Institute *for* Healthcare Improvement

The Conversation Project

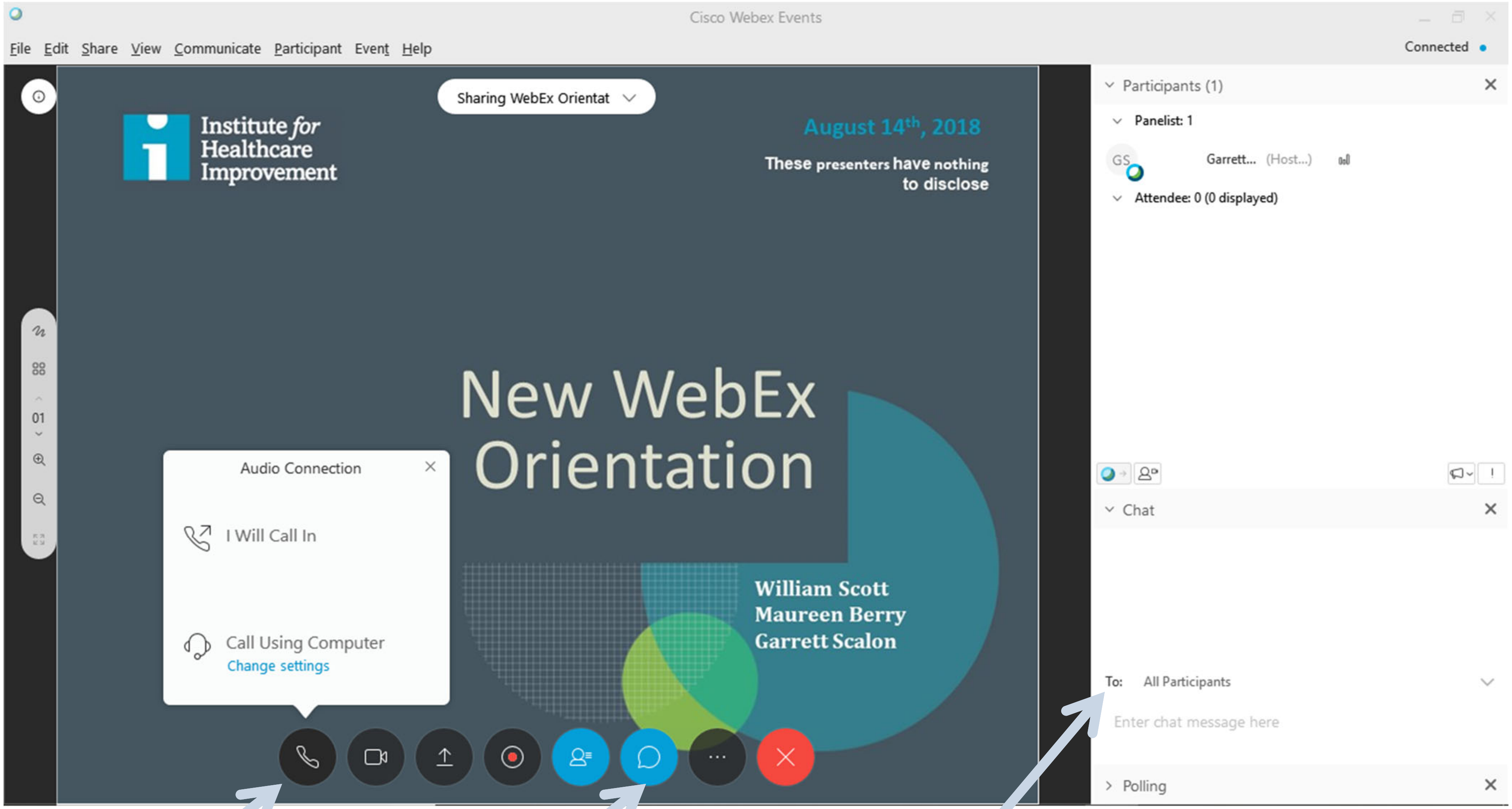
New Resources and Updates at TCP to Help Support "What Matters to Me" Conversations

September 16, 2020

Dr. Erik Fromme
Kate DeBartolo

the **conversation** project

WebEx Reference



Institute *for* Healthcare Improvement

August 14th, 2018

These presenters have nothing to disclose

New WebEx Orientation

William Scott
Maureen Berry
Garrett Scalon

Audio settings

Open chat

Chat to "All Participants"

ation pr

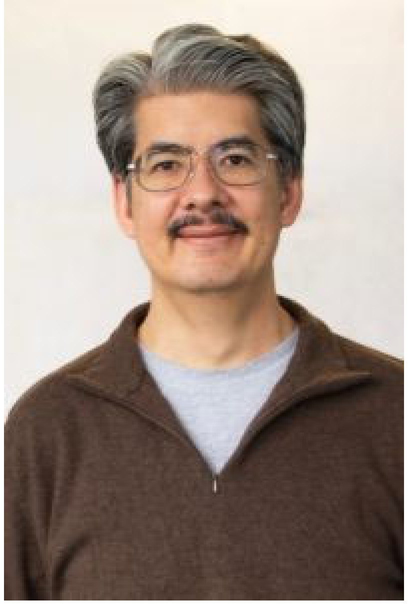
Intros/Chat Warm Up

Type into the chat box:

Your location, organization and type of organization?
(faith-based, healthcare, community, government, individual volunteer, etc.)

Make sure you send your message to
"All Participants."

On Today's Call



Kate DeBartolo
Senior Project Director

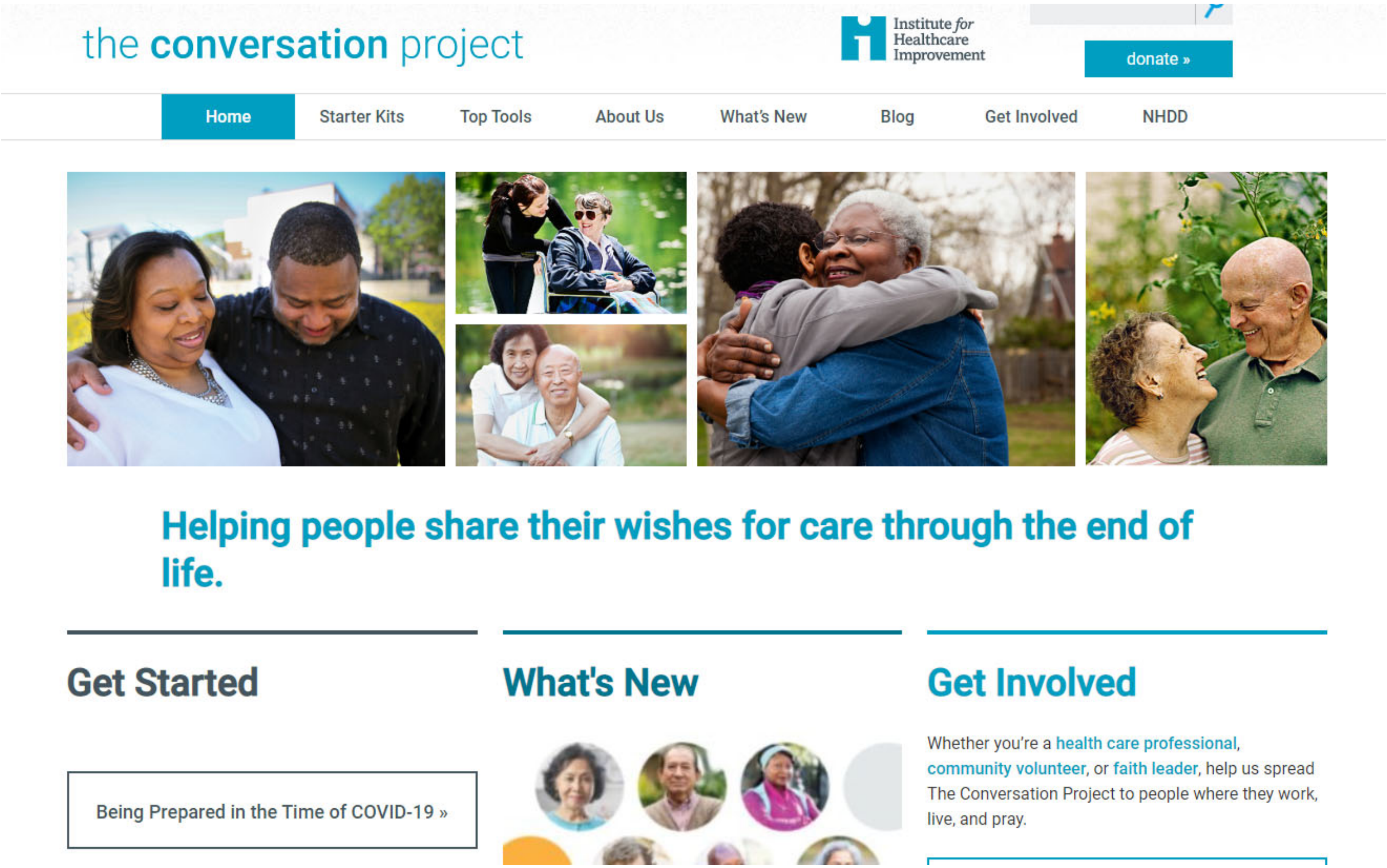
Krissy Cronin
Project Coordinator

Dr. Erik Fromme
Ariadne Labs

Agenda

- Updates from TCP
- Introduction of our new patient guide to serious illness conversations with Ariadne Labs
- Time for Q&A

New at TCP



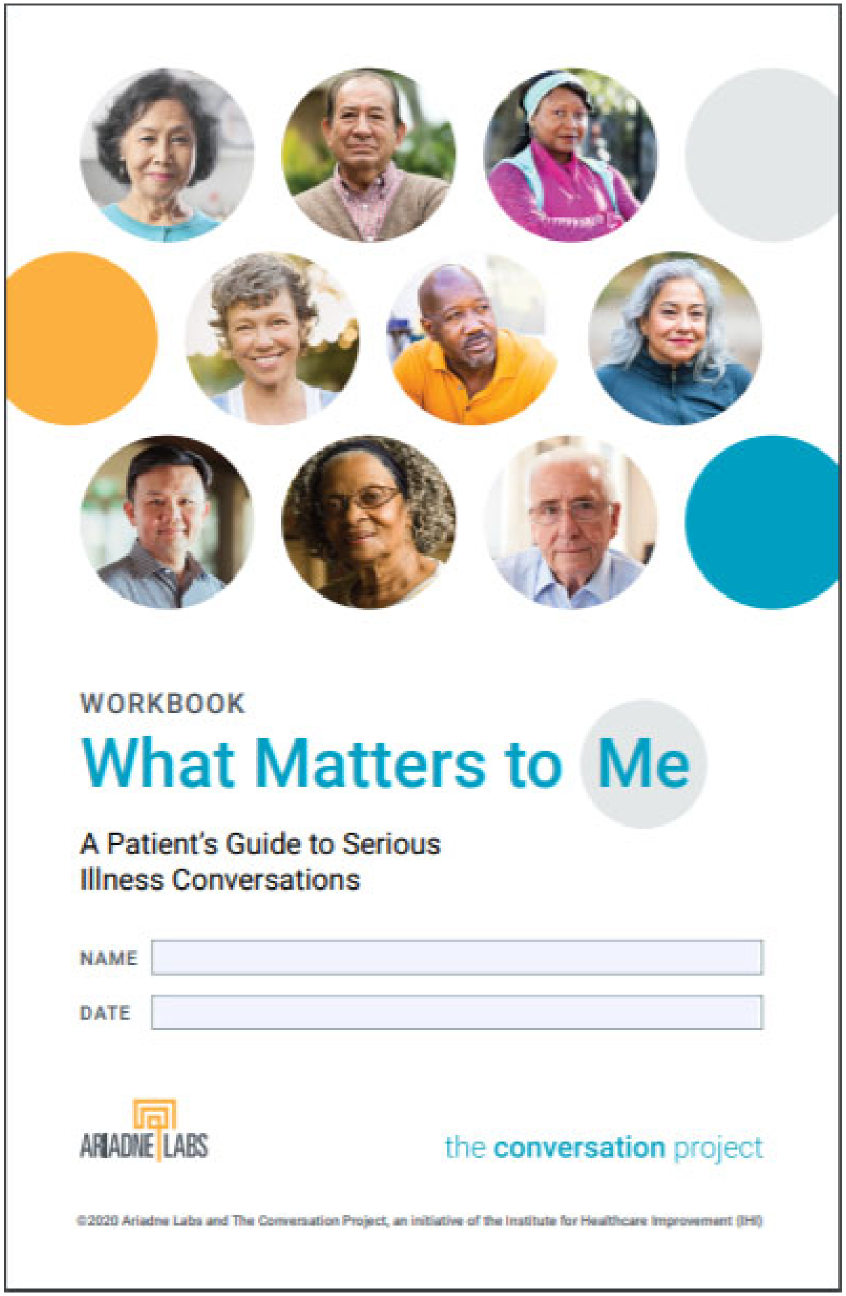
Helping people share their wishes for care through the end of life.

Get Started

What's New

Get Involved

Whether you're a health care professional, community volunteer, or faith leader, help us spread The Conversation Project to people where they work, live, and pray.



WORKBOOK

What Matters to Me

A Patient's Guide to Serious
Illness Conversations

NAME

DATE

ARIADNE LABS

the **conversation** project

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My Health

What is your understanding of your current health situation?

How much information about what might be ahead with your illness would you like from your health care team?

About Me

MY GOOD DAYS • What does a good day look like for you?

Here are some things I like to do on a good day:

EXAMPLES

Have coffee with a friend • Sit in the garden • Go for a walk • Play the piano

MY HARD DAYS • What does a hard day look like for you?

These are the toughest things for me to deal with on a hard day:

EXAMPLES

Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

MY GOALS • What are your most important goals if your health situation worsens?

These are some things I would like to be able to do in the future:

EXAMPLES

Take my dog for a walk • Attend my son's wedding next September • Go to church services • Talk to my grandchildren when they come to visit

My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.

Note: These scales represent a range of feelings; there are no right or wrong answers.

As a patient, I'd like to know...

○ ○ ○ ○ ○

Only the basics about my condition and my treatment — All the details about my condition and my treatment

When there is a medical decision to be made, I would like...

○ ○ ○ ○ ○

My health care team to do what they think is best — To have a say in every decision

What are your concerns about medical treatments?

○ ○ ○ ○ ○

I worry that I won't get enough care — I worry that I'll get too much care

How much medical treatment are you willing to go through for the possibility of gaining more time?

○ ○ ○ ○ ○

Nothing: I don't want to go through any more medical treatments — Everything: I want to try any medical treatments possible

If your health situation worsens, where do you want to be?

○ ○ ○ ○ ○

I strongly prefer to be in a health care facility (hospital, rehab, or nursing facility) — I strongly prefer to be at home

When it comes to sharing information about my illness with others...

○ ○ ○ ○ ○

I don't want those close to me to know all the details about my illness — I am comfortable with those close to me knowing all the details about my illness

MY FEARS AND WORRIES • What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

EXAMPLES

I don't want to become dependent • I don't want to be in pain • I don't want other people to see me in pain • I don't want to be a burden on my loved ones • I'm worried that I won't be able to get the care I want • I don't want to get stuck in a facility where no one will visit me

MY STRENGTH • As you think about the future with your illness, what gives you strength?

These are my main sources of strength in difficult times:

EXAMPLES

My friends • My family • My faith • My garden • Myself ("I just do it")

MY ABILITIES • What abilities are so critical to your life that you can't imagine living without them?

I want to keep going as long as I can...

EXAMPLES

As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious

If I become sicker, which matters more to me: Pursuing the possibility of a longer life, or pursuing the possibility of a good quality of life?

MY WISHES AND PREFERENCES • What wishes and preferences do you have for your care?

If my health situation worsens, here's what I want to make sure DOES happen:

EXAMPLES
I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes when I say I want to switch to comfort care only

And here's what I want to make sure DOES NOT happen:

EXAMPLES
I don't want to become a burden on my family • I don't want to be alone • I don't want to end up in the ICU on a lot of machines • I don't want to be in pain

What else do you want to make sure your family, friends, and clinicians know about you and your wishes and preferences for care if you get sicker?

My People

Are there key people (family, friends, others) who will be involved in your care going forward?

Who would you want to make medical decisions on your behalf if you're not able to? This person is often called your health care proxy, agent, or surrogate.

Name, contact info, relationship to me

○ Yes ○ No **I have talked with this person about what matters most to me.**
○ Yes ○ No **I have filled out an official form naming this person as my health care proxy.**
○ Yes ○ No **I have checked to make sure my health care team has a copy of the official proxy form.**

Who are the main people who will be involved in your care (family members, friends, faith leaders)? For each person you list, be sure to include their phone number and relationship to you.

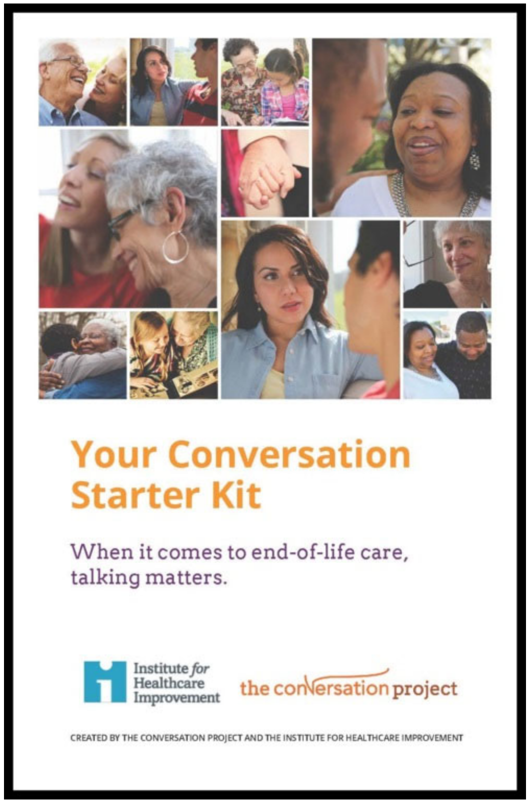
How much do they know about your wishes and preferences? What role do you want them to have in decision-making? When might you be able to talk to them about your wishes?

My Health Care Team

Who are the key clinicians involved in your care?

My primary care provider	*Name*	*Phone number*
My social worker	*Name*	*Phone number*
My main specialist	*Name*	*Phone number*
Other	*Name*	*Phone number*

Two Approaches to Advance Care Planning



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

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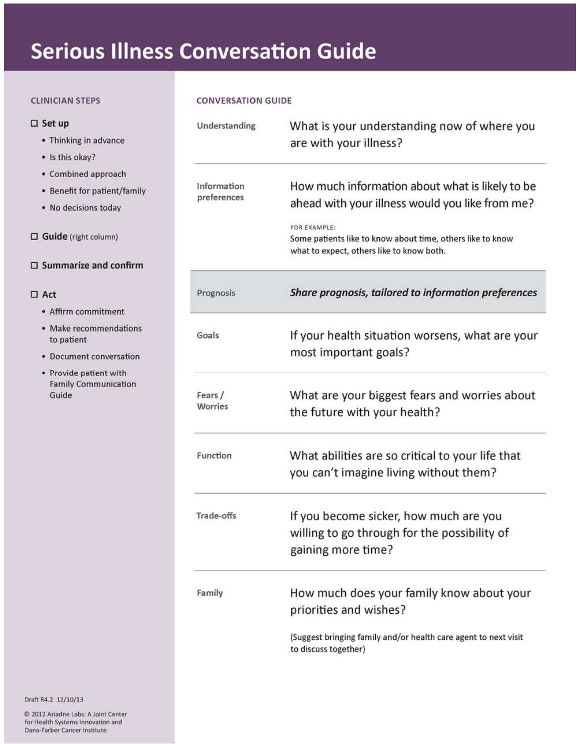
CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT



Serious Illness Conversation Guide

CLINICIAN STEPS

☐ **Set up**
  - Thinking in advance
  - Is this okay?
  - Combined approach
  - Benefit for patient/family
  - No decisions today

☐ **Guide** (right column)

☐ **Summarize and confirm**

☐ **Act**
  - Affirm commitment
  - Make recommendations to patient
  - Document conversation
  - Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.
Prognosis	***Share prognosis, tailored to information preferences***
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes? (Suggest bringing family and/or health care agent to next visit to discuss together)

Draft R4.2 12/10/13

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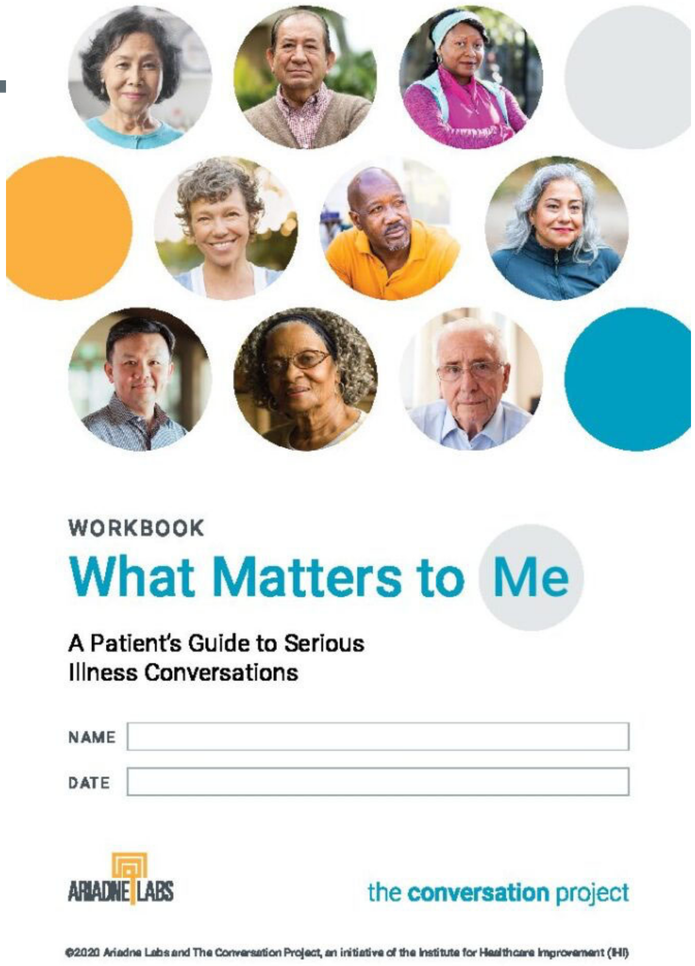
Two Approaches to Advance Care Planning

- The Conversation Starter Kit
  - For any adult
  - To plan for and talk about end-of-life wishes
  - No experts needed

- The Serious Illness Conversation Guide
  - For seriously ill
  - To discuss values and goals if health situation worsens
  - Initiated by clinician

The What Matters to Me Workbook

- To help **seriously ill patients** and their important people prepare to talk to clinicians
  - Follows the questions and order of the Serious Illness Conv Guide
  - Uses simple language and structure similar to The Conversation Starter Kit



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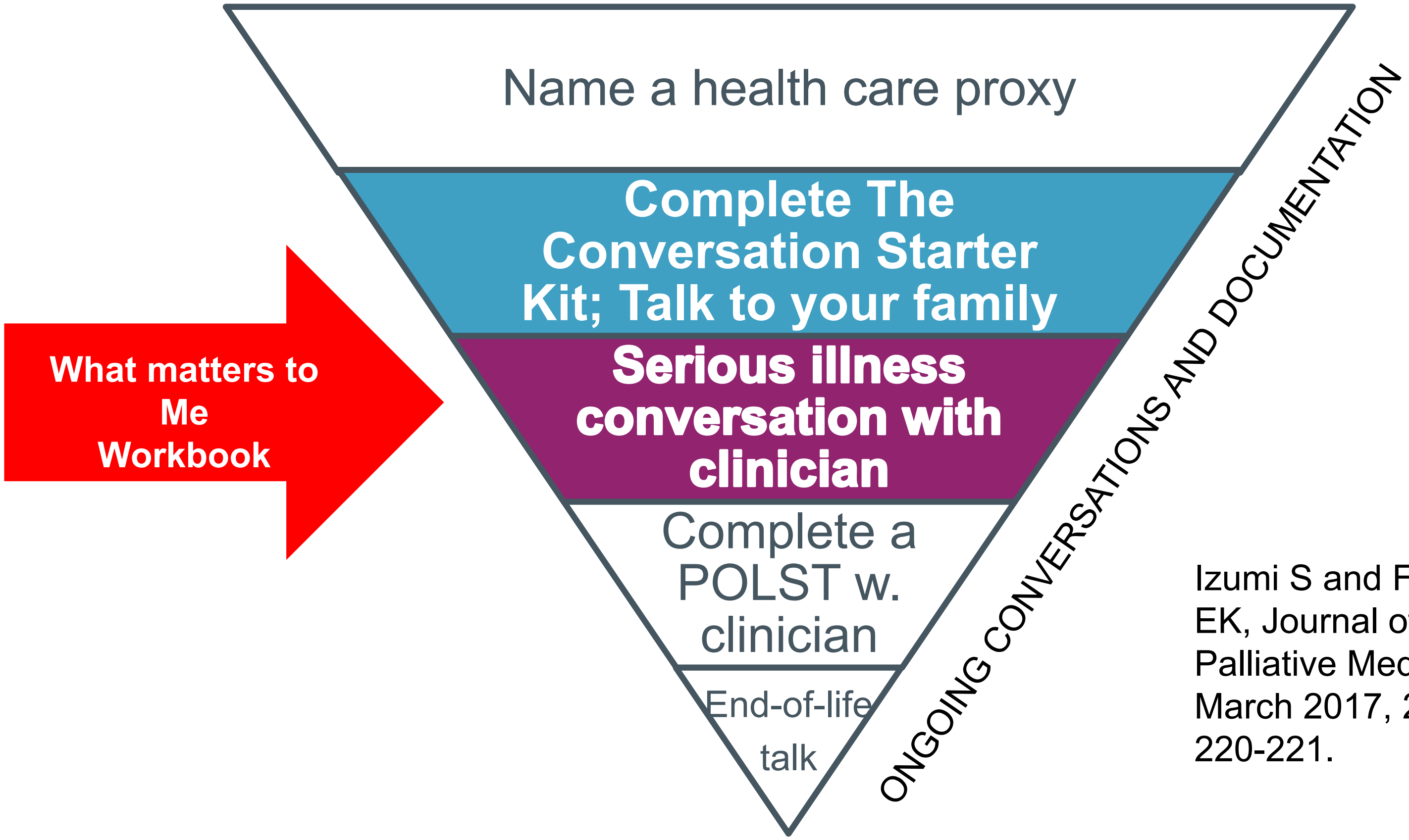


Name a health care proxy

Complete The Conversation Starter Kit; Talk to your family

Serious illness conversation with clinician

Complete a POLST w. clinician

End-of-life talk

ONGOING CONVERSATIONS AND DOCUMENTATION

What matters to Me Workbook

Izumi S and Fromme EK, Journal of Palliative Medicine. March 2017, 20(3): 220-221.

Potential Use Cases

- Daughter downloads Workbook to complete with elderly mother, then brings to doctor's appointment
  - Connects to "How to talk to your doctor"
- Clinician at health system that has implemented the Serious Illness Care Program gives the Workbook to a patient to complete and bring back next visit so they can discuss
- Others…what do you think?

Evaluation

- Using in-depth interviews and surveys of people (patients and caregiver dyads)
- Will ask them to actually complete the guide
- Trying to get as diverse a sample as we can – race, ethnicity, LGBTQ, disabled, etc.
- 4 questions: Utility, safety, acceptability, usefulness.

Interested in Being in the Research Study?

- ✓ If you have a serious illness, or
- ✓ If you are a friend or family member of someone with serious illness who would like to participate.
- ✓ 3 steps:
  1) Complete the Workbook
  2) Talk about it with someone (patient, family, clinician)
  3) Participate in an interview by phone or Zoom (~1 hour) and complete a questionnaire

To join – complete survey at the end of this call or reach out to Kate DeBartolo at kdebartolo@ihi.org

Q&A

- What do you think of the new workbook?
- How might you use this? (personally/professionally)
- Thoughts on getting the word out – who might be interested?

Ways to Engage with TCP’s Network

- Tweet us, tag us on social media
  - Twitter: @convoproject
  - Facebook: The Conversation Project
  - Instagram: convoproject

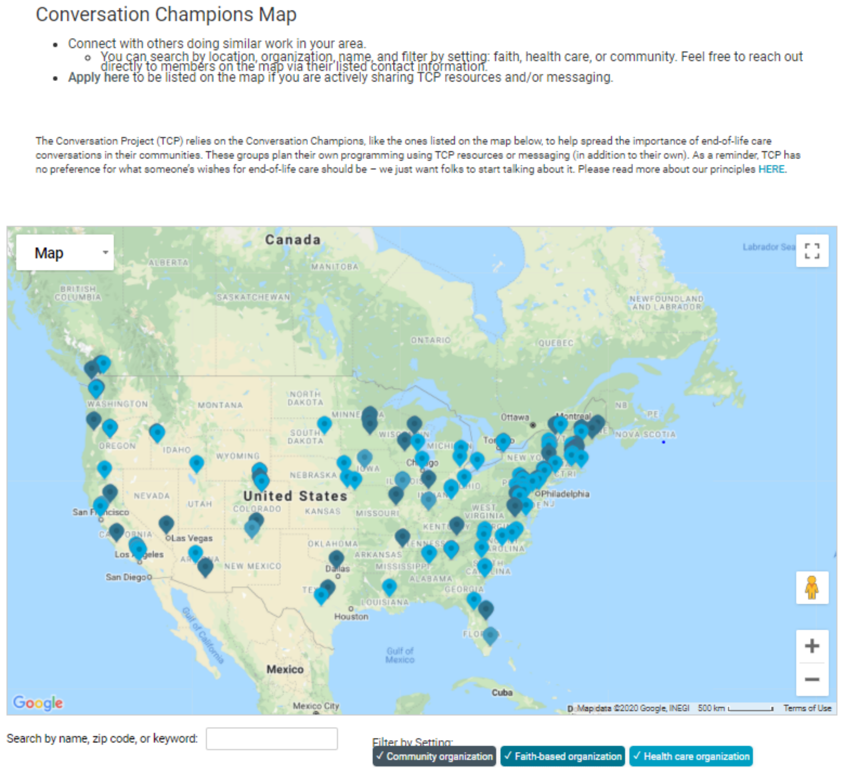
Ways to Engage with TCP’s Network

- Facebook discussion group

https://bit.ly/2ukc7B0

Ways to Engage with TCP’s Network

- Search, connect/network and learn together



Conversation Champions Map

- Connect with others doing similar work in your area.
  - You can search by location, organization, name, and filter by setting: faith, health care, or community. Feel free to reach out directly to members on the map via their listed contact information.
- **Apply here** to be listed on the map if you are actively sharing TCP resources and/or messaging.

The Conversation Project (TCP) relies on the Conversation Champions, like the ones listed on the map below, to help spread the importance of end-of-life care conversations in their communities. These groups plan their own programming using TCP resources or messaging (in addition to their own). As a reminder, TCP has no preference for what someone’s wishes for end-of-life care should be – we just want folks to start talking about it. Please read more about our principles HERE.

Search by name, zip code, or keyword:

Filter by Setting:
✓ Community organization
✓ Faith-based organization
✓ Health care organization

Add your pin!

https://theconversationproject.org/get-involved

Ways to Engage with TCP's Network

- Monthly Newsletters
  - General Newsletter
  - Community Engagement Newsletter
- Sign up and share your events

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New Resource! Workbook: What Matters to Me

The "What Matters to Me" Workbook was jointly created by Ariadne Labs and The Conversation Project **to help people with a serious illness think through and talk about what matters most to them** – to make sure they get the care they want.

https://theconversationproject.org/get-involved

Next Community Call: October

Reaching and harnessing the power of students

Stay tuned for date/time!

https://theconversationproject.org/get-involved

Thanks and Appreciation

The John A. Hartford Foundation

Dedicated to Improving the Care of Older Adults

CAMBIA™

health foundation

Additional Feedback?

- After this call you will be redirected to a survey form

Please take a few moments to answer if you have further feedback that you didn't get to share today