

The Conversation Project: Ensuring Equity and Reaching Diverse Communities

November 14, 2018



**Patty Webster
Naomi Fedna**

WebEx Quick Reference

Welcome to today's session!

Please use Chat to "All Participants" for questions

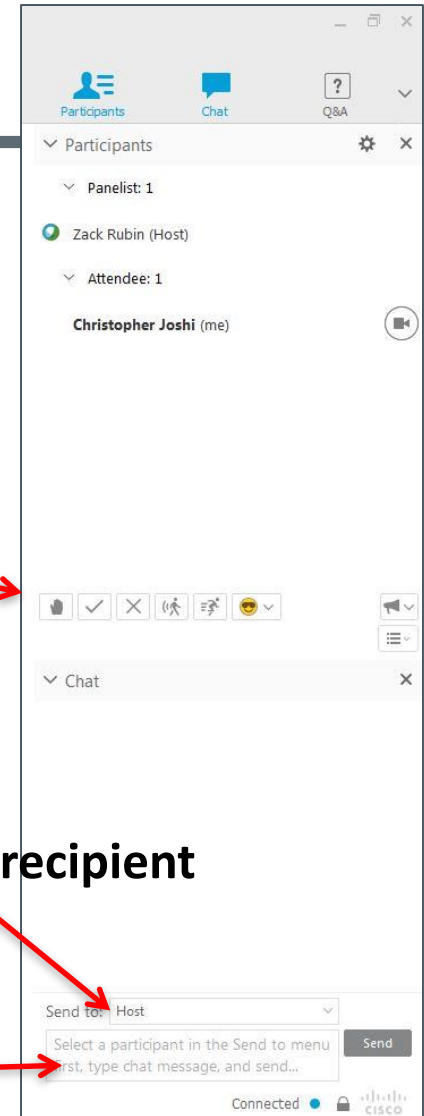
For technology issues only, please Chat to "Host" **Raise your hand**

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)

Enter Text

Select Chat recipient



Ice Breaker Question

Type into the chat box your response to the following question:

How did you learn about this call?

Make sure you send your message to “All Participants.”

Chat warm up

- Are you a Conversation Project (TCP) community member, new to TCP but already involved in advance care planning/end-of-life care work, new to both (working in another area)?
- What kind of work are you doing to promote end-of-life conversations?

Session agenda and objectives

- Background & framing
- Community Panel: Lessons learned
- Q&A with Panelists
- Discussion: *All teach, all learn*
- Additional resources, calls and events

Initial reflections - Chat

What brought you to this call?

- General learning? A burning question(s) you want to explore? Challenges you want to discuss? Successes you want to share?

What experience do you have with reaching diverse communities and ensuring equity in work to promote end-of-life conversations or ACP in general?

- Newbie, Seasoned, Somewhere in Between?



A public engagement campaign dedicated to assure
that everyone's wishes for end-of-life care are
expressed and respected.

the conversation project

the conversation project

What
Matters TO
Me?

As Well As

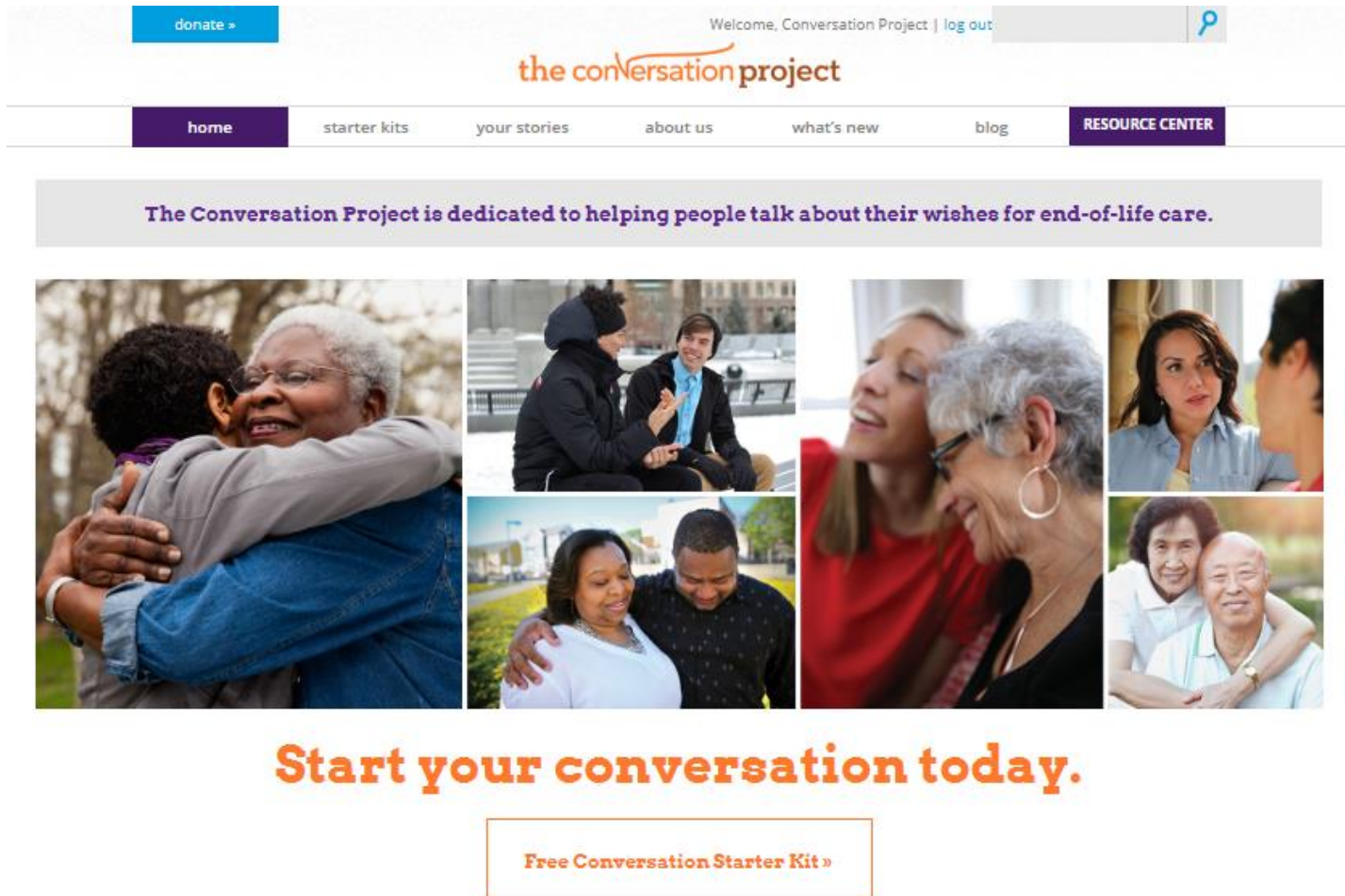
What's the
Matter with
Me?

Public Awareness Community
Engagement

Health Systems Transformation

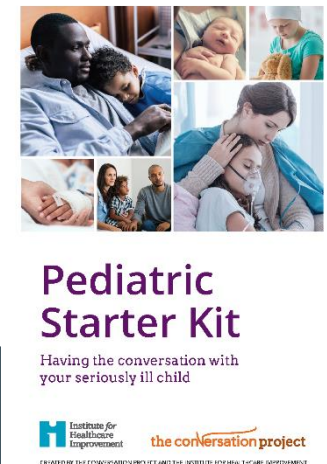
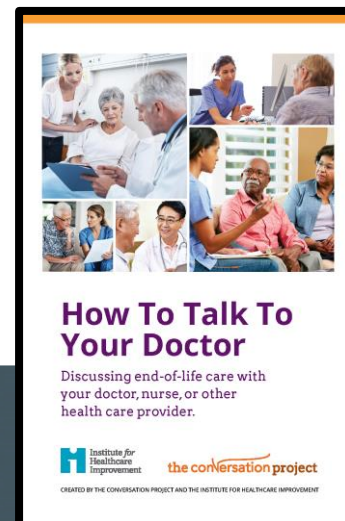
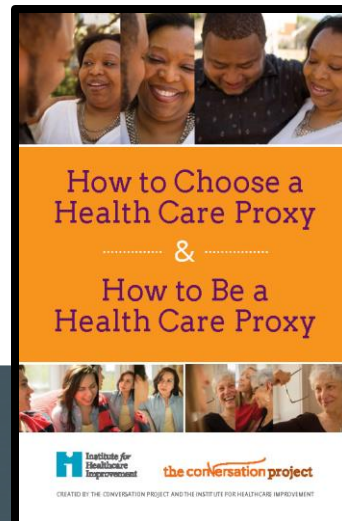
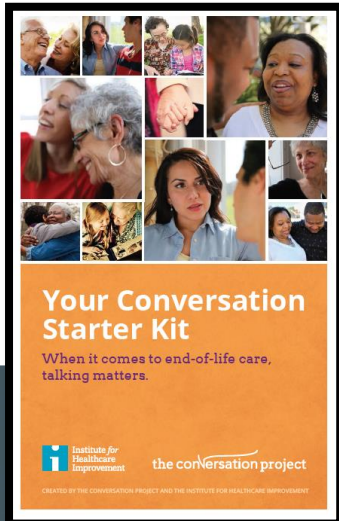


Our Website



Our Tools (multiple language translations)

- Conversation Starter Kit
- Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia
- How to Choose/Be a Health Care Proxy
- How to Talk to Your Doctor Starter Kit
- Pediatric Starter Kit for Parents of Seriously Ill Children



Community Efforts



Recap: Getting Started Questions

- Who do you want to reach? And by when?
- What do you want to support them to accomplish?
- How do you want to reach them?
- What is the context of this topic for population you're trying to reach?
- Who else is already doing this work in your community? Who else could you be working with?
- Who are respected leaders or organizations that could help you advocate for the importance of this work?
- Who will be responsible for actually doing this work in your community?
- How will you measure successes and challenges?
- **How do you plan to reach diverse groups of people in your community?**

Equity Issue

Individuals with incomes of less than \$40,000/year are **HALF** as likely to have an ACP

Individuals who are Black or Hispanic are **HALF** as likely to have had conversations about their own end-of-life care wishes

Source: The Conversation Project National Survey (2013, 2018)

Lessons learned: Approach

Shift from doing *to*, doing *for* → doing *with*

- *Meaningfully engage*
- *Leverage assets*
- *Collaborate with humility*

Lessons learned: Factors to consider

- Shifting from reactive work to intentionality
- Understanding the make-up of your own community
- Seeking leaders/partners you can engage to help introduce this to a more representative audience
- Eyes wide open: Recognize your biases, understand systemic biases (distrust)
- Watch for tokenism
- Do your homework – come equipped with questions, cultural humility

Takeaway from call?

- Questions to ask, factors to consider
- Learning from others, learning together

Panelists



Ms. Sandy Stokes
*Chinese American
Coalition for
Compassionate Care*



Rev. Sabrina Gray
Bethel AME Church



Mr. Mark Starford
*The Board Resource
Center*

Chinese American Coalition for Compassionate Care



Sandy Chen Stokes, RN, MSN

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Chinese American Coalition
for Compassionate Care

www.caccc-usa.org

Bethel AME: Planning Ahead



Rev. Sabrina Grey
Bethel AME Church
sbwgrace77@gmail.com

Planning Ahead

(a future reality)

Who would you want to make care decisions for you if you cannot?

What kind of medical treatment do you want or not want?

Do you need strategies to have conversation?

Would you like support to document your wishes?



Spring 2018 Planning Ahead Groups

Ages 18 -100

Register after service or contact

Rev. Sabrina Gray

617-230-3242 | planningahead@bethelboston.org



In collaboration with

the conversation project

The **Board** Resource Center

*Making Complex Ideas Simple*SM



Mark Starford
mark@brcenter.org
www.brcenter.org

We prioritize our work
to reach individuals
who feel discounted
due to difficulties
reading or
understanding
complex ideas.

Our Work

We develop tools and trainings that encourage greater self-determination:



- Healthcare
- Emergency Preparedness
- Abuse Prevention
- Civic Participation

Lessons Learned

1. Listen
2. Engage “end-users” in all aspects of developing/implementing trainings and tools
3. Develop a diverse advisory group
4. Use everyday plain language – only
5. Field test materials with diverse groups
6. Willingness to make changes

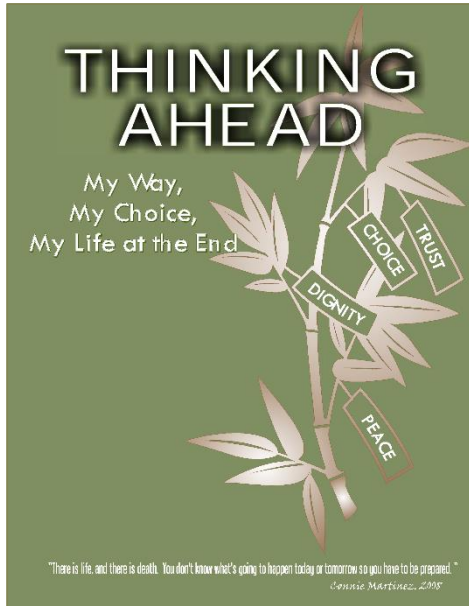


Lessons Learned From Project



Thinking Ahead

My Life, My Choice, My Life at the End

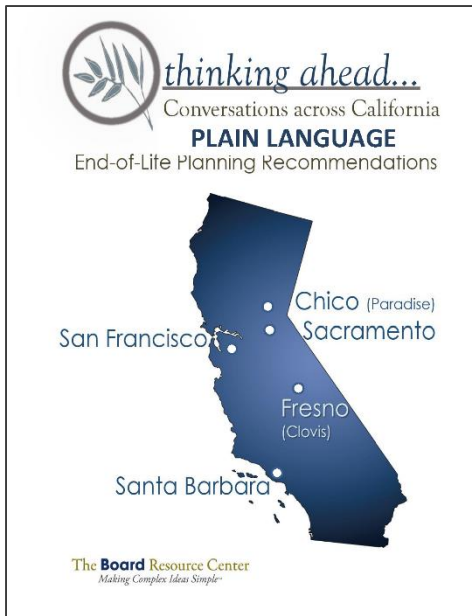


1. Define intended users
2. User engagement
3. Allow extra time
4. Test in varied communities
5. Use plain language
6. Use icons, symbols, media

Lessons Learned From Project



Thinking Ahead *Conversations Across California*



1. “Inclusive” learning groups
2. Interactive conversations
3. Visual and text reports
4. Everyday language

Q&A with Panelists

Questions, thoughts, what's resonating?

Open discussion: Chat / Raise Hand

- What lessons (from roadblocks, successes) have you learned?
- What should we all be thinking about that hasn't yet been addressed?

Wrap up

- Final thoughts: questions you'll take with you, factors to consider
- What will you do by next Tuesday?

Additional Resources, Upcoming Calls and Events

Sampling of Resources

- **Recent TCP blog:** Ensuring Equity: Reflections, Resources and Learning Together
<https://theconversationproject.org/tcp-blog/ensuring-equity-reflections-resources-and-learning-together/>
- **Ethno Geriatrics Training:** modules from Stanford School of Medicine for health care providers to raise awareness of specific cultural, racial, and ethnic influences on health and health care of older people from specific ethnic backgrounds.
<https://aging.stanford.edu/>
- **Nextavenue.org:** The Ways Inequality Affects Black Americans at the End of Life
<https://www.nextavenue.org/end-of-life-inequality-black-americans/>
- Others?

Ensuring Equity: Reflections, Resources and Learning Together

Posted on 11/02/2018



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Tags

Welcome
Ellen Goodman
Talking Matters
Health Care Proxy
Faith
Alzheimers
Health Plans
Millennials
Conversation Ready
Book Review
Family
Guest Post
Health Professionals

The Conversation Project (TCP) has delivered countless presentations across the country about who we are and what our mission is. During these presentations, to help our audience gain a better sense of what we do, we share a video of our campaign that was featured on **ABC World News with Diane Sawyer**. In the segment, the camera follows the Jennings family as they have the conversation. The family sits in their well-furnished living room as they prompt the patriarch of the tribe to share his end-of-life wishes. They laugh and cry together as they reminisce on the past and touch upon vulnerable points of conversation. The video is incredibly poignant—you can't help but be inspired to have the conversation with your loved ones.

After showing this video, Kate DeBartolo (TCP's director), tends to follow it by saying, "We know not all families look like this..." DeBartolo, who herself is a white woman, adds on, "We know that most families are not white, middle-class families." And she's right, most families don't look like this. She says this as a reminder to the audience that "the conversation" is not simple and it becomes even more complicated when we take into account the identities of the people we aim to serve.

Join us on our community call as we continue to learn more about ensuring equity!
Wednesday, November 14, 3PM ET

[Click here to register!](#)

When we say our mantra, "We want to ensure that everyone, everywhere expresses

The Ways Inequality Affects Black Americans at the End of Life

[Read more and join us at the inequality black americans](#)

November 2, 2018



• By Rachael Meadows Fernandez November 2, 2018
• By Rachael Meadows Fernandez

November 2, 2018

Credit: Adobe Stock
Part of the [Living to the End of Life Special Report](#)

(Editor's note: This content is provided by [The John A. Hartford Foundation](#), a Next Avenue sponsor.)

Jodi Savage was her grandmother's caretaker in her last days. Like many black Americans, her grandmother's cultural beliefs and religious background led to very little discussion around the end of life. Culturally speaking, black Americans on the whole tend to avoid discussing end of life topics for fear of speaking things into existence. Focus is placed on making the best of the time you're given. A lack of cultural competency from physicians led to a misunderstanding of Savage's grandmother's needs and minimal support through the death planning process. Savage endured all of this while trying to remain strong as her grandmother battled Alzheimer's.

Resources: Broader scope

- **Facilitating racial justice workshop**
<http://interactioninstitute.org/training/fundamentals-of-facilitation-for-racial-justice-work/>
- **100m Healthier Lives:** unprecedented collaboration of change agents who are fundamentally transforming the way we think and act to improve health, wellbeing and equity. <https://www.100mlives.org/>

Upcoming events / activities

- **End Well's Design for the End of Life Experience Symposium, Dec 6, 2018 San Francisco, CA:** End Well brings people from all disciplines together to engage in conversations about what it means to live and die well <https://www.endwellproject.org/>
- **Hospice and Palliative Nurses Association Campaign:** #ISaidWhatIWant encourages all nurses to lead by example by establishing their own advance care plan. Visit advancingexpertcare.org

Upcoming Community Calls

The next Conversation Project Community Call will take place on:

Wednesday, Dec 19th, 3:00-4:30 pm ET

Date and Time	Topic
Wednesday, Dec 19 th , 3:00 – 4:00 pm ET	Community Planning 101
Wednesday, Jan 16 th , 3:00 – 4:00 pm ET	Community Planning 201
Wednesday, Feb. 20 th , 3:00-4:00 pm ET	NHDD

We want your feedback!

- After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today's topic, what would you like to learn more about?
- Any other comments on today's session?