - This website can show you how: ucsf-prepare.org

2. Share Your Wishes: This is MOST important

- What is most important in your life? Family, pets, hobbies, etc.?
- If you know what you want for your medical care, share this now
- Talk with your family, friends, and medical providers about the care you want
 - This website can show you how: ucsf-prepare.org
- You can share what you want by phone and/or a selfie video
 - You can also talk to others by video call: <https://tcm.ch/3dOJw97>

3. Consider an advance directive. This form allows you to name your decision maker and write down what you want for your medical care.

- If you have an advance directive, find it, review it, and share it
- To get a form go here: ucsf-prepare.org
 - It is OK if you can't sign it or get witnesses right now
 - Reading it can still help you learn a lot about your wishes
 - Filling out parts of it can still help your family and providers
 - You can scan/fax (the most secure), email, or even send pictures of the form from your cell phone to those you trust



The UC Health Care Planning effort has been ongoing since 2018.

Right now, we know that there have been a lot of changes to our daily lives.

UC Health believes that Health Planning is an important part of all of our patients' care. So, we will continue to educate people about care planning.

We also encourage you to talk to your family, friends, and medical providers about what matters most. With social distancing, you may need to talk to them by phone.

If you want to fill out an advance directive, it is OK if you cannot get witnesses or a notary right now. Filling out parts of the form can still help your family and medical providers.

We have now added a new extra sheet about planning for COVID-19.

Thank you,

UC Health

Advisory Board requested and helped to create COVID related materials

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RE-AIM Intervention Fidelity

Table 4
RE-AIM Framework For This This Multisite Advance Care Planning Pragmatic Trial

Dimension	Components	Data
Reach	Number and representativeness of eligible patients -Is intervention reaching target population	See Table 5
Effectiveness	Intervention effects on targeted outcomes a) Primary Outcome: b) secondary outcome ^a : 1) New ACP EHR documentation for those w/o ACP in the past 3 years 2) Healthcare utilization among decedents	Forthcoming in trial publication
Adoption	Number and representativeness of participating settings and providers -Extent those targeted to deliver the intervention are participating	UCLA: 41 clinics eligible and population health and primary care leadership agreed that all could be included. Five clinics did not have care coordinator so only randomized to arm 1 or 2. UCSF: 11 clinics eligible, population health and primary care leadership allowed three clinics to be included due to other pressing quality metrics required at the time of study launch. UCI: 6 clinics eligible and population health and primary care leadership agree that all could be included.
Implementation	The extent to which the intervention was consistently implemented by staff members	Consistently implemented (a) Standardized, validated algorithm to identify eligible patients with serious illness (i.e., EHR phenotype) (b) Standardized messaging across sites (c) Standardized protocols and ACP documentation for healthcare navigators across sites (d) Standardized tracking of ACP outcomes across sites Allowed adaptations between sites (a) UCSF and UCI used the PREPARE AD and UCLA used their own AD (b) UCSF had one additional mailing of AD information per Population Health leadership request due to COVID (c) EHR build to identify and send automated ACP messages had coding variations (i.e., “genotype”), but the resulting processes the same (i.e., the same “phenotype”)
Maintenance	The extent to which an intervention becomes part of routine organizational practices, and maintains effectiveness	ACP messaging adopted by population health, oncology, surgery, and other research studies at the UC’s and the VA Algorithm and EHR build to identify and send automated EHR ACP messages adopted in primary care across sites Adopted EHR build and messaging by surgery at UCSF

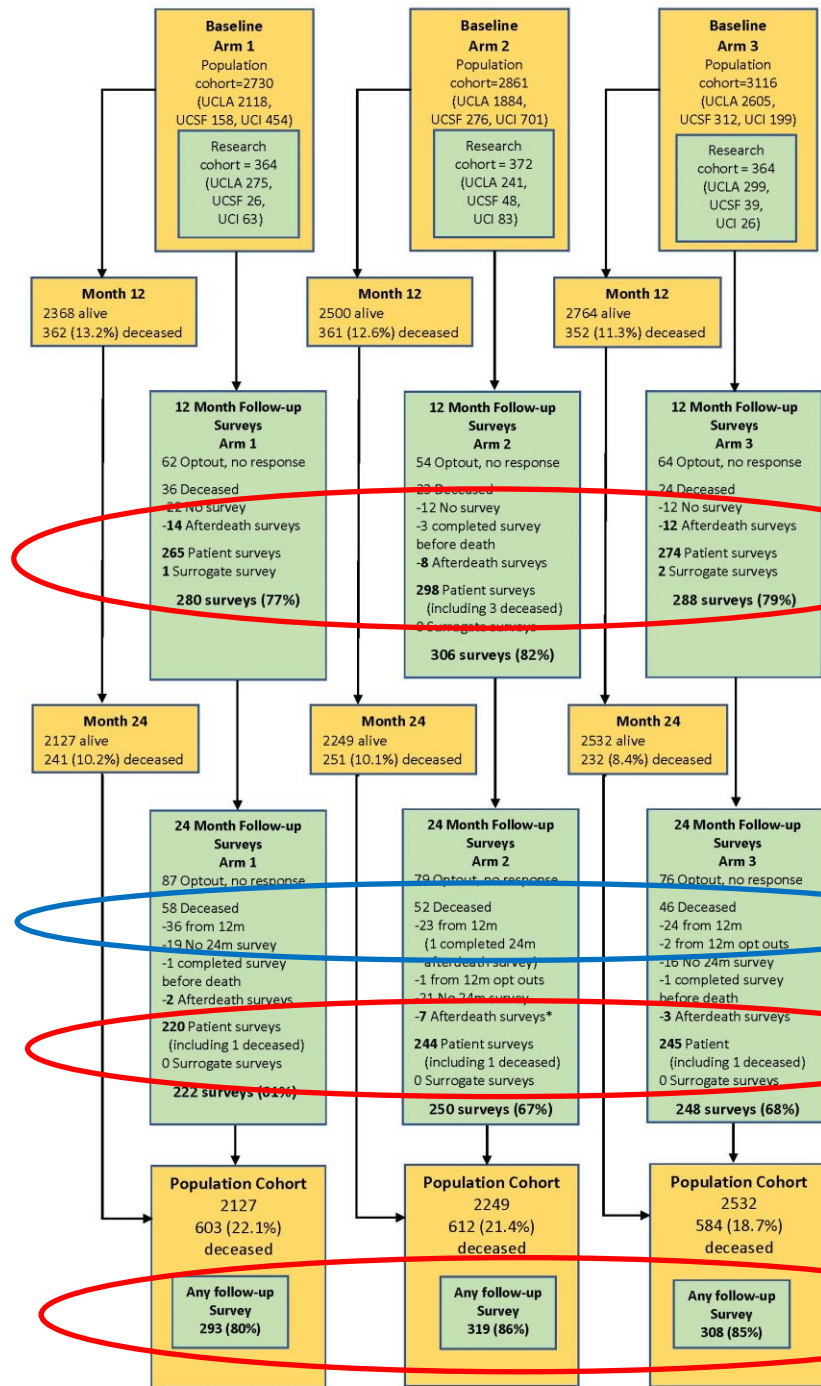
ACP = advance care planning, EHR = electronic health record.

^aFor a research subset we will also assess self-reported outcomes not listed here.

Population Cohort: Intervention Fidelity

	N=8707
At least 1 intervention sent in EHR (i.e., triggered by a primary care visit during study)	92%
Have active EHR patient portal	78%
Opened EHR ACP message	64%
Healthcare navigator outreach (Arm 3 patients only)	91%

Research Cohort, Survey Follow up and Mortality



12 Month survey follow up = 80%

Research cohort 14% Deceased

24 Month survey follow up = 70%

Any Follow up survey = 84%

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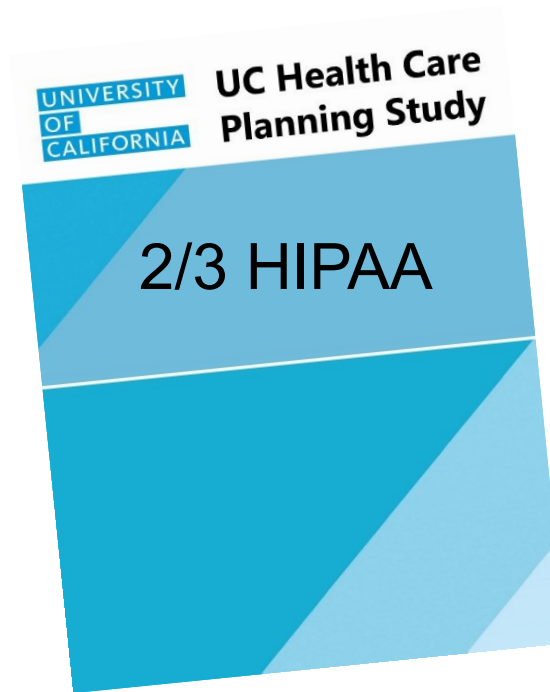
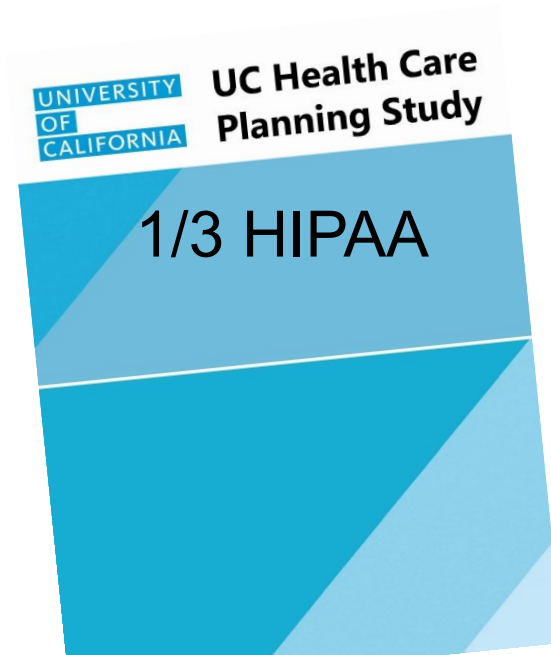
Standard HIPAA Authorization Forms Decreased Response Rates for a Multi-site Pragmatic Trial



Anne M. Walling, MD, PhD^{1,2}, Neil S. Wenger, MD, MPH¹, Aaron J. Chau, BS³, Jennifer Reihm, MPA⁴, Lisa Gibbs, MD³, Maryam Rahimi, MD⁵, Ron D. Hays, PhD¹, and Rebecca L. Sudore, MD^{6,7}

Nested Study: Needed HIPAA for Research Cohort chart review

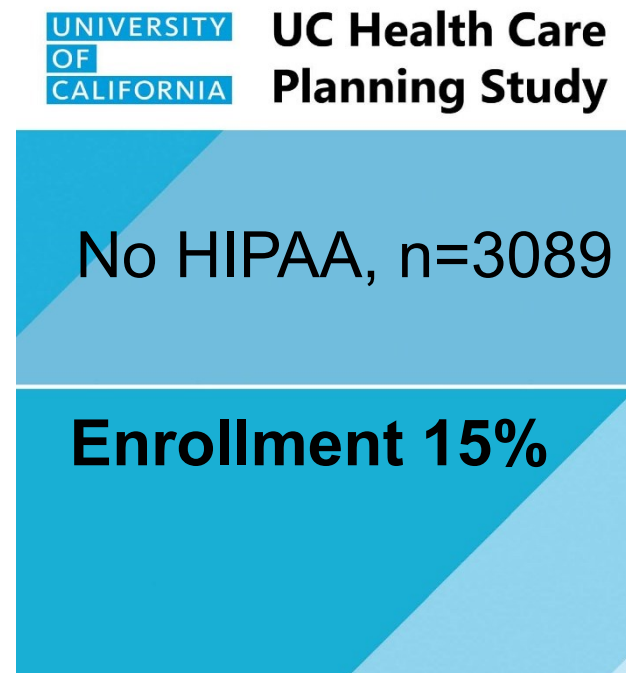
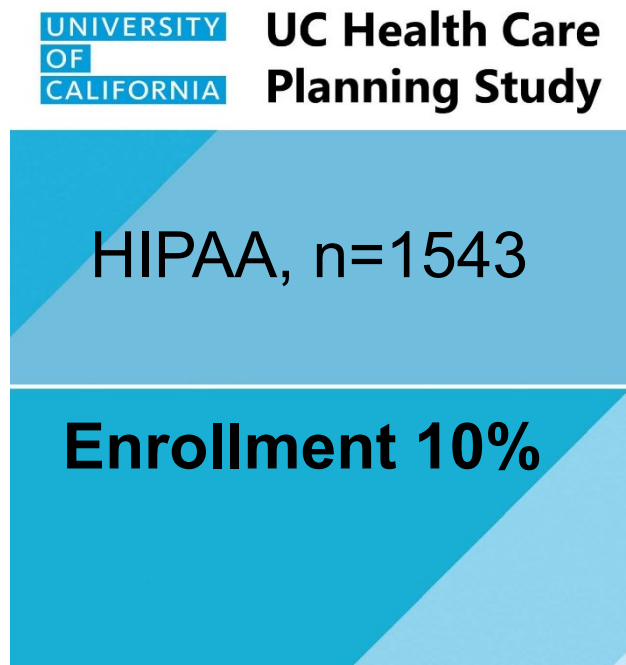
- Advisory Board and team worried about mandated, difficult-to-read HIPAA forms (Consent forms able to use 5th-grade reading level)
- Assessed enrollment at 3 months



Standard HIPAA Authorization Forms Decreased Response Rates for a Multi-site Pragmatic Trial



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1/3 less enrollment can have a large impact in population-based studies.

Phone outreach was needed to hundreds of patients to discuss and complete HIPAA for the research cohort.

- **> 12th grade level**
- **Understandability 42%, Actionability 40%**
- **Federal Plain Language Guidelines 50%**

Standard HIPAA Authorization Forms Decreased Response Rates for a Multi-site Pragmatic Trial




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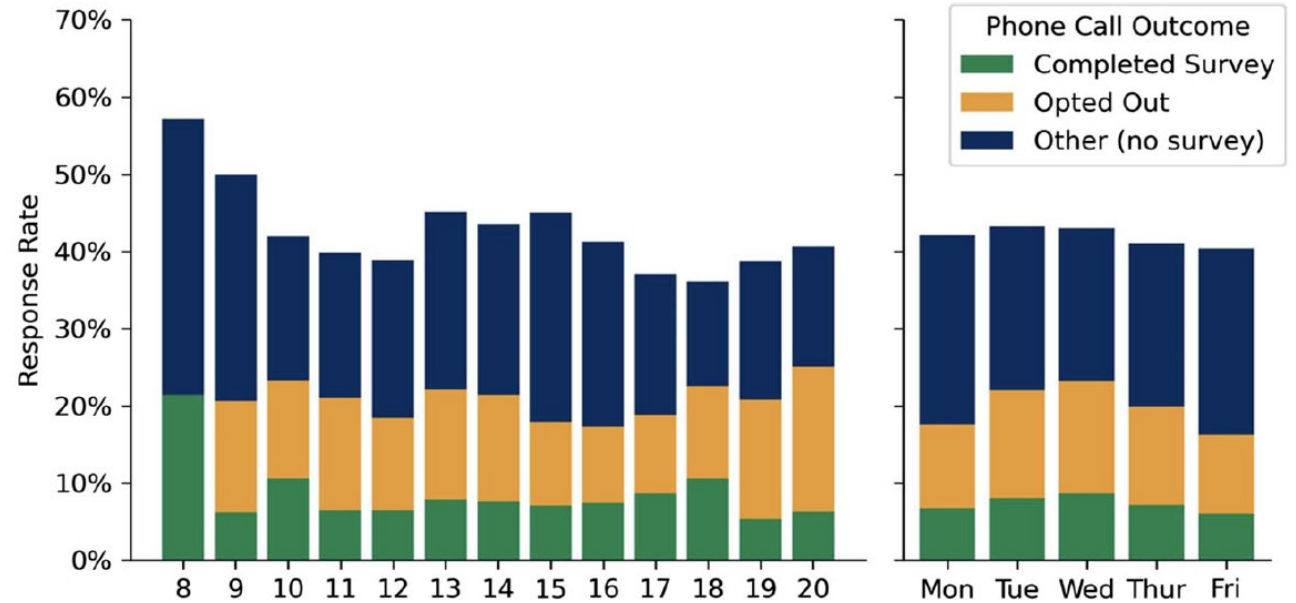
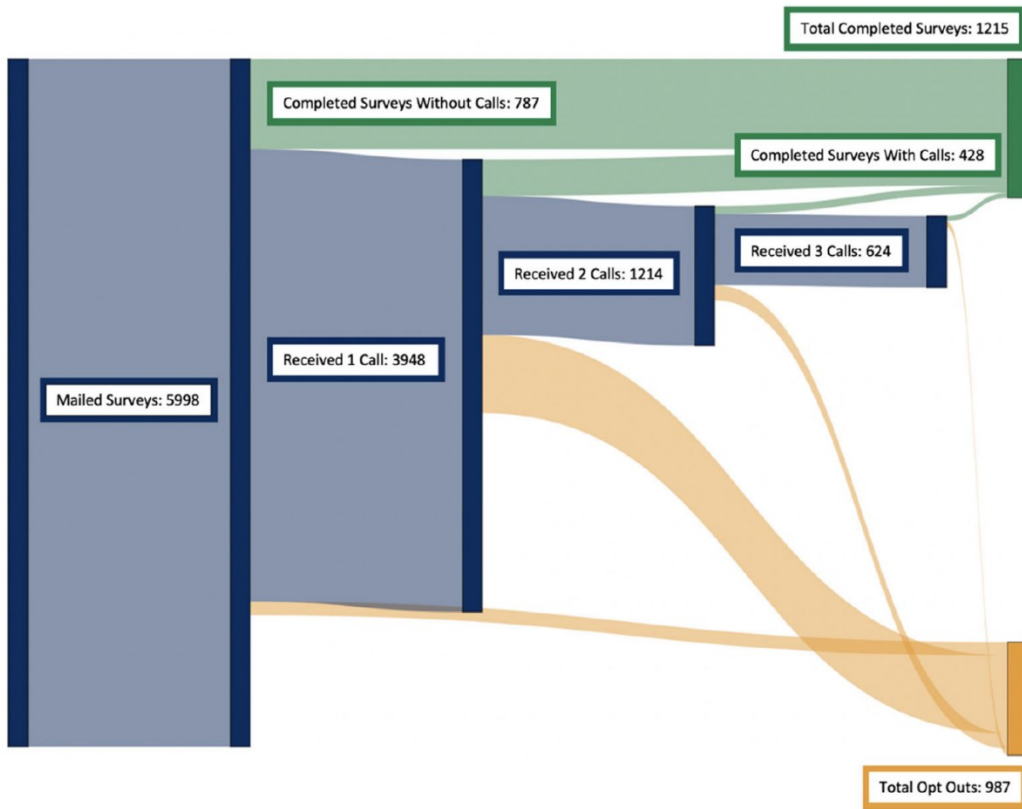
**Policy Changes:
UCSF now working
with central UC IRB
to simplify HIPAA
forms!**

Table 4 Suggestions to Improve HIPAA Form Literacy Domains

Literacy domain	HIPAA Form	Suggestions
Readability ^{15,21}	Grade level 12 • Percent complex words: 17%	Grade level 8 or below • Reduce percent of complex words
Understandability ^{15,21} Word choice	• High percent complex words • Uses excess words • Duplication (sections A and D) • Uses abbreviations (“CRO” and “N/A”)	• Use common, everyday language • Omit excess words to reduce document length • Avoid abbreviations
Active voice	25% of the sentences are written in passive voice	Use active voice • Makes it clear who is supposed to do what • Eliminates ambiguity about responsibilities
Organization	Lacks concise summary • Details about information that will be shared scattered throughout (sections B, C, G) • Lacks sign/no sign scenario language Content overload—reader must read through all possible sharing options	Put the most important information at the beginning and include background information (when necessary) toward the end • Start by stating purpose and the bottom line • Arrange content in a logical order
Section and sentence length	The following key sections are too lengthy: • Section A. What is the purpose of this form? • Section I. Can I cancel my permission?	• Reduce sentence length • Chunk content into shorter sections
Layout and design	• Key study details (title, PI name, sponsor) are not well differentiated from main content • Section I. Can I cancel my permission? Presents a series of options in prose form, requiring the audience to read (vs. skim) • Uses all sans serif fonts when document is presented in print format	Use call out box to draw attention to key points for easy reference Use bulleted lists to: • Help readers skim and scan • Make it easy to identify all steps in a process Use sans serif for headings, serif font for body text when document is presented in print format
Actionability ²¹ Uses visual aids	Initial spaces are located at the end of sentences making them difficult to spot	Use visual aids to make it easier to act on the instructions • Align initial spaces along the left margin • Make initial spaces or check boxes bold
Provides simple instructions	Spreads action items (check boxes and initial sections) throughout the document	Consolidate choices and organize information into manageable, explicit steps


Telephone Outreach Enhances Recruitment of Underrepresented Seriously Ill Patients for an Advance Care Planning Pragmatic Trial

Aaron J. Chau, BS¹, Rebecca L. Sudore, MD^{2,3}, Ron D. Hays, PhD⁴, Chi-Hong Tseng, PhD⁴, Anne M. Walling, MD, PhD^{4,5}, Maryam Rahimi, MD⁶, Lisa Gibbs, MD¹, Kanan Patel, MBBS, MPH², Fernando Javier Sanz Vidorreta, BS⁴, and Neil S. Wenger, MD, MPH⁴ 



Up to 3 calls were needed and call hours extended to 8pm as many older adults with serious illness still working or have childcare responsibilities

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Patients recruited by phone vs. mail more likely to represent the baseline population:

- Socially vulnerable (Social Vuln. Index 0.41 v 0.35, $P < 0.001$)
- Report being a racial/ethnic minority (35% v 28%, $P = 0.006$)
- Report being non-English speaking (16% v 10%, $P = 0.005$)

Characteristics of Baseline Population and Research Cohort

A diverse Research cohort largely representative of the seriously ill population

	Research Cohort	Population Cohort
Age	70 (15)	73 (14)
Female	48%	50%
Race/ethnicity		
Hispanic/Latinx	18%	17%
Asian	9%	12%
Black	7%	8%
White	61%	54%
Spanish-speaking	10%	9%

Objectives

- **Implementation Lessons**

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Implementation Challenges for a Multisite Advance Care Planning Pragmatic Trial: Lessons Learned



Key Lessons Learned Over the Course of This Pragmatic ACP Trial

- (1) Understanding that ACP is not owned by any one clinician or clinical service requiring buy-in from multidisciplinary teams and leadership
 - (2) Fostering working relationships with health system leadership early in the process and aligning studies and clinical programs to their priorities
 - (3) Engaging patient and caregiver advisors throughout the entire project to ensure that the innovations, messaging, outcomes, and study materials meet their unique needs
 - (4) Allowing time to standardize the EHR infrastructure for documentation and data extraction on the topic of interest
 - (5) Creating robust algorithms to identify the seriously ill cohort of interest, including identifying patients who have died
 - (6) Monitoring secular trends and allocating time and resources to address needed modifications and/or additional requests from the health system
 - (7) Standardizing operational workflows within health systems, such as scanning in ADs to ensure they are available at the point of care and for outcome ascertainment
 - (8) Building new relationships as leadership and clinical champions may change over time;
 - (9) Using both CFIR and RE-AIM implementation frameworks to plan and evaluate ACP innovations
 - (10) Choosing your team wisely with individuals with complementary skillsets and those who can also serve as a source of mutual support
-

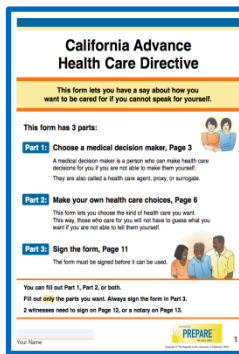
Population-based, Cluster Randomized trial

TRIAL RESULTS WILL BE PUBLISHED IN 2025! Stay Tuned!!

24-month study period

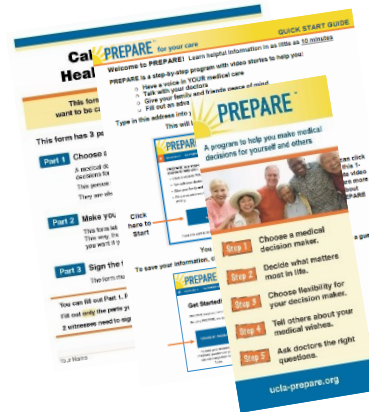
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PREPARE ADs



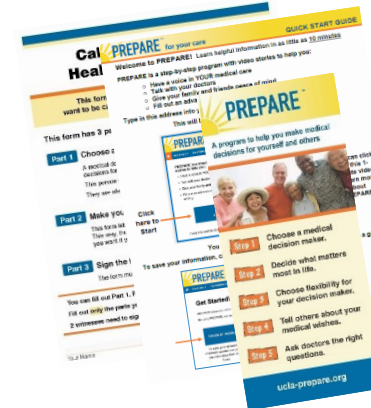
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PREPARE ADs
+ Website



1/3

ADs +
PREPARE +
Navigator



NEXT STEPS IN IMPLEMENTATION

- Seriously ill algorithms identification mechanism
 - Integrated into 2/3 UC sites EMR and 1 on the way
 - Integrated into central UC Data Warehouse
- Infrastructure for automated ACP messaging in the EMR in Primary Care integrated into UCSF, UCLA, and UCI on the way

Take Home Points

- Evolved ACP is focused on preparing patients and surrogates for communication and decision making
- ACP is only as good as systems/workflows built to ensure success
- Easy-to-use materials can empower people to engage in ACP
- HIPAA and Consent need to be in lay language
- Research materials must be co-developed with communities to decrease disparities in enrollment
- There are many steps to ensure the implementation of a health system intervention and ongoing maintenance

THANK YOU!

- Patient-Centered Outcomes Research Institute (PCORI)
- PCORI Palliative Care Learning Network
- Study Advisory Board
- UC Office of the President
- UCLA Health System, Population Health and Faculty Practice Group
- UCLA, UCSF, UCI Informatics and EPIC build teams
- Countless others across all three health systems

