Implementing Pragmatic Advance Care Planning Interventions in the Health System Context

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The Colorado Pragmatic Research in Health Seminar Series

March 3, 2021

Tweet: @Hdaylum

Division of Geriatric Medicine
SCHOOL OF MEDICINE
UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**

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Methods for Planning for Pragmatic Research:
An Advance Care Planning Journey

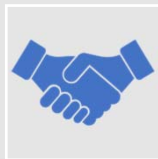
Learning Objectives

Illustrate: Illustrate options for multi-level stakeholder engagement

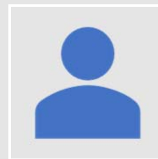
Compare: Compare opportunities from diverse funders

Develop or refine: Develop or refine plans for public goods

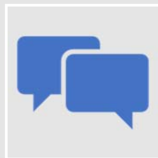
What Is Advance Care Planning?



Personal Values & Readiness



Decision-making, including Choosing an Agent



Discussions

Accessible Documentation

Advance care planning is a process that supports people at any age or stage of health in understanding and sharing their personal values, life goals, and preferences for future medical care.

Sudore et al. Journal of Pain and Symptom Management, 2018.

Why Does Advance Care Planning Matter?

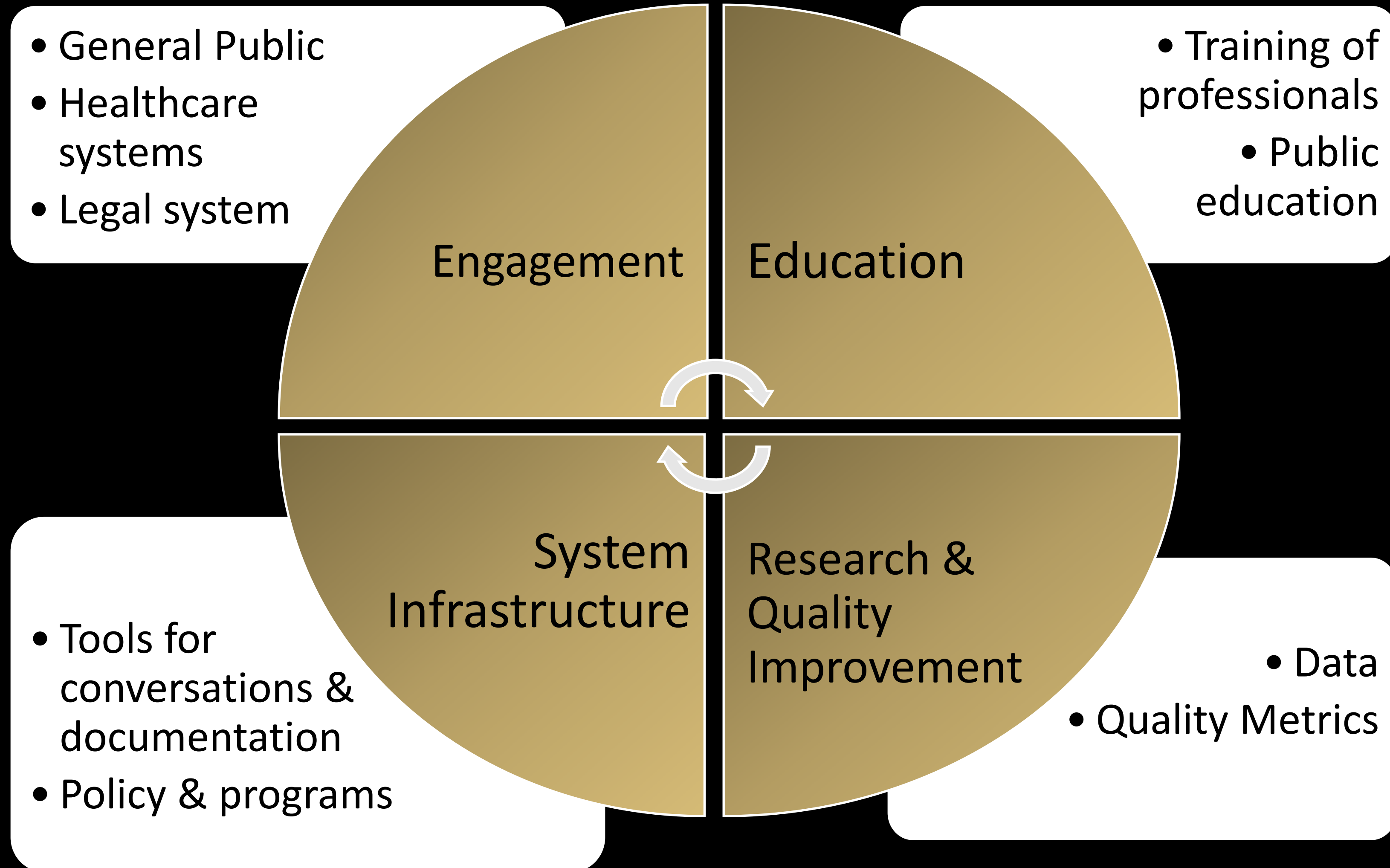
- ~30% of older adults will need a decision maker to make decisions.
- Fewer in-hospital deaths and more hospice use.
- Decision makers often choose comfort care, especially if there was an advance directive.

Bischoff KE et al. JAGS. 2013 Feb;61(2):209-14.
Silveira, MJ et al. New England Journal of Med. 2010.362:1211-8.

Difficult Questions

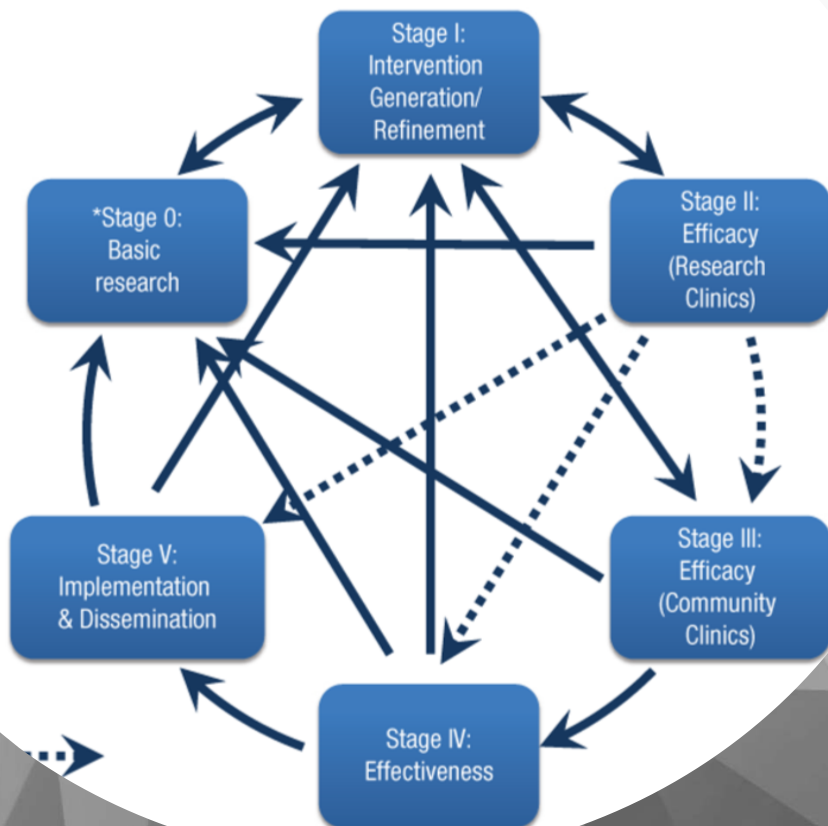
- Where should conversations happen?
- Who should be involved?
- How can we engage others in advance care planning?

Levers of Culture Change for ACP



Health Canada. Implementation Guide to Advance Care Planning in Canada. 2008.

NIH Stage Model

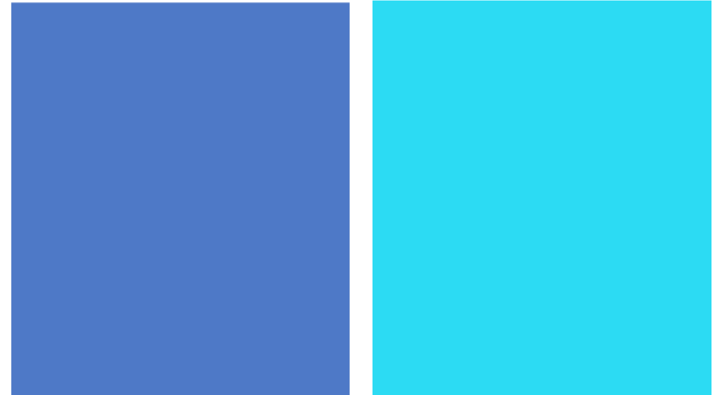


Onken et al. Clin Psychol Sci. 2015

Pragmatic Considerations

- Stakeholder Experiences
- Research Questions
- Real-World Interventions
- Accessible Data
- Reflect and Adapt

Places & People of Culture Change



- **Primary Care Group Visits**

Science of ACP Group Visits

- Purpose:

Develop an ACP Group Visit intervention to engage patients in ACP as a health behavior

- Theory:

Group dynamic impacts attitudes and learning to influence behavior change, leading to ACP actions

ENgaging in Advance Care planning Talks (ENACT) Group Visits

Considerations for Multiple Funders

The Colorado Health Foundation

- Quality Improvement
- 5 Group Visits (Single Arm Feasibility)

National Palliative Care Research Center

- Refining Intervention with Stakeholders
- Implementation Manual

National Institute on Aging (NIA) K76

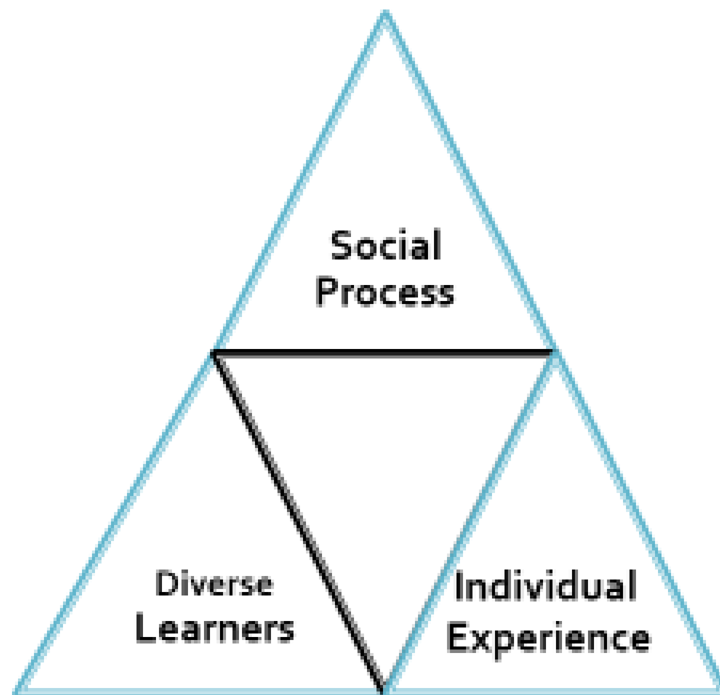
- Randomized Controlled Trial
- Recruitment Video

NIA Alzheimer's Disease Supplement

- Adapting for Cognitive Impairment

ENACT Theoretical Framework

Collaborative Learning Theory



Advance Care Planning
Behavior Change Theory

Bruffee. Collaborative Learning. 1993
Sudore et al. Novel Engagement. JAGS. 2008.

Advance Care Planning Group Visits

Intervention Components:

Interactive conversations of advance care planning

Education and support through group dynamics

ACP Group Visits Intervention

Patient goal setting for advance care planning actions

Uses outpatient billing codes & documentation

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

Clinic Support: What Does an ACP Group Visit Look Like?

Session 1 → 1 Month Apart → **Session 2**

8-10 Participants

Physician + Social Worker

CONTENT

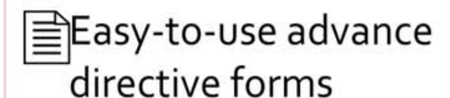
Check in, vital signs, medication review (30 min)

Introductions, rapport building (15 min)

Facilitated ACP discussion (60 min)

Individualized goal setting (15 min)

RESOURCES



In Outpatient Clinic

Advance Care Planning Discussion Topics

Values clarification

Ongoing conversations (patients, family, decision makers, clinicians)

Surrogate decision makers (flexibility)

Advance Directives (medical power of attorney, living will)

Common medical treatment options (risks, benefits, burdens)

Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. Med Clin N Am (2015)

Patient Experience:
Acceptability & Usefulness

"They expressed their experiences and it put me at ease to realize that there are people out there who have the same thoughts as I do, and they are in the same situations that I am in where their loved ones cannot bear talking about the subject. … It gave me more encouragement to find a way to encourage my loved ones to listen to what I have to say."

Patient Engagement: ACP Behavior Change

Pre-Contemplation

- "I'm here primarily concerning the notifications of people in case of any type of emergency."

Contemplation

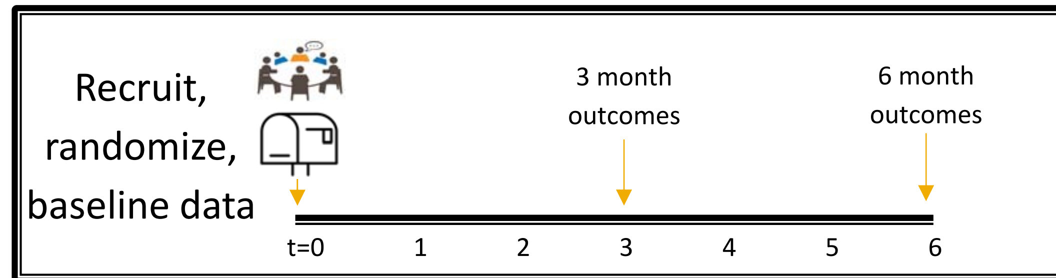
- "How do you get there though? You may have all these preconceived ideas about I just want to go when I'm ready, and then at the last minute, it is sort of like, hmmm…"

Preparation

- "At this point, it seems like the next step is really on me, on us."

Pilot RCT of ENACT Group Visits

Pilot RCT timeline:



Outcomes:

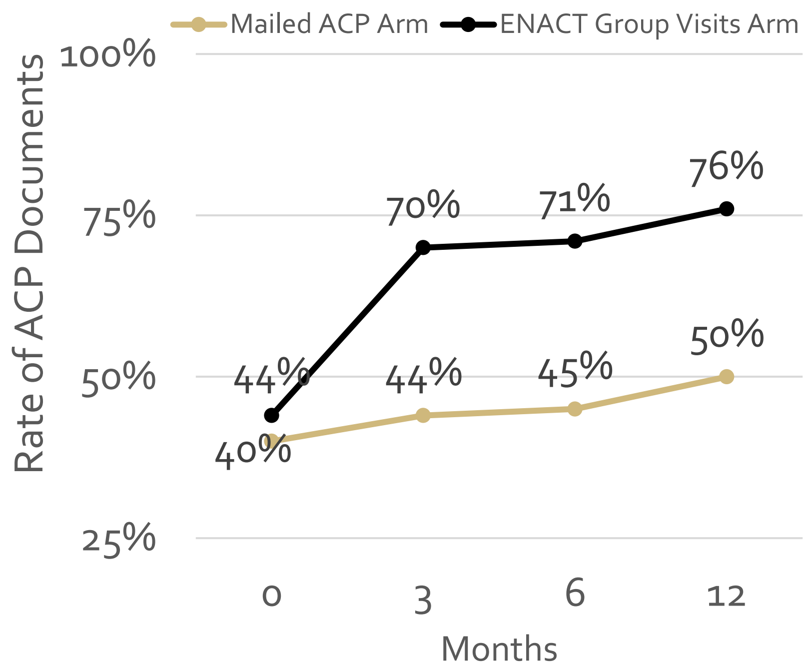
- **EHR review**
- **ACP readiness**
- **Stakeholder interviews**

Seniors Clinic
Referrals (n = 835)
Patients (n = 110)
Recruitment rate = 13%
Group size: 3-11 patients
First session patients (n=41)
Second session patients (n=34)
Retention/completion rate = 83%

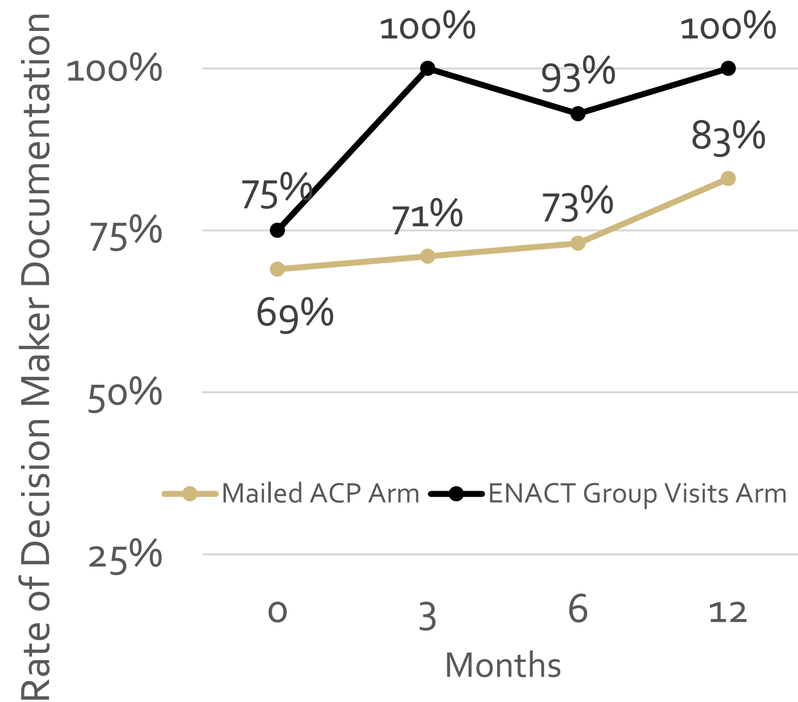
N=110
Mean age 77 years
60% female
79% white
63% married
22% caregivers

Efficacy: ACP Documentation

ACP DOCUMENTS



DECISION MAKER DOCUMENTATION



$p<0.01$ at 3, 6 and 12 months

ACP Engagement

Readiness Questions (Sudore et al) How ready are you to…	6 months, N=100		
	Control Mean (SD)	Intervention Mean (SD)	p-value
Sign official papers naming a medical decision maker to make medical decisions for you?	4.39 (0.99)	4.80 (0.66)	**0.015**
Talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	4.28 (1.22)	4.74 (0.83)	**0.03**
Talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?	3.59 (1.30)	3.994 (1.19)	0.16
Sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?	4.26 (1.05)	4.69 (0.91)	**0.03**

Acceptability of the group for ACP discussions

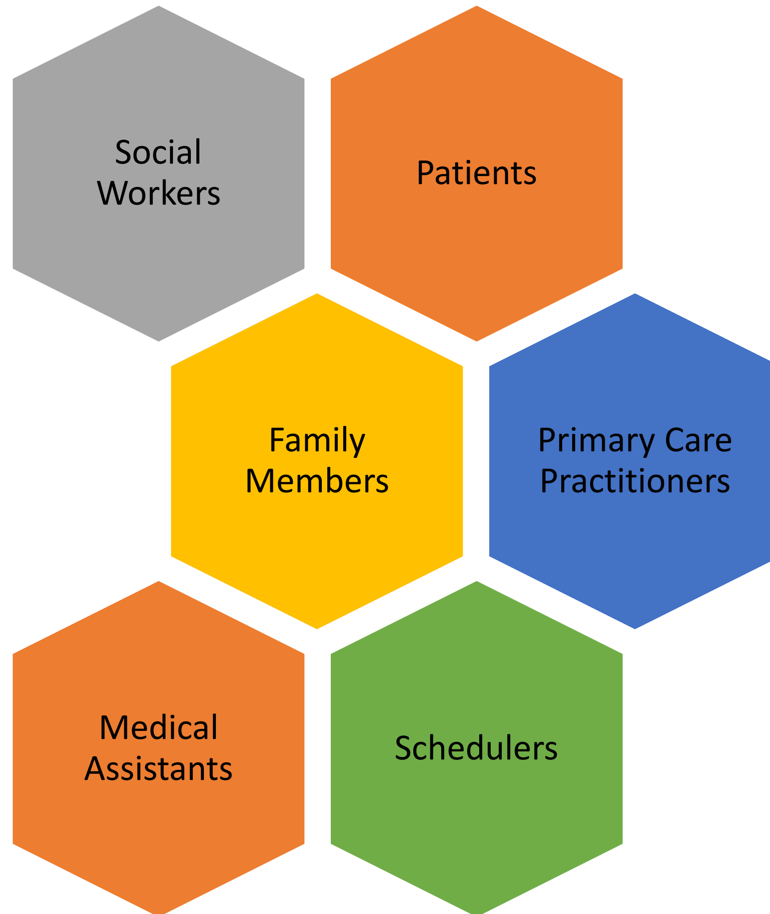
Patient: "Being there, being able to ask the questions, **hearing the other participants share was very meaningful**. It was a significant advantage. I think it brought up some things that I hadn't considered."

Primary care practitioner: "Even though I may be good at having those conversations with my patient and making sure we're establishing those goals, **I need them to talk to other people about it…** I think it's easier for some people to talk about it with strangers, initially. It can help set the stage for them to go talk about it in the real world."

Engaging Multiple Stakeholders

Practice Implementation Manual

Online Facilitator Training Modules



Patient Recruitment Video

Peer Partners in Groups

Public Good: Patient Awareness

NIA R01: Stage III Efficacy RCT

Inclusion Criteria
- ≥ age 70
- English- or Spanish-speaking
- At least one clinic visit in past year

Obtain PCP permission

Exclusion Criteria
- Lack of phone, inability to travel to clinic, moving out of the area within 6 months,
- Hearing impairment that limits participation

Eligibility Screening

Informed Consent (demonstration of decision making capacity)

Enrollment

Baseline Assessment

Block randomization by cognitive impairment (present vs no CI)

Intervention Arm
- Send Colorado easy-to-use advance directive and PREPARE pamphlet by mail
- Two 2-hour group visits with facilitated ACP discussion and goal setting

Control Arm
- Send Colorado easy-to-use advance directive and PREPARE pamphlet by mail

6-month follow up
- Chart review to assess ACP documentation
- Phone calls to assess patient-reported outcomes
- Acceptability interviews with participants from each arm

Location – Denver Metro Area

5 Primary Care Clinics

500 patients

Goal of 15% with cognitive impairment, defined by MOCA <26

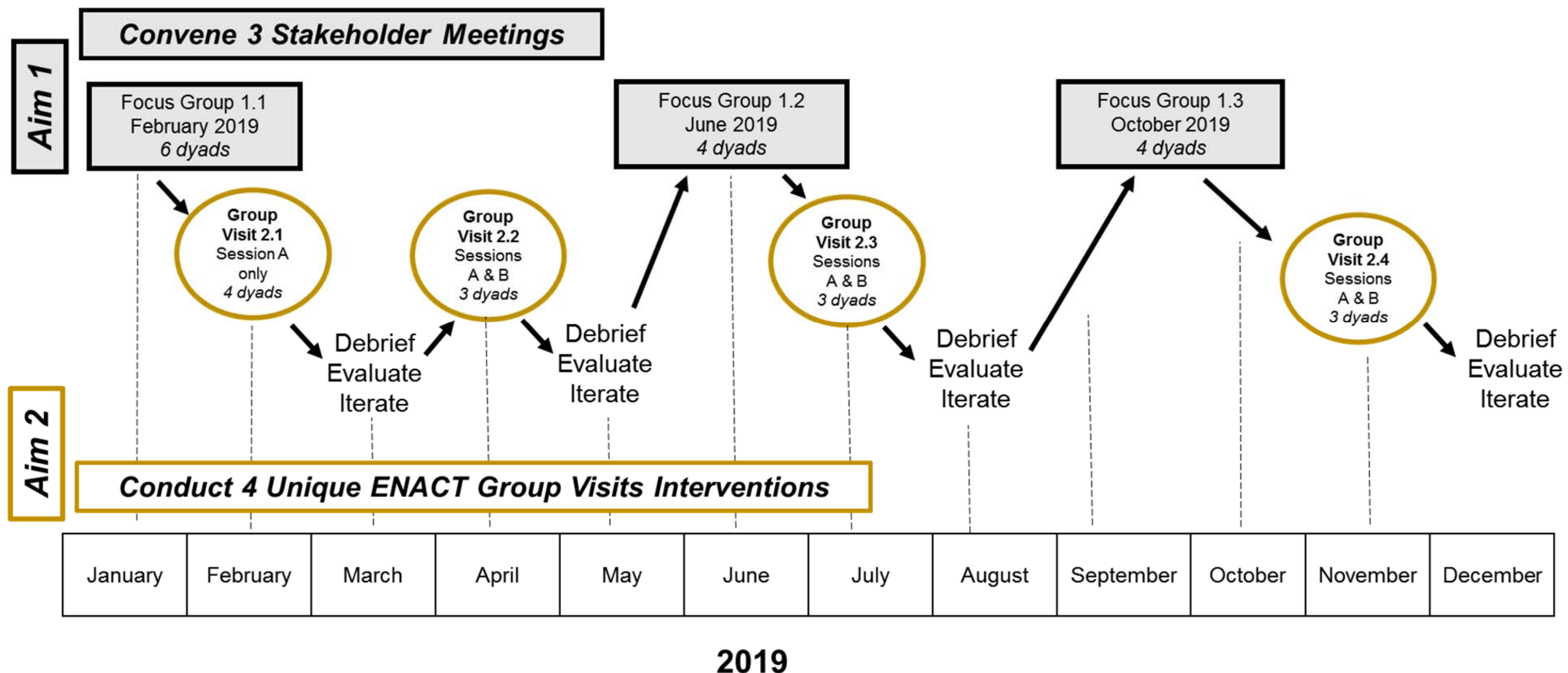
5-6 facilitators, including advanced practice providers

Adaptations

- Spanish Group Visits
  - Partnering with Denver Health
- Virtual Group Visits
  - Partnering with Dr. Allison Wolfe
- Cognitive Impairment Group Visits
  - Partnering with Dr. Bri Bettcher

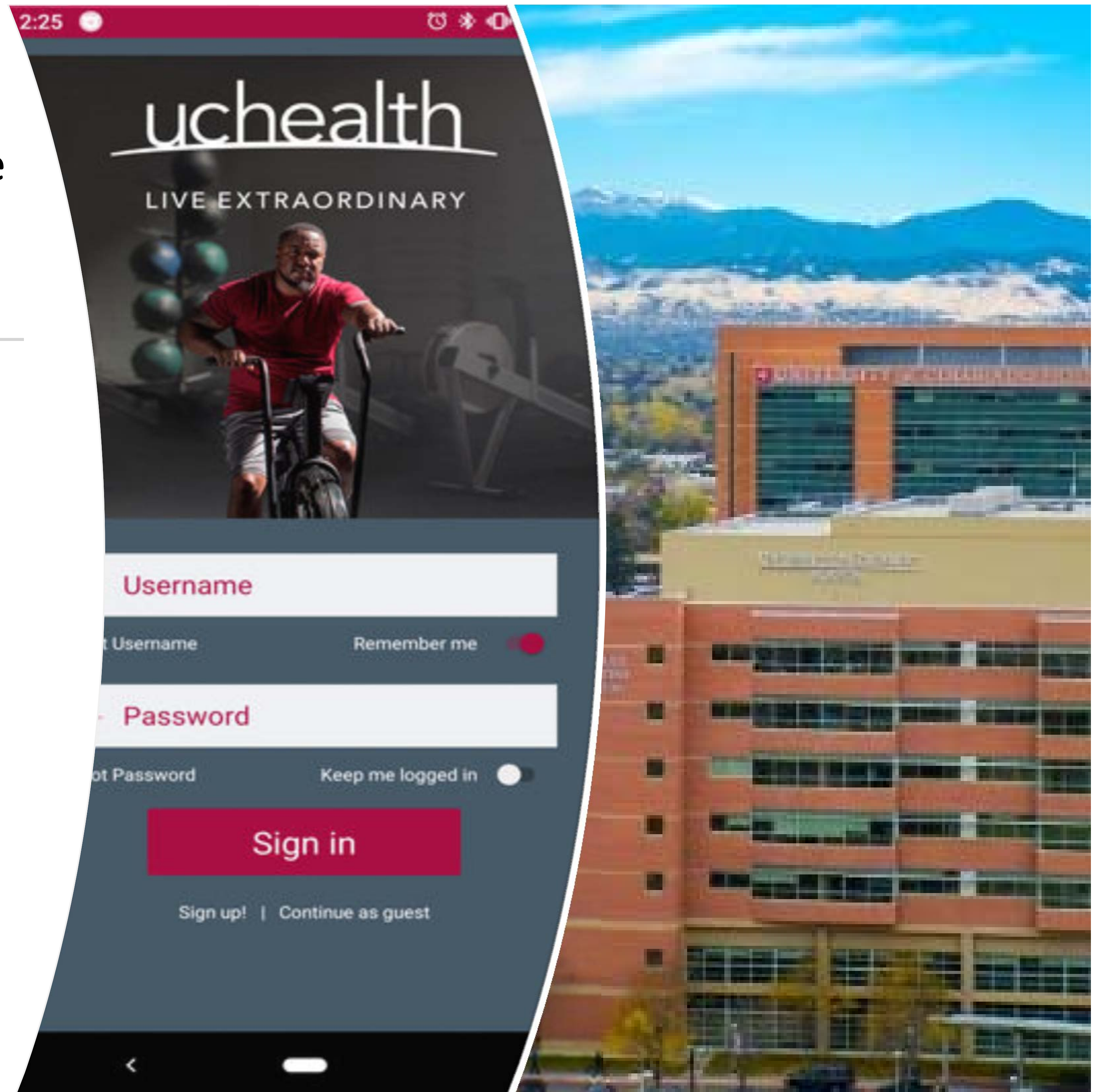
Adapting for Cognitive Impairment

- Longitudinal Patient and Care Partner Stakeholder Input
- Iterative Refinement
- Multi-method evaluation



Places & People of Culture Change

- **Primary Care Group Visits**
- **mHealth Approach – Patient Portal**



Rationale for Engagement via Patient Portal

In 2017, My Health Connection had no information for advance care planning

Colorado law for the Medical Durable Power of Attorney does not require witnesses or notary

Example from the literature:

A portal process resulted in filling in advance directive forms, which were printed, signed, brought to clinic

Input from stakeholders and partners: Designing for Clinical Use

Patients and Family Advisors

- ACCORDS Research Patient Advisory Committee
- Family Medicine Clinic
- Seniors Clinic
- UCH Patient and Family Advisory Committee

Clinical Operations

- Computer analysts
- Legal Counsel
- Health Information Management
- Health Literacy
- Population Health Leadership
- Marketing

Healthcare Team Members

- Healthcare Providers
- Care Managers
- Social Workers
- Medical Assistants
- Nurses
- Palliative Care Teams

Patient Stories & Leadership Testimonies

- "All of our providers and staff are focused on ensuring patients receive the very best care and experience.
- I've personally seen how important these conversations and documents are"

– Liz Concordia, UCHealth CEO

uchealth | Hillary | Health Record | Tools | Appointments | Messaging | Billing | Settings | Hillary Lum Log Out

Your Choices - Advance Care Planning

Advance Care Planning | UCHealth

One day you may be in a position where you cannot make medical decisions for yourself. Sometimes this happens because of an accident or severe illness. It can be difficult to think about not being able to make medical decisions for yourself, but you can make it easier by sharing with others the care and treatment you would want if you became unable to make your own health care decisions. Doing so is sometimes called advance care planning.

Advance care planning is a way to:

- Tell others what type of care you prefer.
- Let others know what to do when you cannot make your own decisions.
- Choose who you want to act on your behalf when you cannot make your own decisions.

An advance medical directive is any written instruction regarding the making of medical treatment decisions on your behalf. An advance directive may be:

- A Medical Durable Power of Attorney (an MDPOA)
- A living will (medical declaration)
- A CPR directive
- A Medical Orders for Scope of Treatment

Advance care planning is personal but there are tools available in My Health Connection to help you. These are serious decisions. Take the time you need and talk to the people you want to talk to about your wishes so they understand what you want. This may be family members, close friends, doctors, or your attorney.

If you have any advance directive or advance care planning documents on file, you will see them below. This includes any current or past documents. If you have an existing advance directive document that you would like your health care providers to know about, please bring a copy to your provider's office so they can add it to your record.

Helpful Links

I want to choose my medical decision maker and update this information in my medical record (must be 18 to complete this form). The information I submit will be uploaded into my medical record associated with this My Health Connection account. View and print these completed documents from the link below in "Documents on File".

MDPOA
Identify your health care decision maker and complete a Medical Durable Power of Attorney form

Example MDPOA
View an example of a completed form

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Design and Implementation of Patient Portal–Based Advance Care Planning Tools

Hillary D. Lum, MD, PhD, Adreanne Brungardt, MM, MT-BC, Sarah R. Jordan, MA, Phoutdavone Phimphasone-Brady, PhD, Lisa M. Schilling, MD, MSPH, Chen-Tan Lin, MD, Jean S. Kutner, MD, MSPH

Three Implementation Phases

Phase 1 (May 2017)
- New Webpage
- Online Message for ACP questions to centralized team

Phase 2 (July 2017)
- Electronic Medical Durable Power of Attorney

(includes messages to provider and patient)

Phase 3 (Oct 2017)
- Display advance directives to patient via patient portal

The Colorado Health Foundation™

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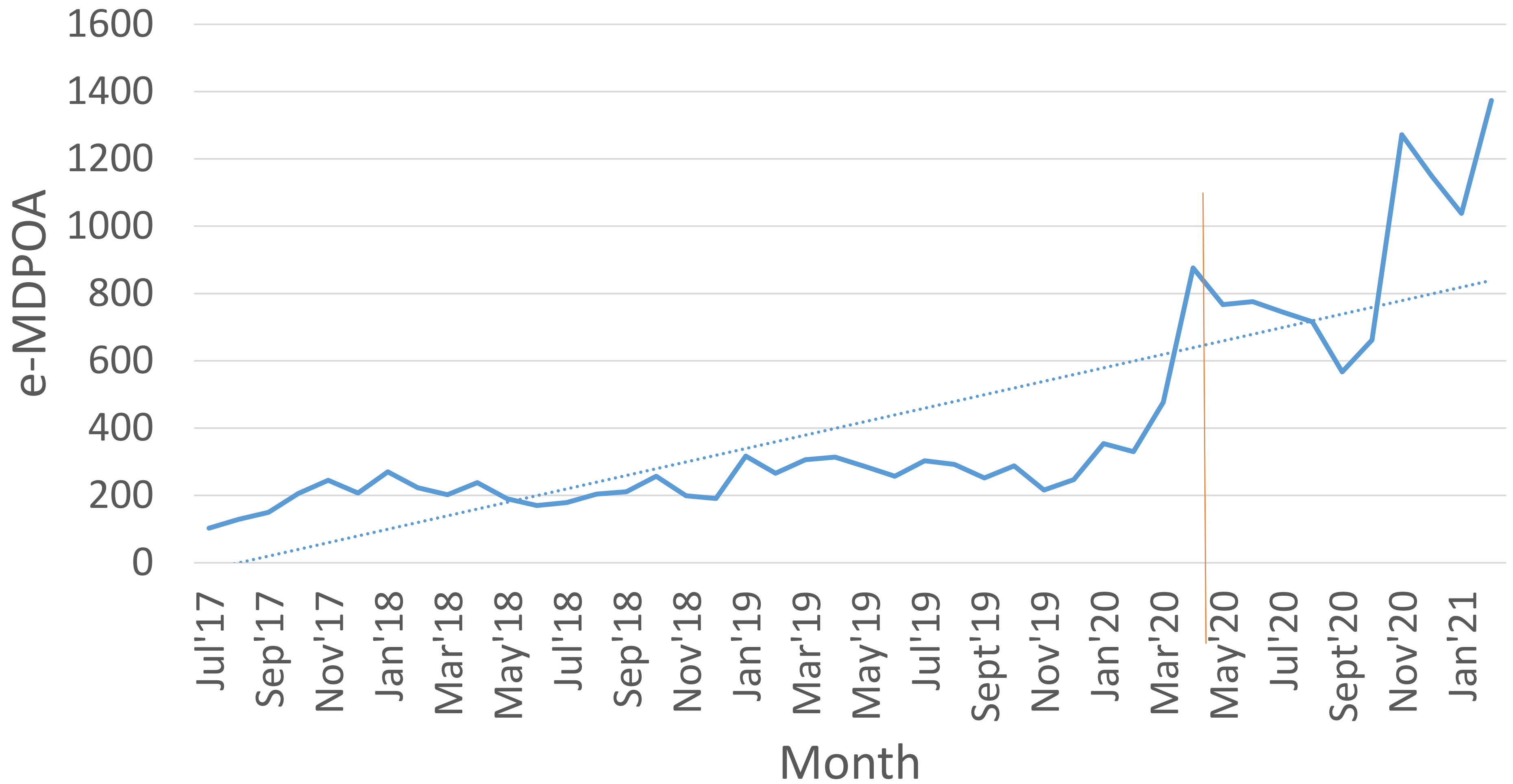
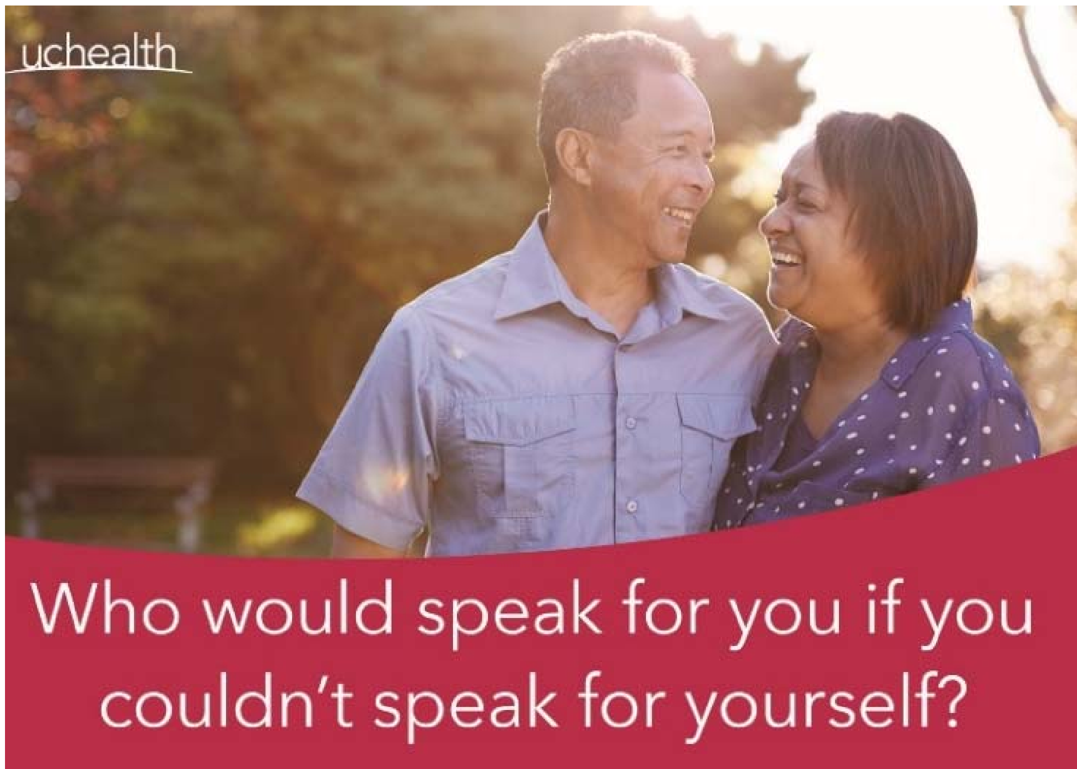
Use of My Health Connection ACP Tools



Patient Experience: Portal ACP Tools



"Being able to go online and kind of do a little research myself, it made me more comfortable with it, and then I could bring up that kind of conversation. So I think it's absolutely a necessity to have it online to at least get people started."

Female, 30 years old

Sharing Program Highlights to Key Leaders

My Health Connection (MHC)
ADVANCE CARE PLANNING TOOLS

Hillary Lum, MD, PhD
hillary.lum@cuanschutz.edu
v3.1.2021

2017-2021

18,000 Patients have used the ACP Tools

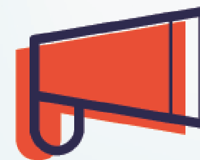
Since January 2020, there has been been a huge surge in electronic MDPOAs submitted through MHC due to COVID-19.

Electronic MDPOA Features:

DECISION MAKER & MEDICAL PREFERENCES

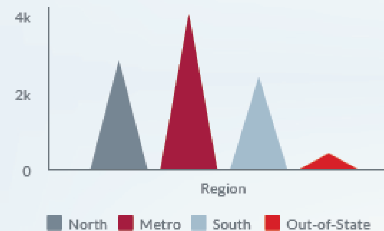
VIEWABLE & DOWNLOADABLE

PATIENT & PROVIDER COMMUNICATION

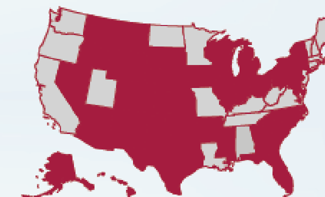


Every day, about 50 UCHealth patients *Choose a Medical Decision Maker thru MHC*

Available Across UCHealth and Affilitates



Regional Use



Patients from 28 States
1 in Germany

Extraordinary Partners in Care: Five-year goal

Every person who receives care through UCHealth will have their goals of care assessed and documented at least annually to include relevant changes in health, functional status or social situation.

- This documentation will be accessible to and may be updated by all care team members.
- Patients and their care teams will engage in shared decision making that takes into account the person's personal expertise about their goals and preferences, and also acknowledged provider's belief/value system.
- Supports and options are in place that make care in the patient's preferred location the default (rather than ED or hospital admission).

Courtesy of Dr. Jean Kutner, Chief Medical Officer, University of Colorado Hospital

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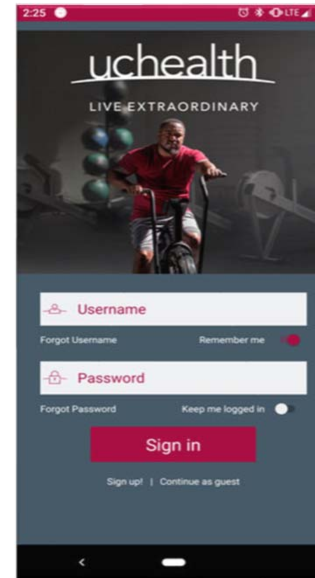
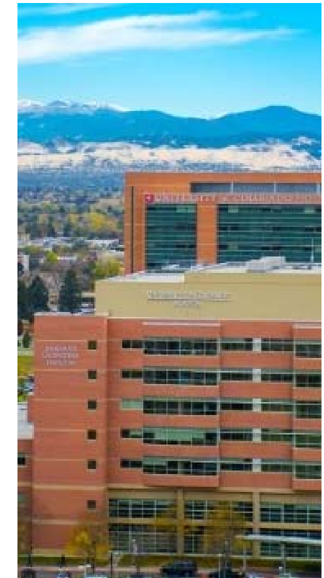
Places & People of Culture Change

- **Primary Care Group Visits**
- **mHealth – Patient Portal**
- **A Community Website**





Colorado Care Planning Website

- A public-facing website of Colorado advance care planning information using iterative, diverse stakeholder input.

ROADMAP

Follow this roadmap for guidance through the advance care planning process. Each stop along the way provides you with information to help you choose which steps and documents are right for you.

READ MORE

WHAT IF I...

Everyone has their own personal journey, and often our journeys have different needs. Check out this page for tailored resources on what makes you, you. For example, "What if I am a Veteran" and "What if I need an Advance Directive in Spanish".

READ MORE

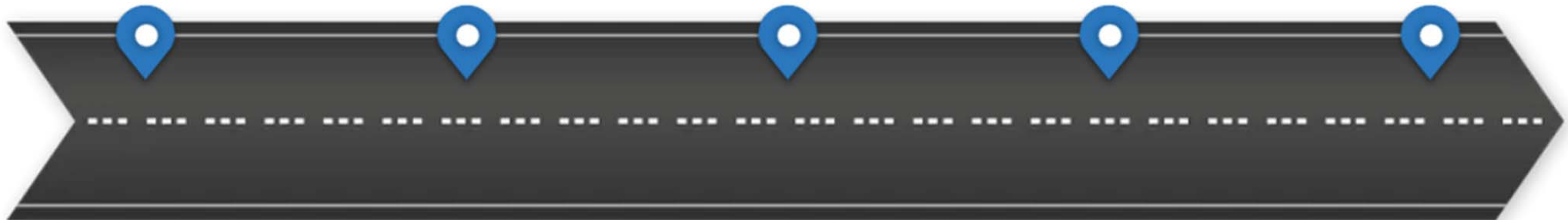
COLORADO COMMUNITY RESOURCES

Advance care planning may bring up additional topics such as housing, caregiving and insurance. Use this page to find resources near you such as housing, caregiving and insurance.

READ MORE

Here's a roadmap for future medical planning in Colorado. Start exploring!

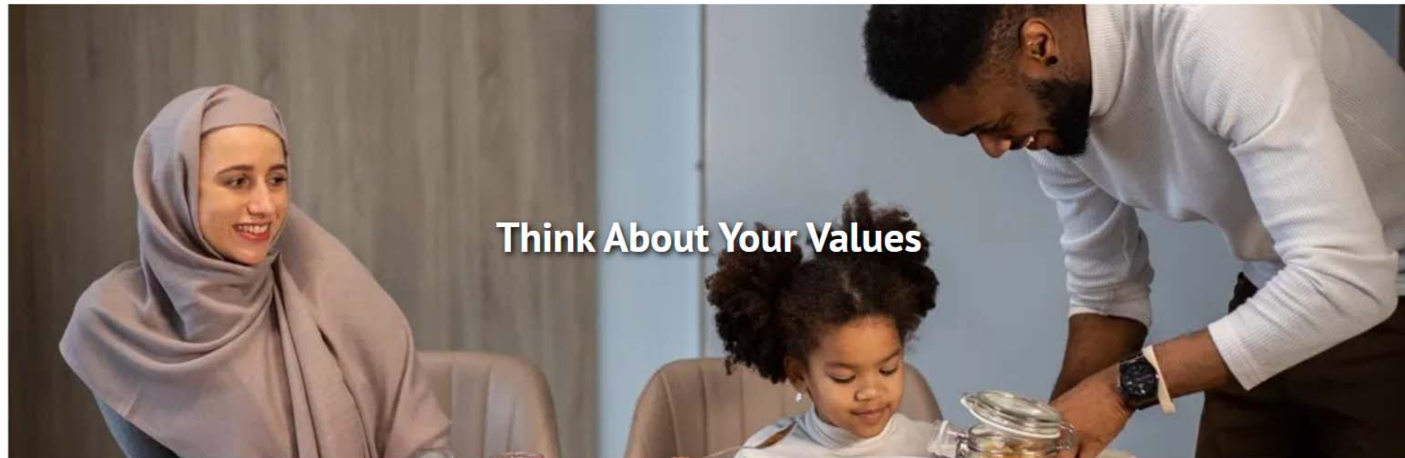
Think About Your Values | Choose A Decision Maker | Write Down Your Wishes | Make Medical Choices | Share Your Wishes



Public Goods

www.coloradocareplanning.org

HOME ROADMAP WHAT IF I... RESOURCES CONTACT



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.

CENTER FOR IMPROVING
VALUE IN HEALTH CARE

the conversation project
in boulder county

Resources & Websites

- Advance Care Planning – Center for Improving Value in Health Care (CIVHC): https://www.civhc.org/programs-and-services/advance-care-planning/

  Kari Degerness, MBA, LNHA
  - kdegerness@civhc.org

- The Conversation Project – Boulder County http://theconversationprojectinboulder.org/

- Easy to Read Advance Directive www.prepareforyourcare.org

Key Pragmatic Approaches

Multiple Voices

- Ongoing formal and informal input from stakeholders to refine ACP approaches

Multiple Funders

- Leveraging different funding to address scientific and stakeholder needs

Multiple Deliverables

- Developing implementation tools, practical resources, and community resources

Reflections

Be creative	Create things that people can use
Partner	Collaborate with different people, especially patients and community members
Listen	Seek to understand what others need, incorporate their input
Persist	Highlight important things, sometimes funders, health care systems, payors and policy makers will agree

Implementation: Barriers to clinic integration

Patient: "It was a little bit tight, I think if they had a **little bit more room between people**, that might help a little bit."

Medical Assistant: "We need to have the patients in the room on time and also we need to take the vitals, so **it's been kind of stressful.** A little bit more help, that would make it a little bit different."

Social Worker: "The only weakness I can think of is the rooming process. Typically on Friday afternoons have some less staff for check in. We have gotten started a couple minutes late. **Our medical assistants have gotten a little overwhelmed**."