The Conversation Project: Ensuring Equity and Reaching Diverse Communities

November 14, 2018

Patty Webster
Naomi Fedna
Welcome to today’s session!

Please use Chat to “All Participants” for questions

For technology issues only, please Chat to “Host”

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)
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.”
Where are you located on the map?
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.
What Matters TO Me?

What’s the Matter with Me?

As Well As

Public Awareness Community Engagement

Health Systems Transformation
Our Website

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

Start your conversation today.

Free Conversation Starter Kit »
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
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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www.caccc-usa.org
sandystokes@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?

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

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
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
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?**
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. Visit [https://www.endwellproject.org/](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](http://advancingexpertcare.org)
Upcoming Community Calls

The next Conversation Project Community Call will take place on:

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

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td>Wednesday, Dec 19th, 3:00 – 4:00 pm ET</td>
<td>Community Planning 101</td>
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<tr>
<td>Wednesday, Jan 16th, 3:00 – 4:00 pm ET</td>
<td>Community Planning 201</td>
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<tr>
<td>Wednesday, Feb. 20th, 3:00-4:00 pm ET</td>
<td>NHDD</td>
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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?