Moving Advance Care Planning Upstream:

Using Serious Illness Conversations to Promote Goal-Concordant Care and Increase Patient, Family, and Clinician Well-Being

Annette Totten, OHSU

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GOBHI
CAMBIA health foundation
Columbia Pacific CCO™ Part of the CareOregon Family

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ORPRN
Oregon Rural Practice-Based Research Network

UNIVERSITÉ LAVAL
Faculté de médecine
Réseau de recherche axé sur les pratiques de première ligne (RRAPPL)

UTOPIAN
UNIVERSITY OF TORONTO PRACTICE-BASED RESEARCH NETWORK

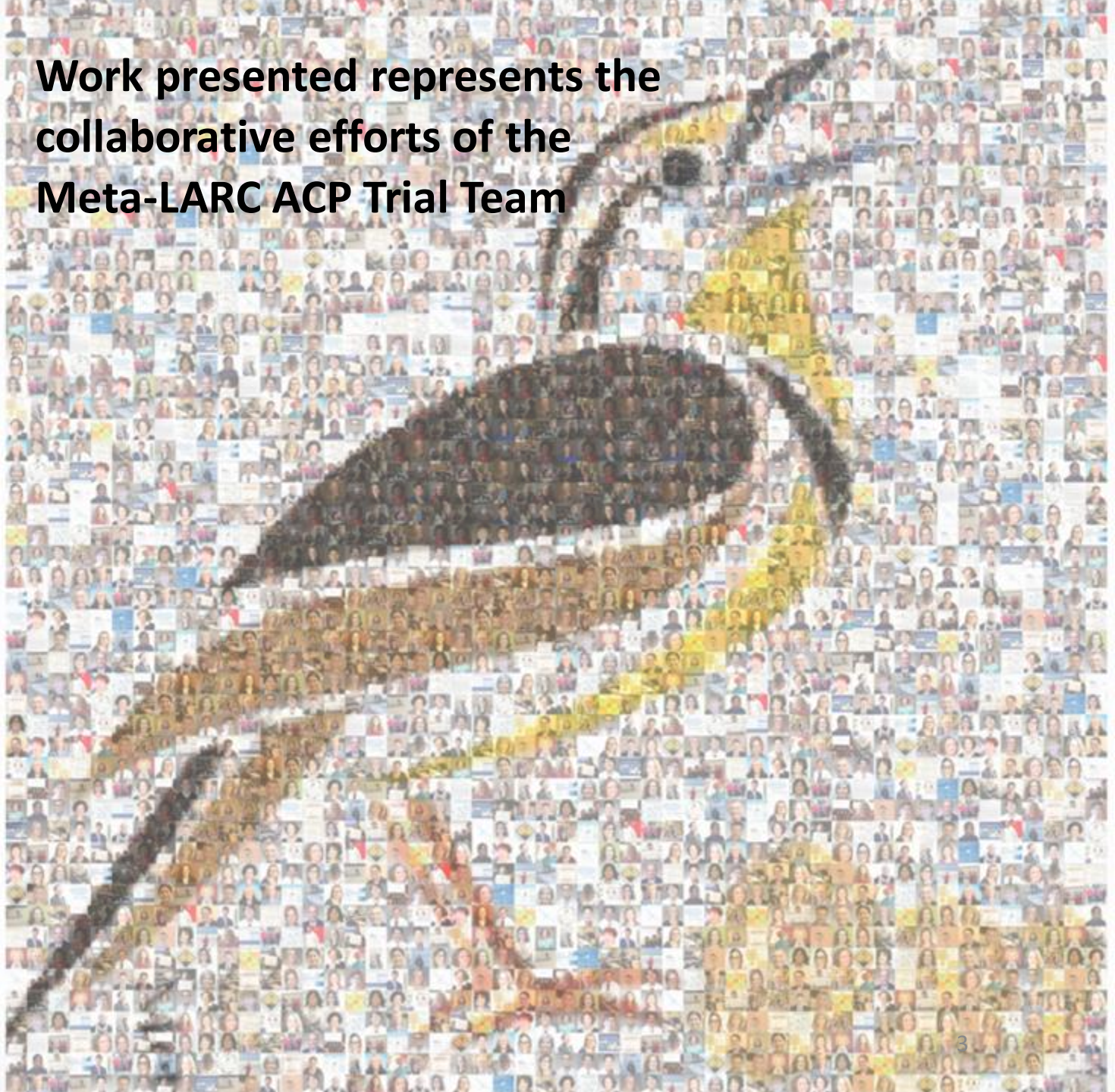
SNOCAP
State Network of Colorado Ambulatory Practices & Partners

Wisconsin Research & Education Network

IRENE
Iowa Research Network

Duke Clinical & Translational Science Institute
Primary Care Research Consortium

Work presented represents the collaborative efforts of the Meta-LARC ACP Trial Team



Participating Practices

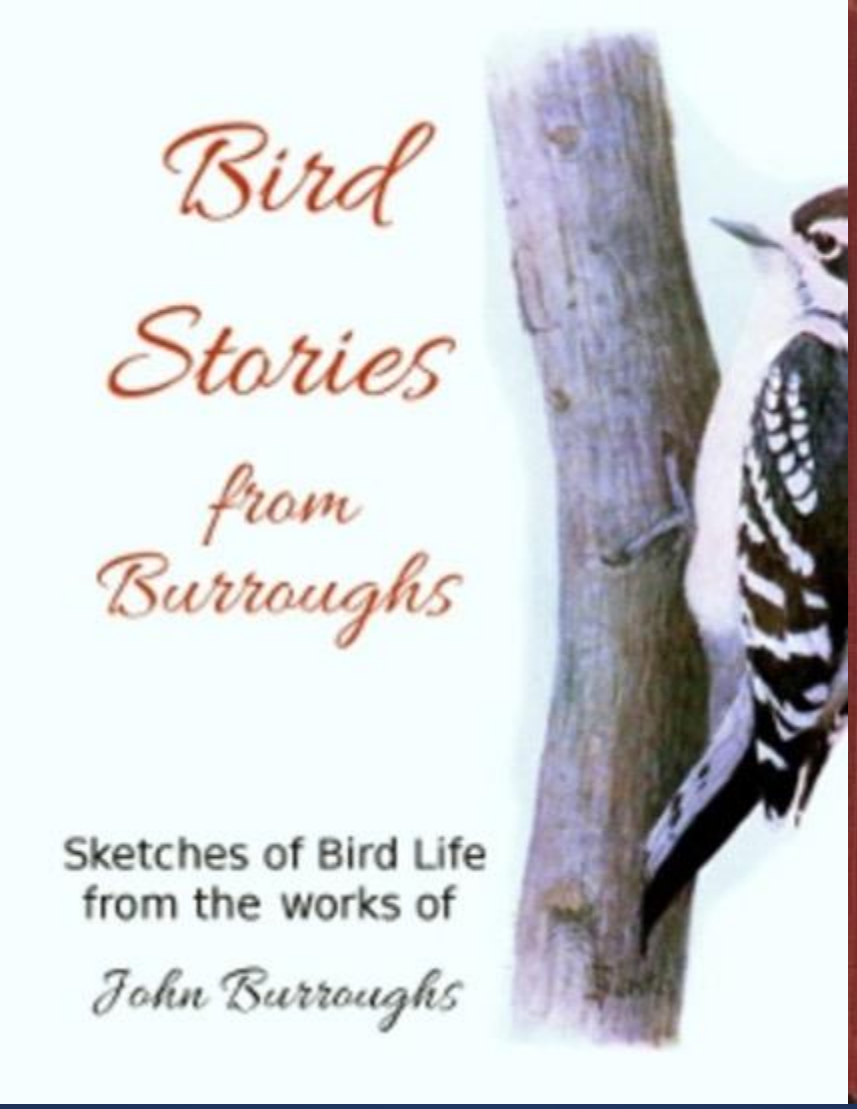
META LARC ACP TRIAL

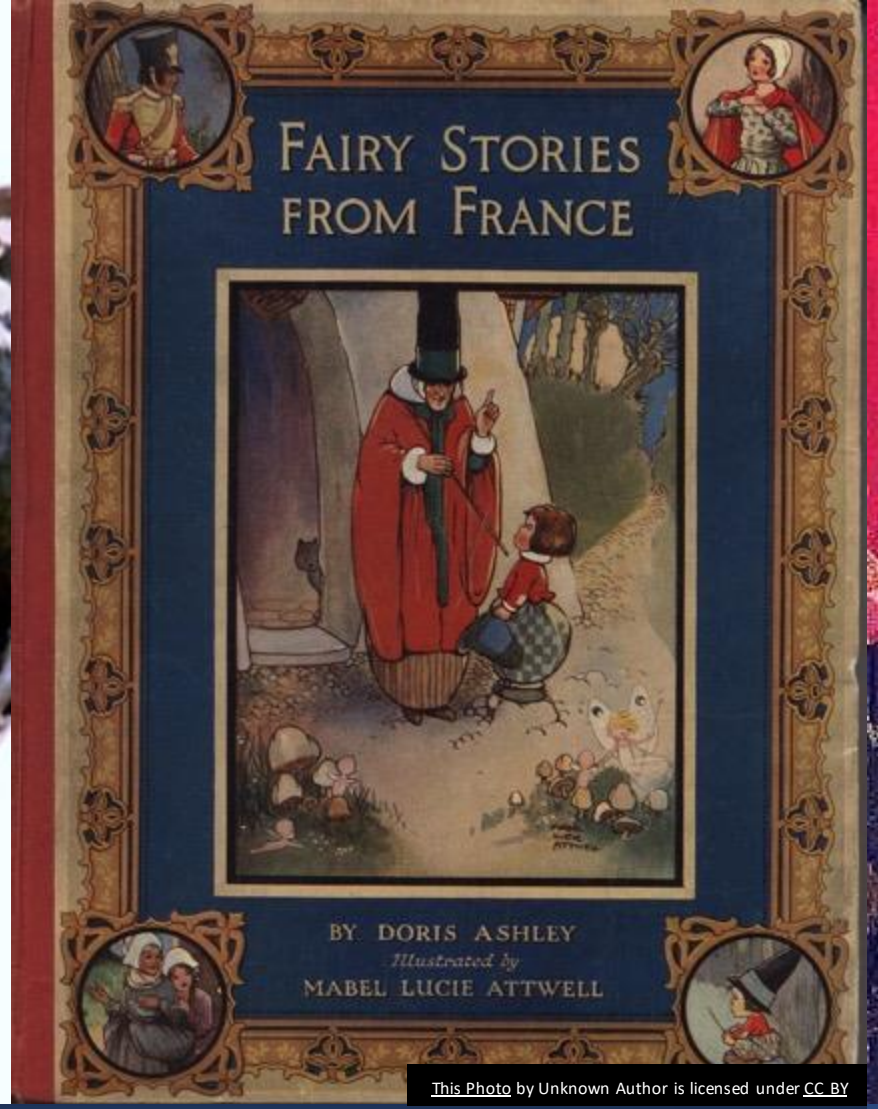
- Knoxville Hospital & Clinics: Knoxville, IA
- Regional Family Health: Manchester, IA
- University of Iowa Health Care - Muscatine: Muscatine, IA
- UI Health Care - River Crossing: Riverside. IA
- University of Iowa Health Care - Scott Boulevard: Iowa City, IA
- West Broadway Clinic, P.C.: Council Bluffs, IA
- Cascades East Family Medicine Clinic: Klamath Falls, OR
- Dunes Family Health Care: Reedsport, OR
- OHSU Internal Medicine: Portland, OR
- Providence Medical Group Newberg: Newberg, OR
- St. Luke's Eastern Oregon Medical Associates: Baker City, OR
- Winding Waters Community Health Center: Enterprise, OR
- Duke Family Medicine: Durham, NC
- Duke Primary Care Henderson: Henderson, NC
- Duke Primary Care Hillsborough: Hillsborough, NC
- Duke Primary Care Midtown: Raleigh, NC
- Duke Primary Care Oxford: Oxford, NC
- Duke Primary Care South Durham/Galloway Ridge: Durham, NC
- Family Care Southwest, P.C , Littleton, CO
- Flatiron Internal Medicine, Louisville, CO
- St. Mary's Family Medical Residency, Grand Junction, CO
- Westminster Medical Clinic, Westminster, CO
- Uncompahgre Medical Center, Norwork CO
- GMF-U Saint-Charles Borromé: Saint-Charles-Borromée, QC
- GMF-U Saint-François D'assise: Québec, QC
- GMF-U de Trois-Pistoles: Trois-Pistoles, QC
- Guelph General Hospital: Guelph, ON
- North York General Hospital: Toronto, ON
- St. Michael's Hospital: Toronto, ON
- Women's College Hospital: Toronto, ON
- Ascension Columbia St Mary's-Germantown Clinic: Germantown,WI
- Divine Savior Healthcare, Inc: Portage, WI
- NorthLakes Community Clinic - Hayward: Hayward, WI
- Platteville Clinic at Southwest Health: Platteville, WI
- Plymouth Family Physicians: Plymouth, WI
- Richland Medical Center: Richland Center, WI

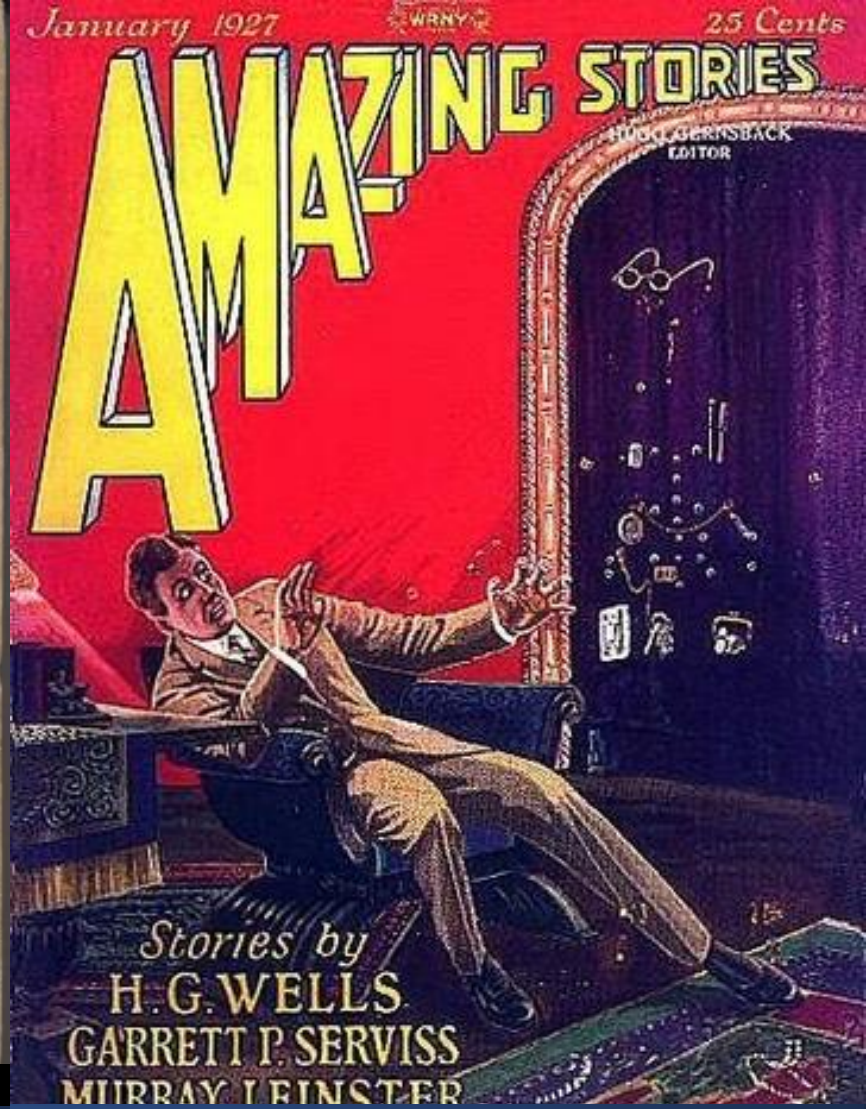
NIA IMPACT PILOT Project

- Cascades East Family Medicine Clinic: Klamath Falls, OR
- Northwest Medical Homes, Springfield, OR
- Westminster Medical Clinic, Westminster, CO
- MidValley Family Practice, Basalt, CO

Workshop Learning Objectives







What are our stories; how are the different

Warm Up and Introductions

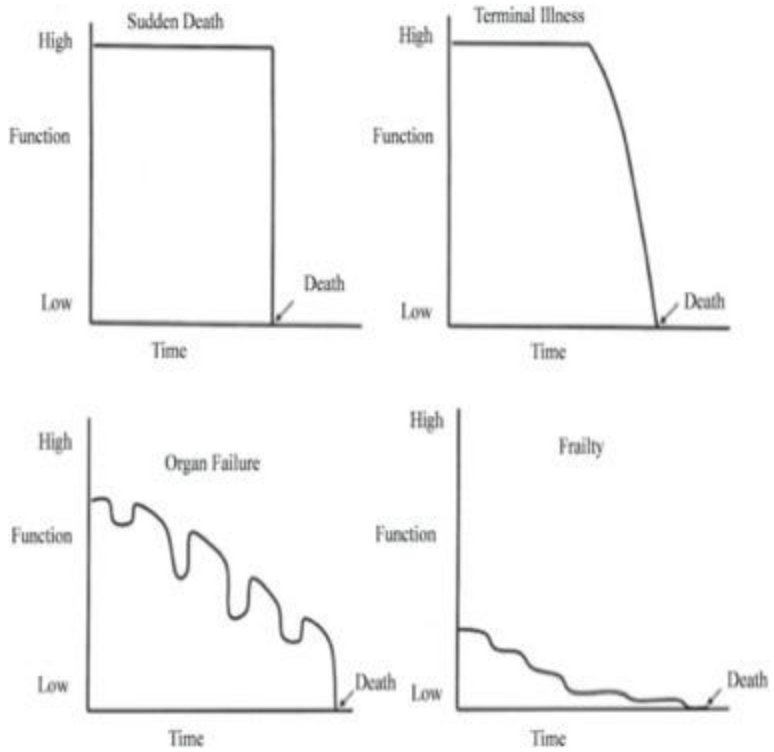
- 1 Minute: Personal Reflection
  - Think about an experience with a relative or patient related to health care received or decisions about health care that you think is relevant to our topic
  - Jot down a few notes
- Answer the following questions
  - More positive or more negative?
  - Who was involved?
  - End of life or earlier?
  - What would you like to change?
- Name, Organization, something from your reflection (if you want)

Goal: Share Perspectives and Ideas

Background

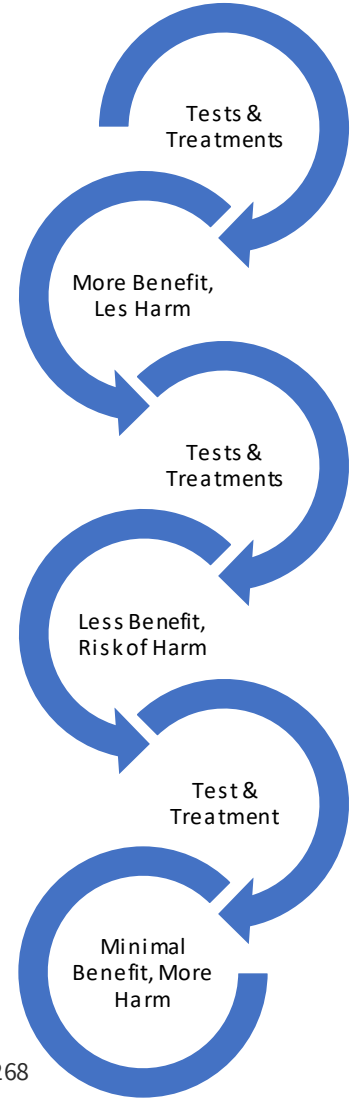
- End of Life verse Serious Illness
  - What is different
  - Why focus on ‘moving up stream’
- Advance Care Planning (ACP)
  - A **process** that supports persons in understanding and sharing their **personal values, life goals, and preferences** regarding future health care
- Serious Illness Conversations: a type of ACP
  - Patient-tested language
  - Structured
  - Can occur over multiple visits/encounters
  - Can involve different health care professional

Issue



Source: Lunney, J. R.,Lynn, J., & Hogan, Cl (2002). Profiles of older medicare decedents. *Journal of the American Geriatrics Society,* 50, 1108–11 doi:10.1046/j.1532-5415.2002.50268

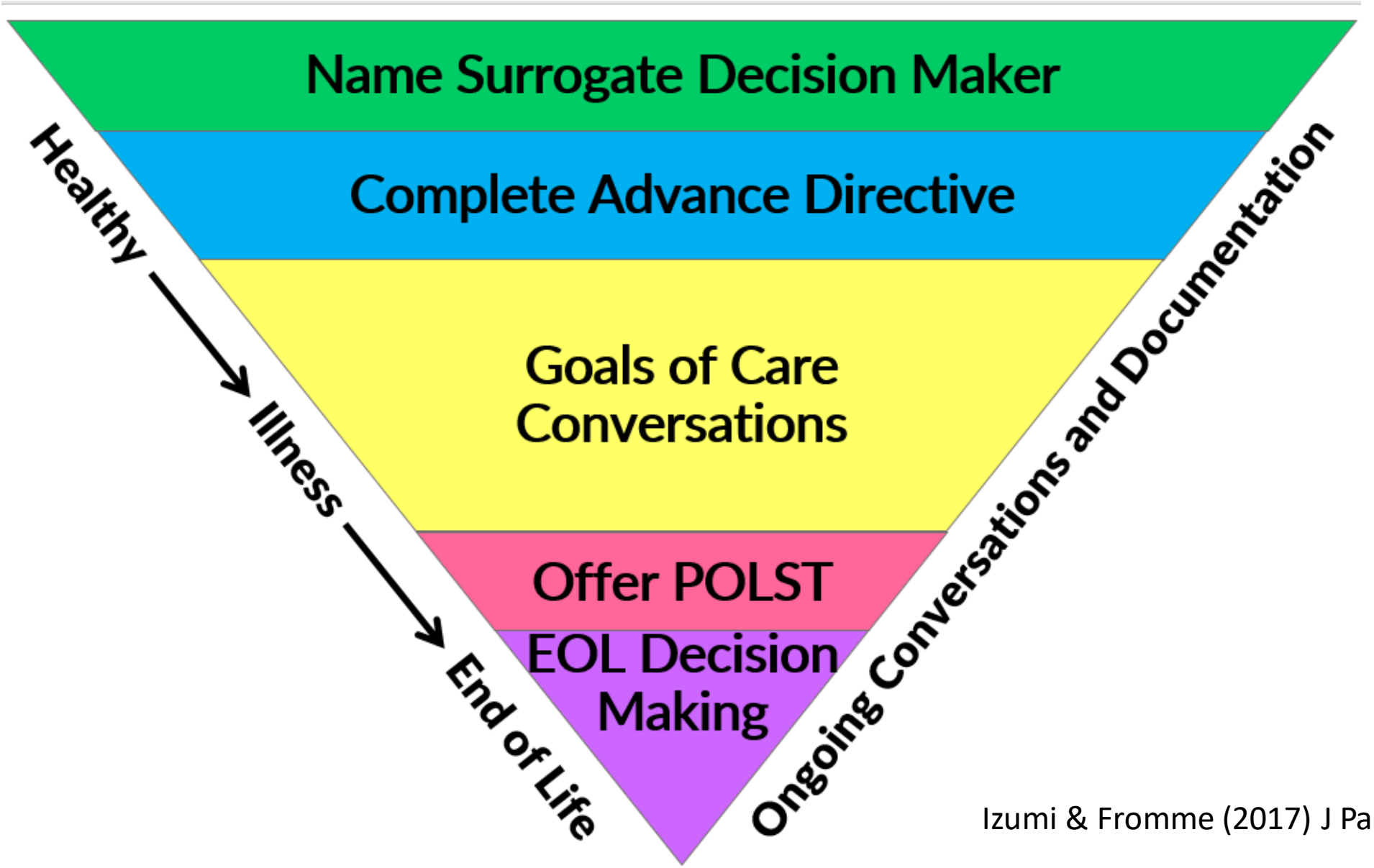
Yet



"***As long as I can make it to Sunday dinner, I want to keep going".*** 75-year-old woman with severe CHF

"Is there a good reason I'm not at home with my cat and a scotch?" 82-year-old man with esophageal cancer

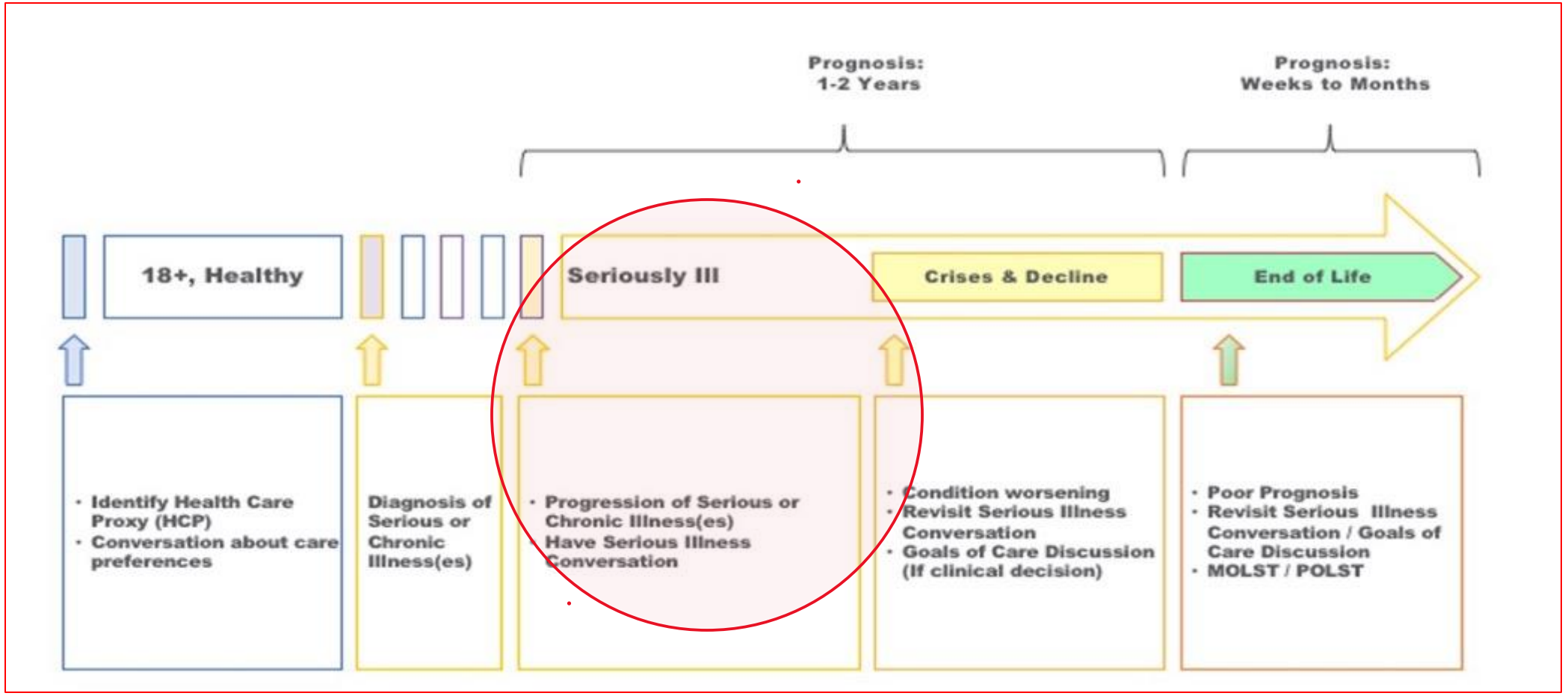
Source: Personal communications with patients and clinicians



Izumi & Fromme (2017) J Pall Med

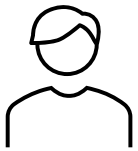
Continuum of Advance Care Planning

One Solution: Move Advance Care Planning "Up Stream" and in Primary Care



Why Advance Care Planning?

I am excited to know that patients can talk to their physicians and families to make their wishes known
--Patient Advisor



"I don't want the time I have left spent in the hospital and doctors' offices."

"Is there a good reason I'm not at home with my cat and a scotch?"

"I can't tell the doctor to let dad go if it means he is gonna die. I can't make such a decision."

--Patients and Families

I've learned that patients are waiting for their provider to bring the subject up. Most people want to avoid the conversation, so it's really up to me to initiate the subject.
---Clinician

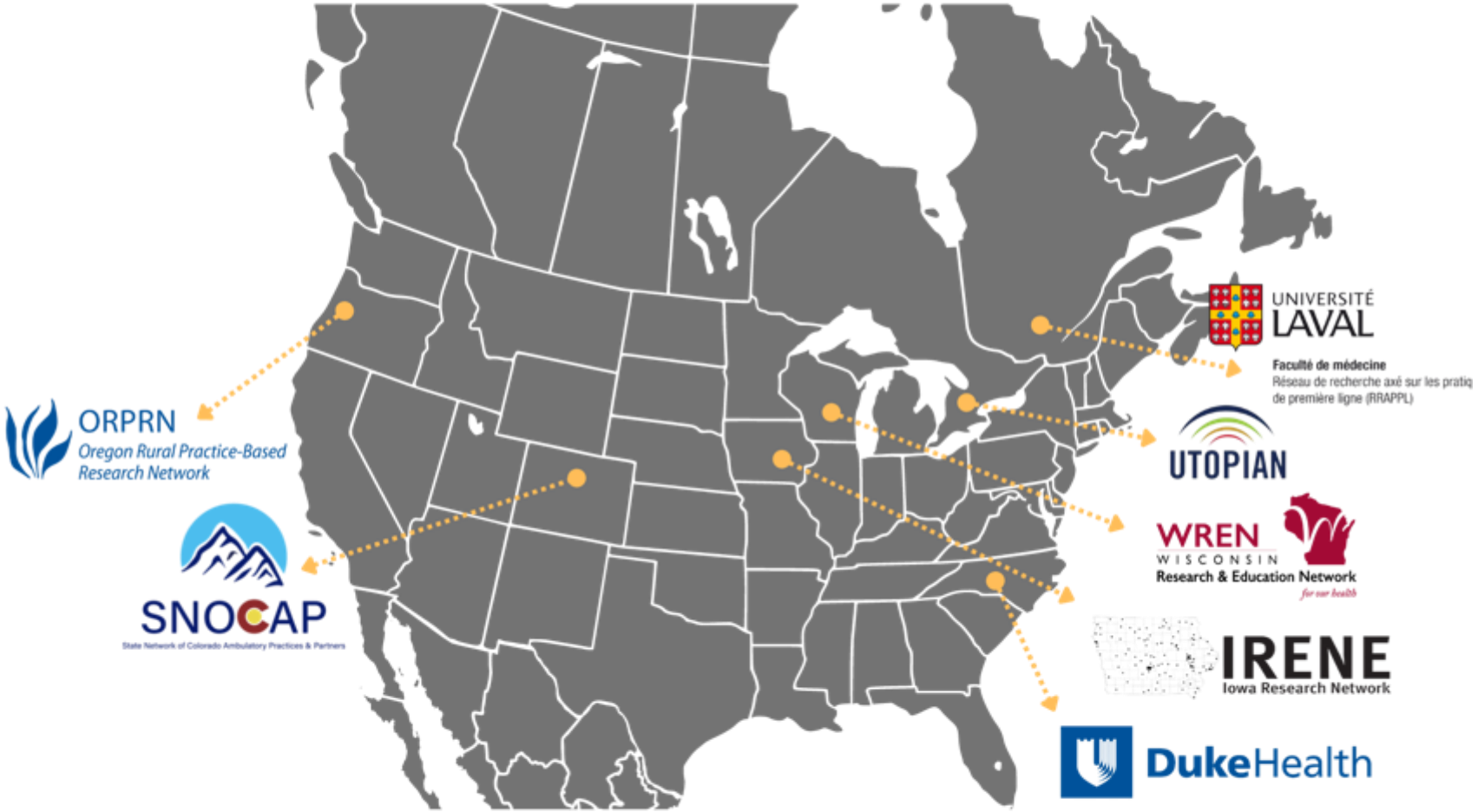
THE META-LARC ACP TRIAL

- Team-based vs. Clinician Focused
- Existing ACP Program: Serious Illness Care Program by Ariadne Labs
- 7 PBRNs, 42 Practices
- Patient surveys: initial, 6-months, 12-months
- Primary Outcomes: Goal Concordant Care; Days at Home
- Over 1000 patients; over 500 Primary Care Clinicians and Staff
- 2 Countries; 5 states; 2 provinces

Testing: This ECHO is a Pilot Project

- Part of a national program to promote better research about ADRD
- Pilot Projects
  - Develop components that could be used in a future clinical trial
  - Identify topics for future research
- Our pilot
  - Modify ECHO to include facilitating advance care planning conversations AND supporting implementation
  - Test ability of practices to track the number of PLWD and families engaged in ACP

Project ECHO
Oregon ECHO Network



Meta-LARC, a consortium of PBRNs

- PBRNs
- Networks of practices and clinicians that collaborate on research and quality improvement
- The Meta-LARC ACP Trial team

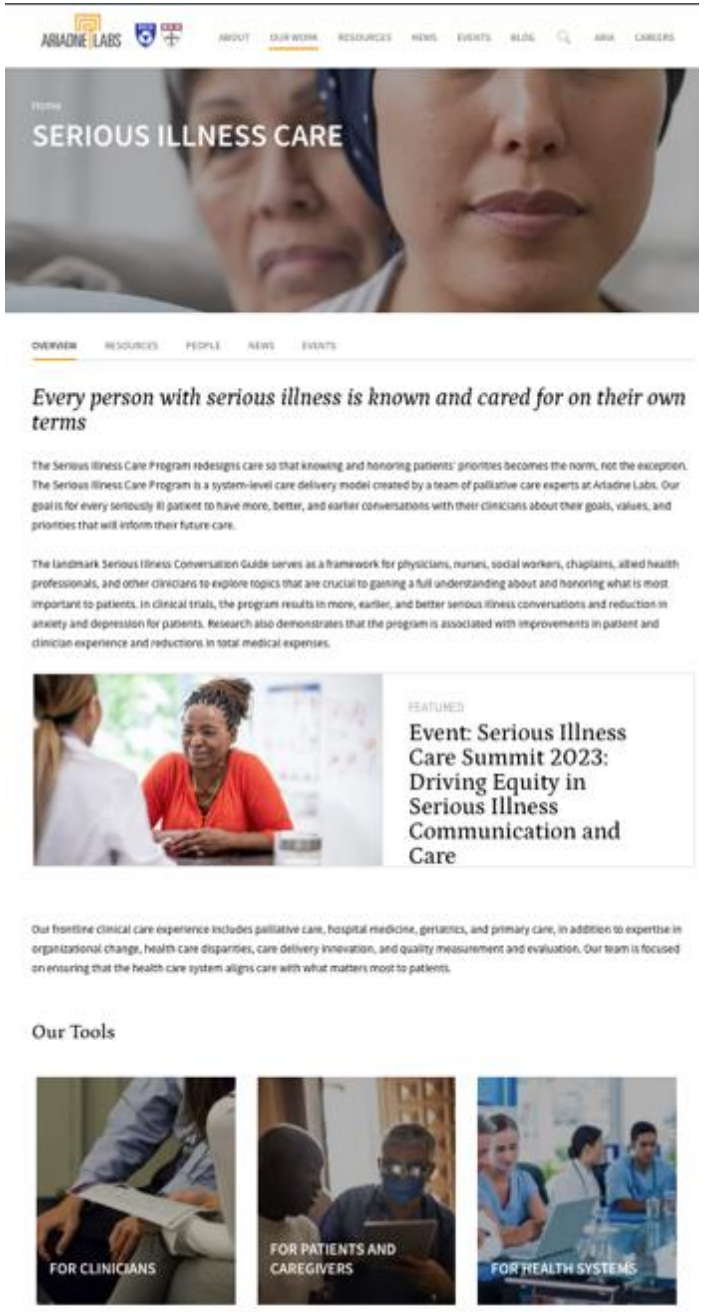
Training and Implementation

”This program demonstrates to me how essential it is to understand what a patient wants out of his/her health care. […]The next time I see a new patient, my first questions will be "What are your priorities? How can I best help you?”

--Participating Clinician after training

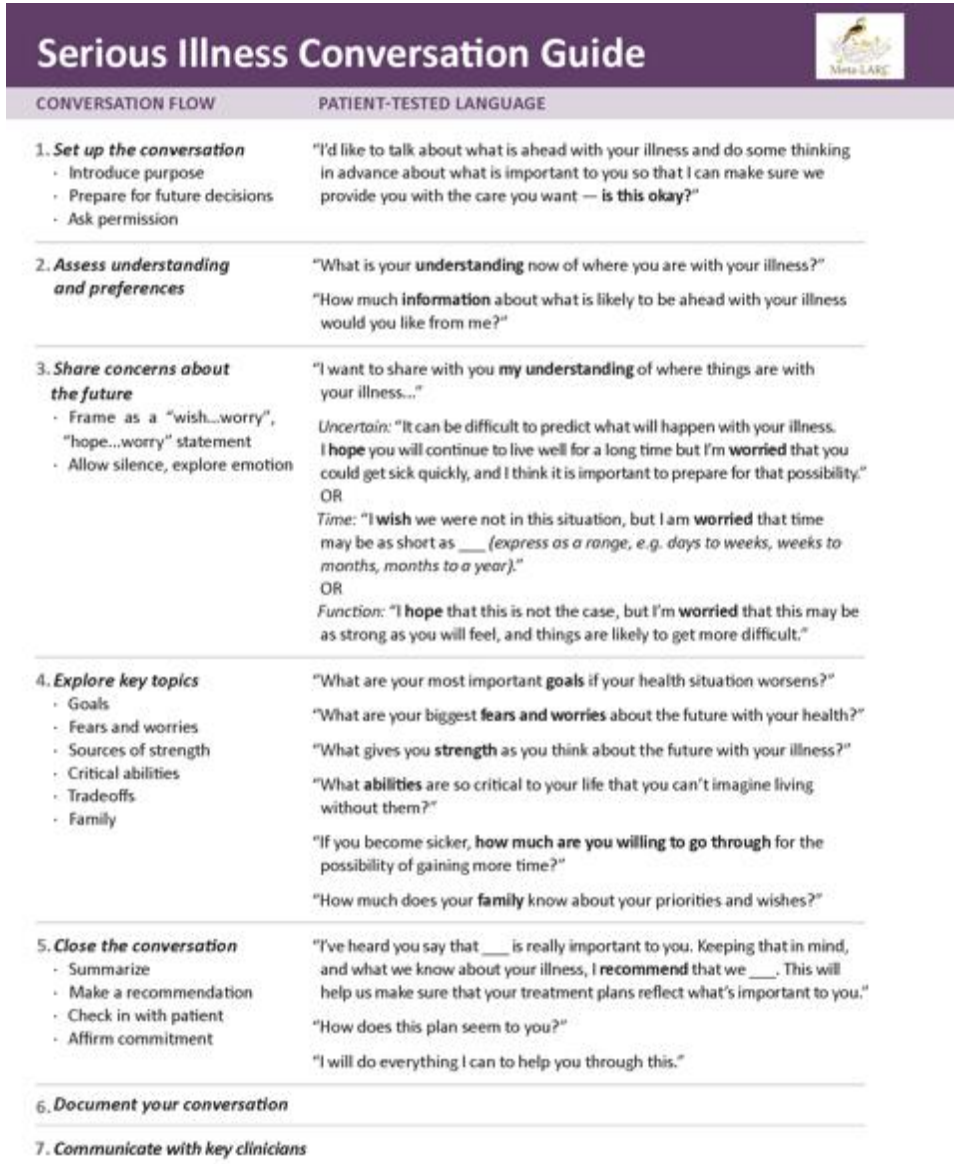
Serious Illness Care Program

- Evidence based approach
- Promote more, earlier, and better ACP conversations
- Developed by Ariadne Labs
- Identifying patients
- Prepare and support patients and families for ACP
- Develop skills to facilitate goals of care conversations
- Documenting conversations in EHR
- Build a system to sustain ACP



Develop skills to facilitate conversations

- Conversations between clinicians and patient with serious illness that:
  - Focuses on learning person's values, goals, and care preferences
  - Starts early in the course of serious illness
  - Provides a foundation for making decisions in the future
  - Should be reviewed/revised over time



Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share concerns about the future*** · Frame as a "wish...worry", "hope...worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness..." *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

SICG Drill

Patient

SET UP the encounter

CLINICIAN	PATIENT
I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want. **Is this okay**?	I'm doing fine right now. I don't know that we need to have a big conversation.
I do this with all of my patients so that I understand what's most important to them. And, I'm going to use this conversation guide to make sure we don't miss anything. Is that okay?	I guess that would be okay

ASSESS the patient's understanding

CLINICIAN	PATIENT
What is your understanding now of where you are with your illness?	I'm feeling better since I got out of the hospital. But, I do know there is a lot wrong with me – my lungs especially. But, I'm a positive person, and I know I can get through this.
In thinking about the future, how much information about what is likely to be ahead with your illness would you like from me?	I want to know everything you know.

SHARE your concern

CLINICIAN	PATIENT
I want to share with you **my understanding** of where things are with your illness…	Okay…
I hope that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are liking to get more difficult.	Oh, goodness. I wasn't expecting that.
This must be really hard to hear…	It is. My family needs me.

EXPLORE the patient's priorities & values [1/2]

CLINICIAN	PATIENT
What are your most important **goals** if your health situation worsens?	Spending time with family. Also, my daughter is getting married next year, and I really want to be at her wedding.
What are your biggest **fears and worries** about the future with your health?	I'm really worried about suffocating. What can you do to make sure I don't suffocate?
Managing your symptoms is really important for us to talk about. Can we set that aside for right now and come back to it later?	Okay

EXPLORE the patient's priorities & values [2/2]

CLINICIAN	PATIENT
What gives you **strength** as you think about the future with your illness?	My spouse is a great support, and my daughter makes me laugh and keeps my spirits up.
What **abilities** are so critical to your life that you can't imagine living without them?	I want to be here for my family. And I want to feel well enough to be able to do fun things with them, like going out to dinner.
If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?	Well, I'd be willing to have more tests and treatments if they help me feel better. But I don't want to die in the hospital hooked up to a machine.
How much does your **family** know about your priorities and wishes?	I think my spouse knows, but we haven't really talked about it. We probably should do that.

CLOSE the encounter

CLINICIAN	PATIENT
I've heard you say that having quality time with your family and having your symptoms well managed are really important to you. Also, that it's been difficult to talk with your spouse about this. Keeping that in mind, and what we know about your illness, I **recommend** that we meet together with your spouse to think through next steps. This will help us make sure that your treatment plans reflect what's important to you. **How does this plan seem to you?**	I know it is going to be tough, but meeting together would be an important next step.
I will do everything I can to help you through this.	Thank you.
Now maybe we can spend some time talking about how to manage your symptoms.	That would be great.

What did you observe/notice?

- Normalizing
- Asking permission
- Not a time to educate or solve problem
- Bookmarking
- Responding to emotion with empathy
  - NURSES mnemonic (Name it, Understand the core message, Respect/Reassure, Support, Explore, Silence)
- Active listening

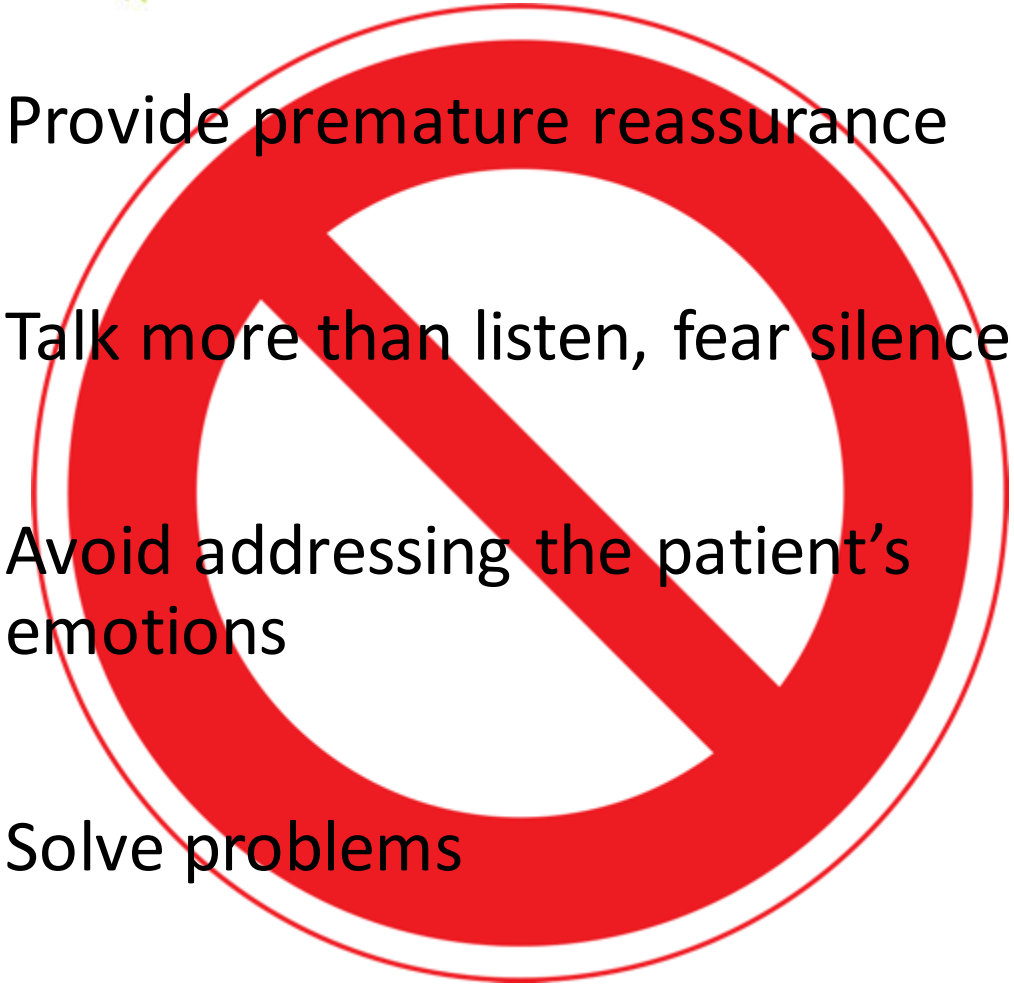
Tips for using the SICG and effective conversation

Provide premature reassurance

Talk more than listen, fear silence

Avoid addressing the patient's emotions

Solve problems



- Talk less, listen more
- Do NOT be afraid of silence, patient needs time to digest
- Address emotions
- No need to solve problems
- TRY THE GUIDE!
- If patient refuses or stops the conversation, that is OK

Role play!

Role play debriefing

How did it go?
Share your experience and thoughts

What went well?

What was challenging?

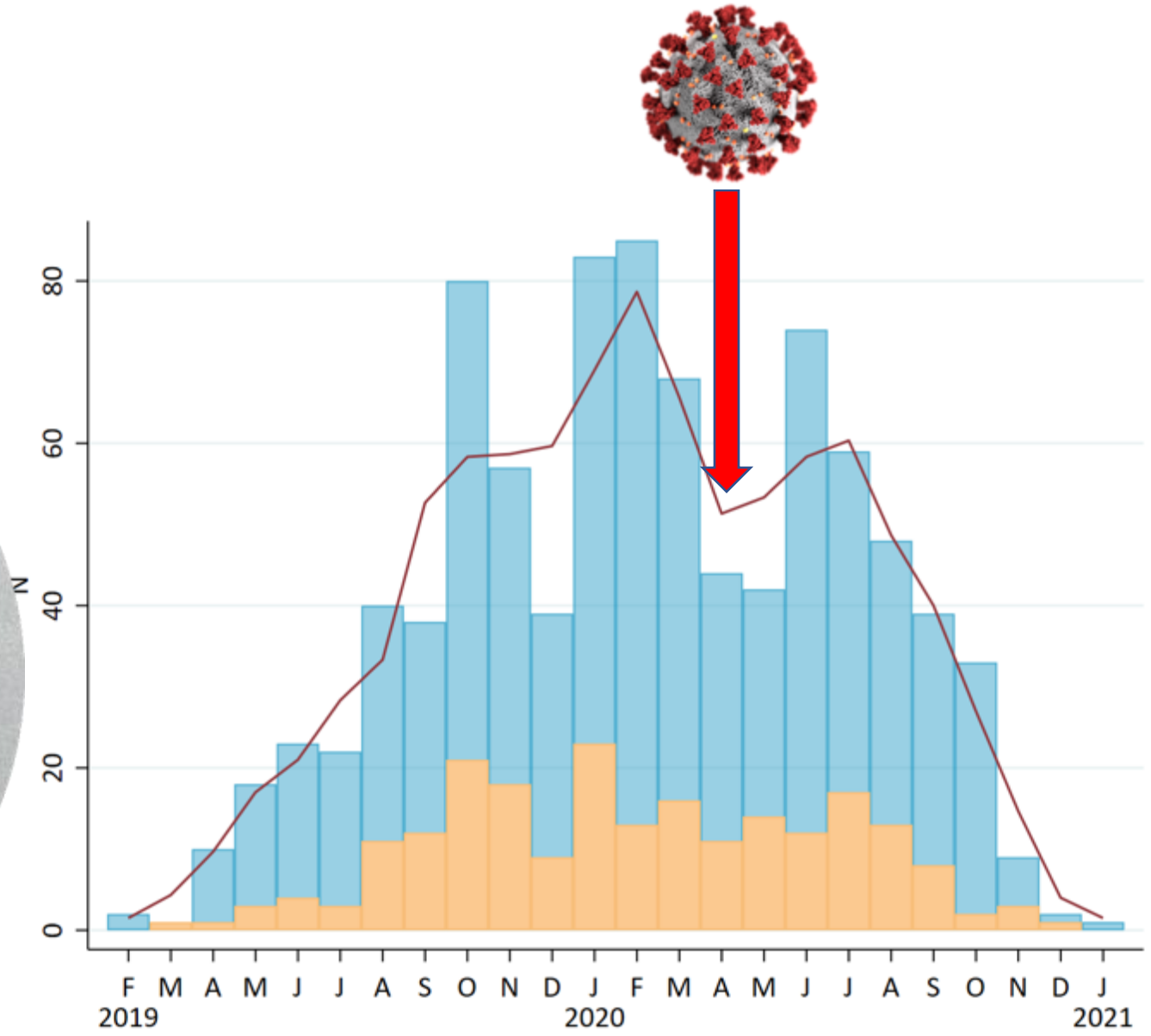
Was there anything that surprised you?

Patient/Family Advisor Experience

"…I just think your model, this model, which I know was iterated and been improved is <u>THE</u> model for patient engagement. And I know it also takes the kind of funding you got from PCORI, at least from the [PFA] point of view. I don't think every research project has the luxury of doing what we are doing right now kind-of-thing. Be that as it may, all of the elements and components that you've built into it, to me, are the model of mutually beneficial, mutually supportive, outcome-oriented patient engagement."

"I don't know, it's funny because I watched people's voices get louder and more comfortable and confident. And I'm heartened by that. And I think that that's an important part of their [PFA] involvement here, that you have a voice."

Recruitment and Data Collection



The case of Dementia: Prognosis and SIC

Mike Putnam Photography

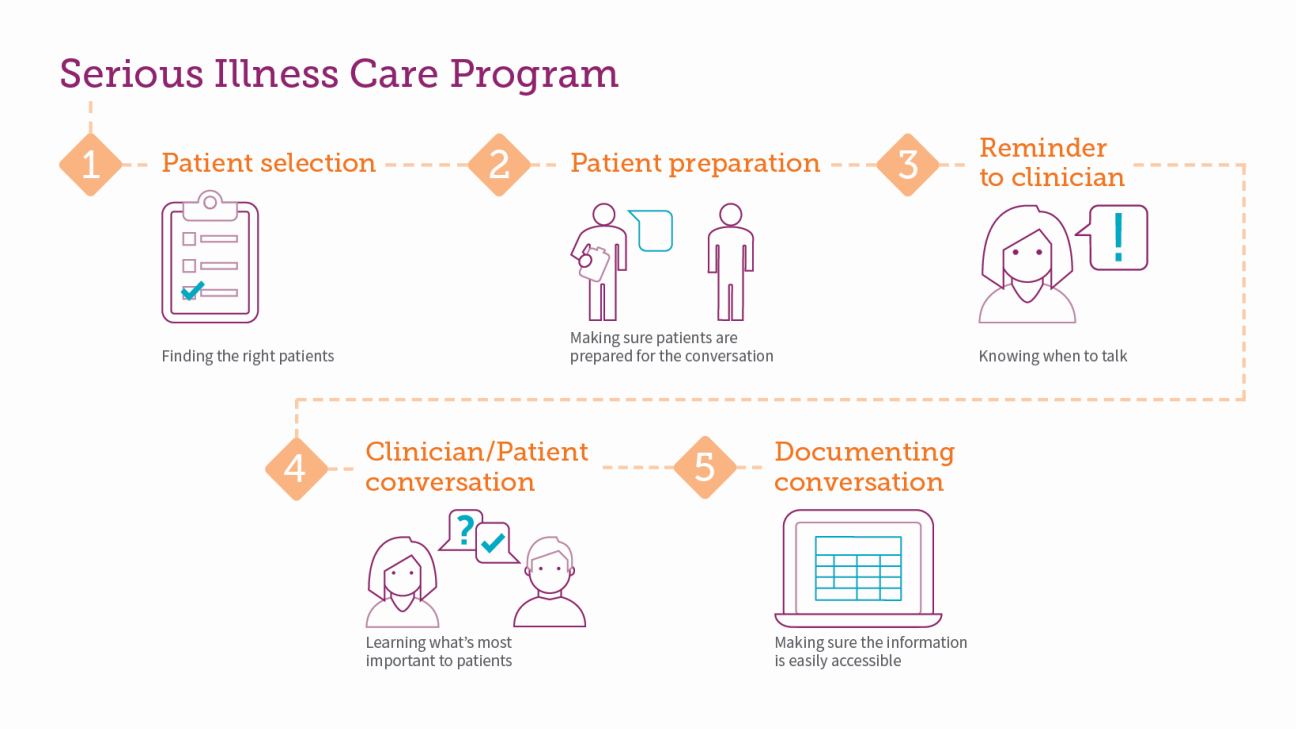
	Alzheimer's	Vascular	Lewy Body	Fronto-temporal
Onset/History	Insidious, presents with depression, delusions, agitation	Abrupt with stepwise decline, Hx of HTN, CAD or vascular disease	Prominent visual hallucinations & fluctuating mental stats	Insidious, personality change & disinhibition
Motor	Late in disease	Balance or hemiparesis	Parkinsonian signs (motor & dementia can present simultaneously)	Can have an apractic gait
Memory	Early; difficulty with new info and retaining	Difficulty with memory retrieval	Can be mildly impaired early	May be normal
Language	Aphasia, decreased verbal fluency	Variable, lesion dependent, most have aphasia	Slowed	Progressive nonfluent aphasia or Progressive fluent aphasia
Visual Spatial	Mild early, progressive	Variable, lesion dependent	Prominent	Preserved
Executive function	Mild early, progressive	Prominent	Impaired	Abnormal judgement (frontal lobe)
Prognosis	10-14 years	5-7 years	5-7 years	3-6 years

Approach to Research: Foundation for Practice

Required

Implementation

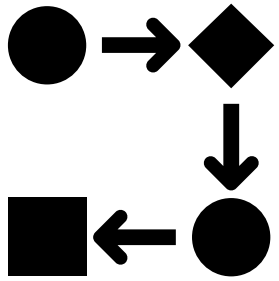
Clinical Workflow Diagram



Discussion Topics:

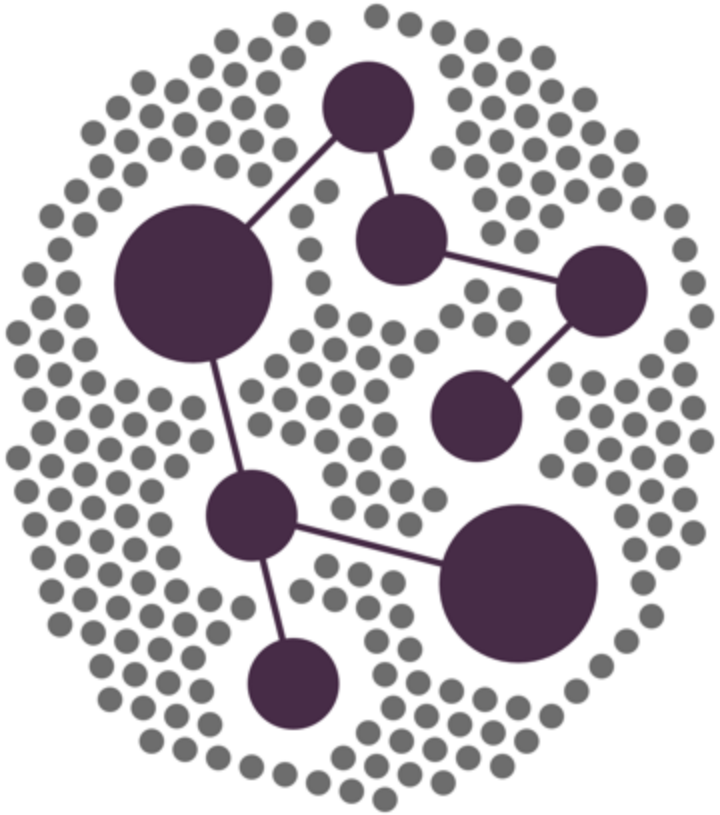
- Consider a range of systematic ways to identify Patients and their families for Serious Illness Conversations

- Think about workflows and preparation
  - What would facilitate ACP conversations in your practice?



Approaches to Identification: Simple to Complex

- Clinician Intuition
  - "Surprise question": Would not be surprised if patient died or lost decisional capacity in the next 2 years.
  - Experience with similar patients
- Assessments
  - In-reach: "Scrubbing" upcoming appointments
  - Outreach: Reviewing lists
    - E.g., All patients over 80, All with specific ICD-10 codes
  - Registries
- Algorithms
  - Few or many variables
  - Equal or decision rules or weighting
  - How will they be repopulated and who is responsible



Preparation: Provider Prospective

Patient & Family

Inviting and Engaging Patients and Families

Challenges

Addressing family dynamics

Step Number	Strategy	Pitfall
Step 1	Notice the conflict	Ignoring the conflict
Step 2	Prepare for the conversation. How will success be defined?	• Believing there is only one truth • Assuming intentions of the other person • Placing blame • Having a fixed agenda
Step 3	Find an unbiased starting point Acknowledge the importance of the issue Invite each perspective	• Sharing one's own perspective before hearing everyone else's point of view • Dominating the conversation
Step 4	Listen, acknowledge, and empathize	Preparing counterarguments
Step 5	Reframe the conflict as a shared interest	
Step 6	Describe the potential options	Providing too many options (limit to no more than 3)
Step 7	Summarize and Strategize	Failure to recognize that not all negotiations end in conflict resolution

A Step-Wise Approach To Dealing With Conflict

You are on your way

- You know how to identify patients for ACP conversations
- You have a plan for the conversations
- Maybe you've begun some conversations

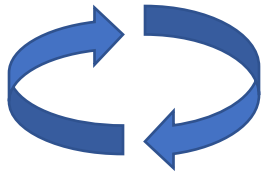
- **Getting Farther Down the Road**
- Documentation of patient wishes need to travel with them over time, and be used by clinicians across health care settings.

Lamas et al, JPM 2018

Next Steps

Updating – ACP is an evolving process

- Patient understandings and perspectives and preferences change over time



- Review periodically
  - Post hospitalization
  - With change in function
  - Annually
  - With change in family situation
  - Annual Wellness visits

- Problem-based charting enables update

- Some EHR now have ACP tabs, enabling direct documentation

Retrieving and Sharing ACP

- Use problem based charting or ACP template if supported by your EHR
- Keep copies of Advance Directives scanned in one place – train staff on where these go, coordinate with your hospital medical records, label them appropriately
- Patients keep originals – encourage snap with smartphone and share snap with MDPOA

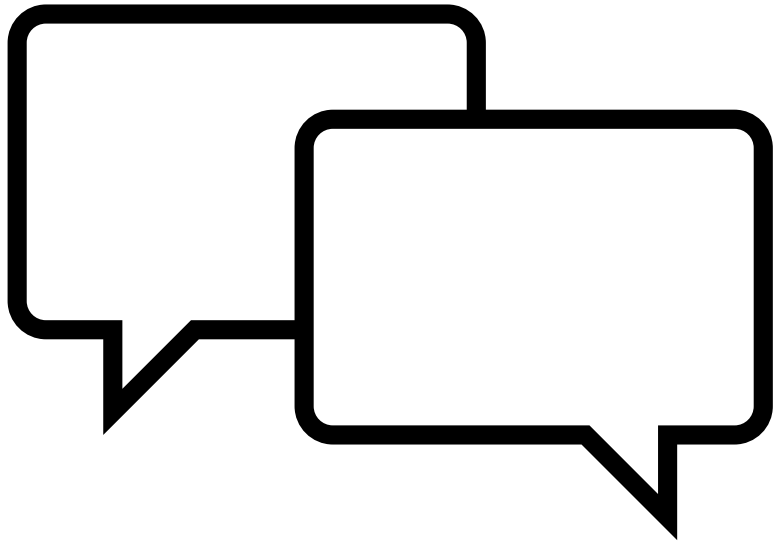
Quick Recap

- Topics:
- Communications
  - Structure: Serious Illness Conversation (SIC) Guide
  - Considerations for People Living with Dementia
  - Family Dynamics
- Implementation
  - Identifying Patients
  - Initiating Conversations
  - Documentation
  - Follow-up

- Key Elements of ACP for PLWD
- Surrogate Decision Maker
  - Identify
  - Encourage discussions
  - Reconfirm selection/availability over time
- Eliciting Values, Preferences and Goals
- Family/Care Partner Involvement
- Adaptive Planning/Follow-up
  - Adjusting as cognitive abilities change

Suggestions: Communications

- Include patients in conversations
- Focus on Process, not Forms
- Normalize ACP— “We ask all our patients….”
- As early as possible
- Adjust questions, content and format, to the level of dementia and personal needs
- Core skills apply: empathy, active listening, attention to non-verbal behavior



Suggestions: Implementation

- Key: Workflow that works for your practice
- Identification Approaches
  - EHR ICD codes
- Invitation and Initiation
  - Materials available for patients and families—many can be customized for your practice
- Documentation
- Billing
- Follow-up

Strategies that can help with implementation and sustainment

Team Approach as Strategy

WHO?

WHAT?

HOW?

Consider Role and Experience/Expertise

Team Development Approaches

- Specific Training (PrimaryCareACP.org and www.ariadnelabs.org)
  - Videos
  - Team role play
  - Establish pairs/buddies for people new to ACP
  - Check-ins and Booster Training
- Identify points of pain and discomfort
  - Frame activities to correspond to scope of work and experience
    - Example: Importance of ACP. "Our entire teams wants to know what is important to you"
    - Example: Not 'Prognosis', but "what I have seen in similar patients" or what might happened
    - Reassure: the team will provide back-up and clinical expertise as needed
- Identify similar experiences
  - with POLST/MOST
  - with Shared Decision Making

Additional Strategies

Group Visits

Questions/Discussion

Who in your team can take on elements of ACP?

What activities (identification, initiation, etc.) can be shared?

How can sharing the tasks fit with your practice workflow?

Study Results: Potential Explanations and Limitations

May need more time for ACP to have an impact

Conclusions

IMPLEMENTATION IS POSSIBLE, EVEN IN PANDEMIC

BUSY, UNDER RESOURCED PRIMARY CARE CAN ADAPT EITHER MODEL TO THEIR ENVIRONMENT

POSITIVE PATIENT OUTCOMES; NO INDICATION OF NEGATIVE IMPACT ON RELATIONSHIPS WITH PATIENTS

Some Key Points

- Success requires dedication
  - And staff/money
- Ask for (or hire) help
- Plan for challenges and change (and pandemics)
- Need to be humble-admit when things don't work and change course
- Share more, share often

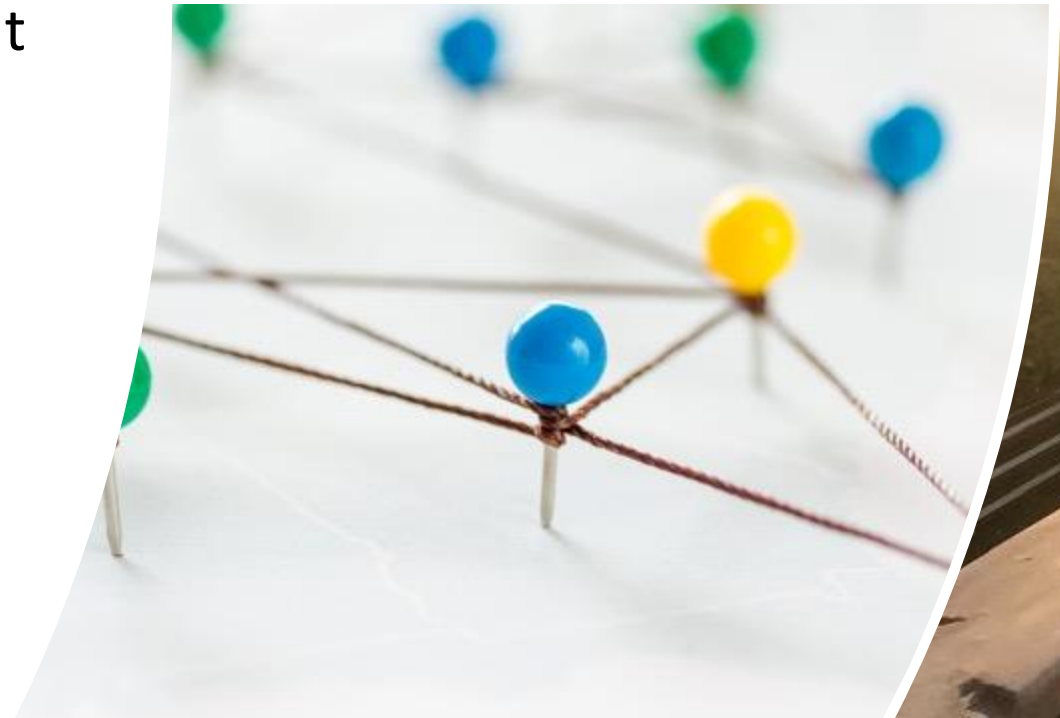
Random Thoughts

- Innovation in Engagement
  - Focus on challenging phases:
    - Early planning (? Panels)
    - Analysis/Academic Dissemination
- Who are we missing?
  - Diversity, Equity and Inclusion
- Making Engagement
  - Routine
  - Best Practice
  - Adaptive

Questions?

Comments?

- MANY Lessons learned
- Connections made
- Have seen the light



“…having a conversation on values – what matters to you, not what’s the matter with you.”

-The Conversation Project

Thank you!

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PrimaryCareACP.org

GOBHI

CAMBIA health foundation

Columbia Pacific CCO™
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AGE+ Communities + Generations + Innovations

OSHER LIFELONG LEARNING INSTITUTE
At the University of Oregon

Ariadne Labs ariadnelabs.org

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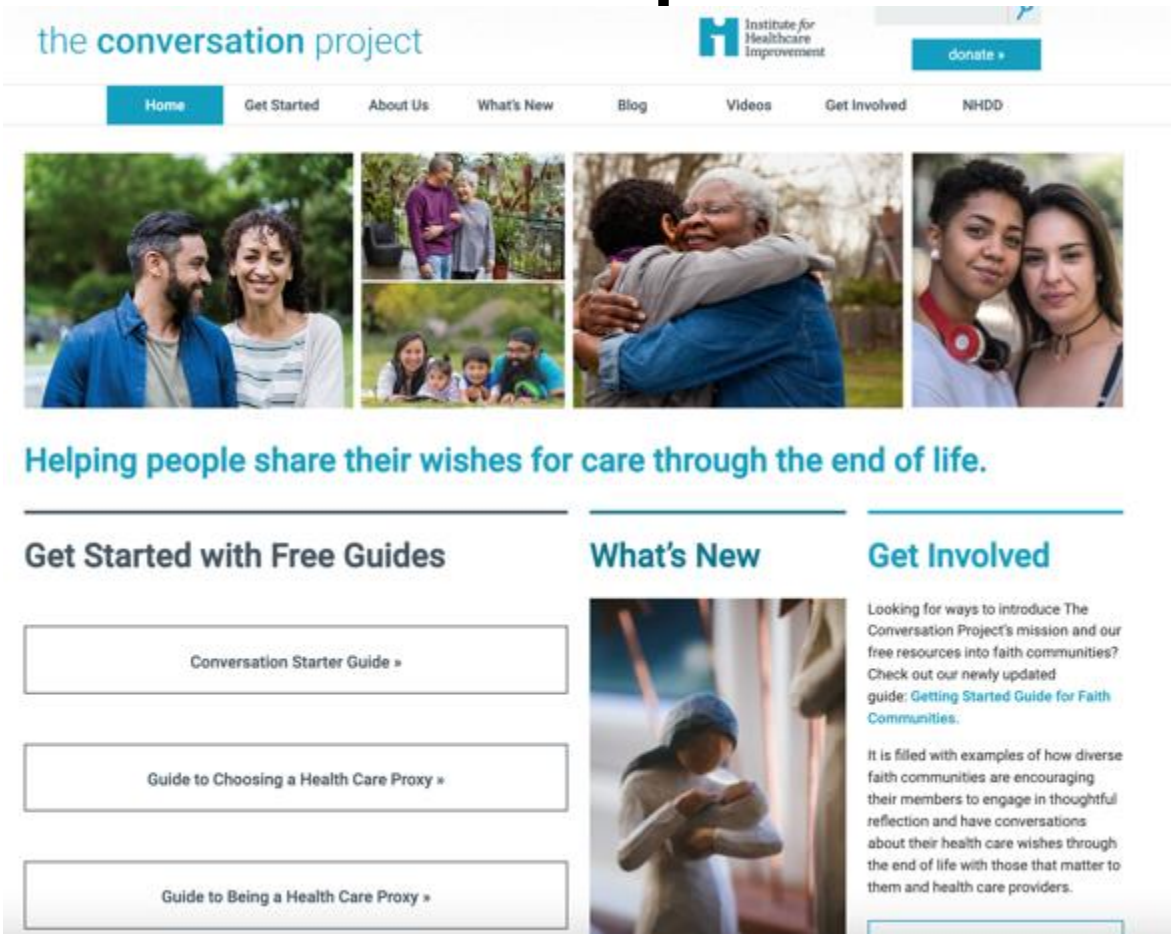
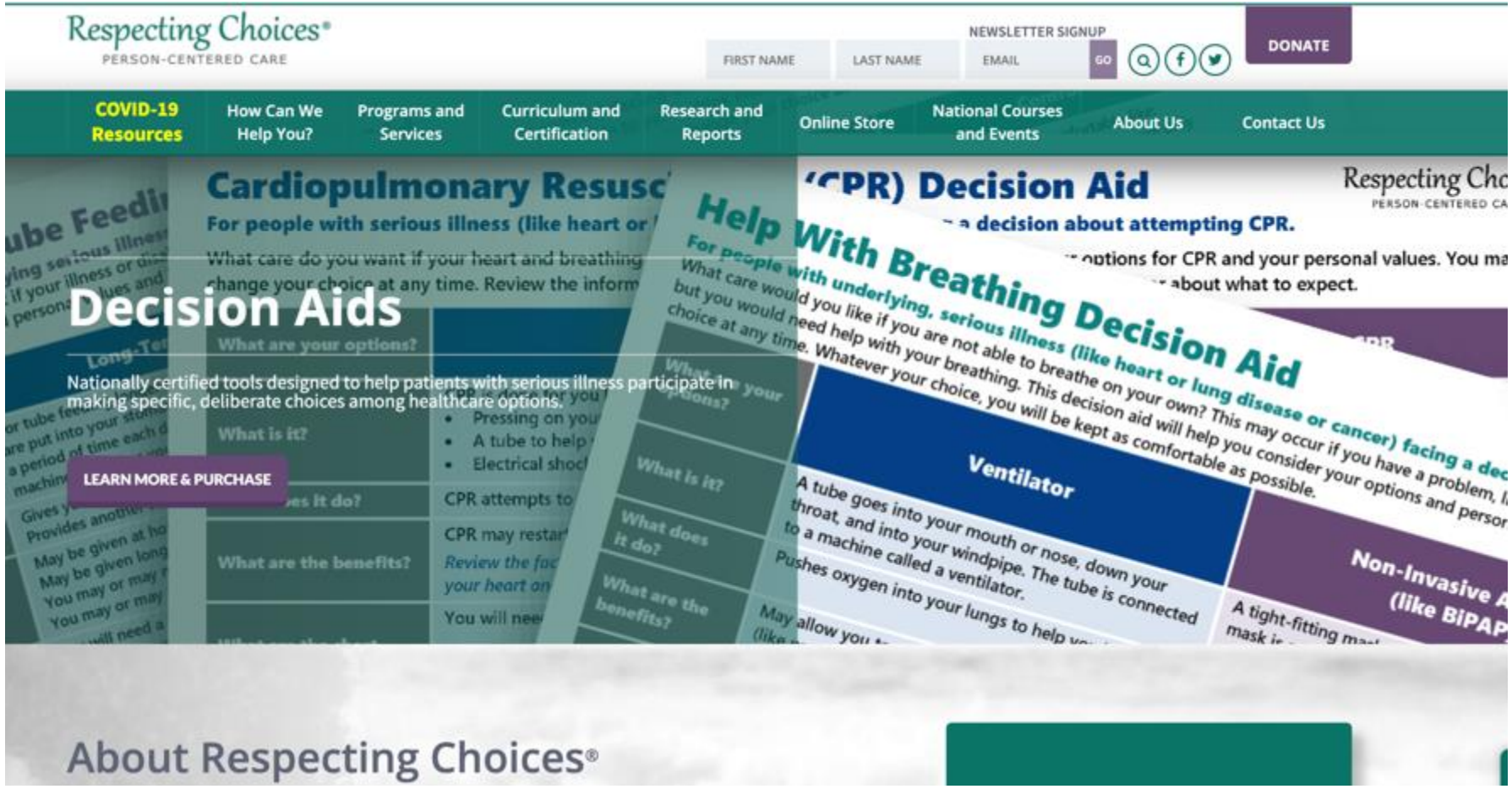
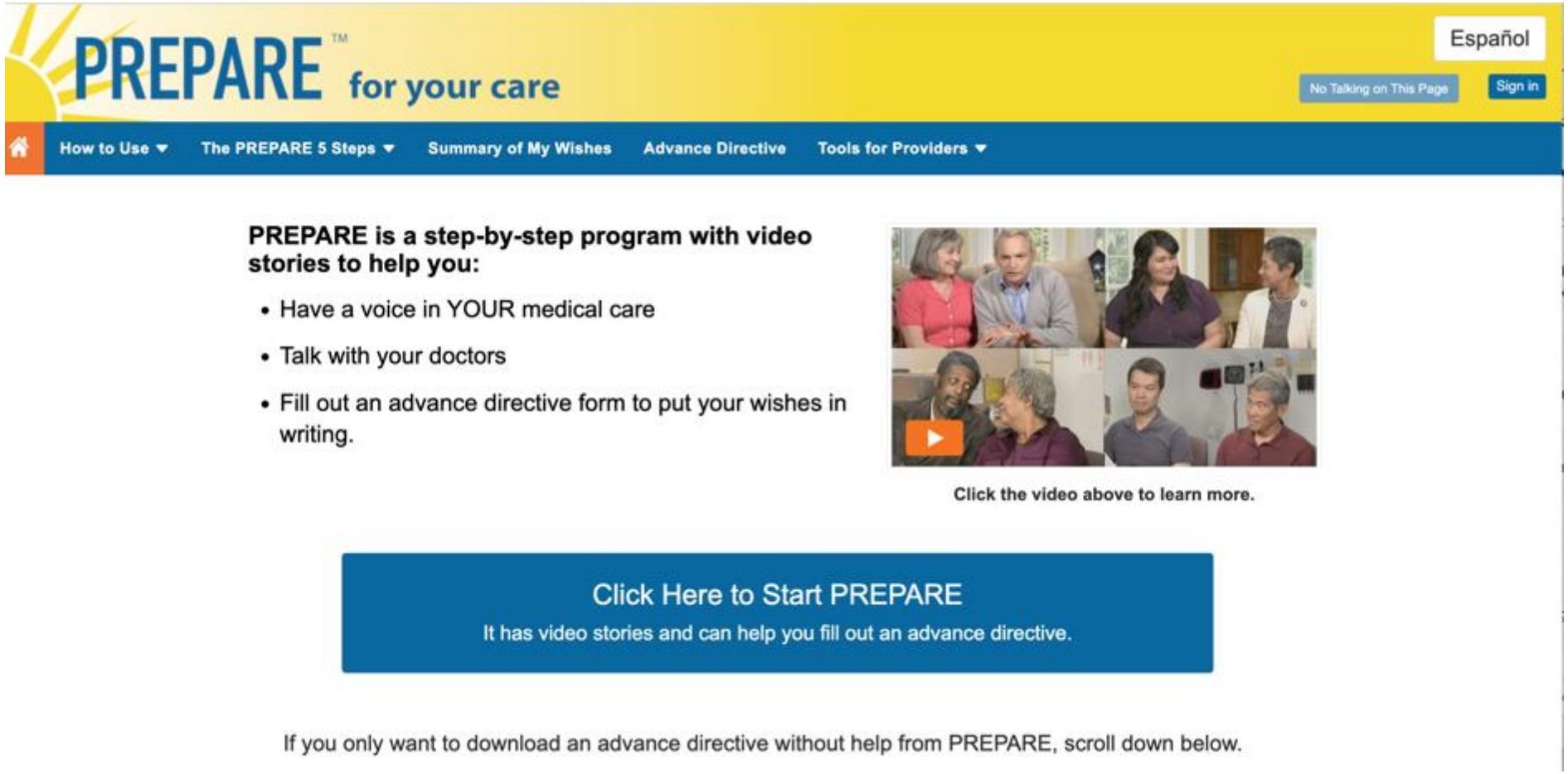


https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf

Respecting Choices
respectingchoices.org



Prepare for your care
prepareforyourcare.org



Five Wishes

www.fivewishes.org/for-myself/