

**The Conversation Project Community Call: *Designing for Sustainability***  
**October 16, 2019**  
**Summary Notes**

*\*Due to technical difficulties, the recording for this call begins midway (at the end of the first of three presentations). The notes below provide detailed information about the unrecorded portion of the call, in addition to a short synopsis of the recorded portion.*

See <https://theconversationproject.org/calls-and-recordings/> for corresponding [slides](#) and [recording](#) from the call.

**Slides #1-5:** Introduction, review of Zoom functionality and warm up chat

**Slide #6:** TCP community update

- Recent blogs of interest – 11 Additional books on living, end-of-life care, and dying as well as a compilation of resources in Spanish

**Slide #7- 9:** Upcoming community call, survey reminder and overview of today's call

**Slides #10-11:** Building local community engagement

- In 2015 – based on several years of learning from groups in the field, TCP created our “*Getting Started Guide for Communities*” to help introduce TCP and conversations into your communities. This guidance and our Community 101 call offers lessons on how to get started and engage with other partners involved in this work
- This guide and Community 101 call walks you through 10 questions to ask yourself/your group as you get started
- One of the next questions we hear most: once we build this local engagement, how do we keep the momentum going? How do we sustain this work?
- Sustaining what: programming or local community engagement?
- Sustaining engagement goes hand in hand with building it. We set out to seek answers to this question and see what groups across the country are doing to sustain this engagement (and how to plan for this at the get-go)

**Slide #12:** Sustaining Local Community Engagement

- In our first quarter community activity survey of 2019, we asked this question; received responses from a wide variety of types of organizations spreading this work throughout their communities (pie chart shows the spread of respondents: healthcare, individual volunteers, faith-based groups, business/employers, etc.)
- We pooled the responses in our blog: [5 Things We've Heard and Things you Can Do to Ensure Sustainability](#)

**Slide #13-14:** Components of sustainability

- The following are some key components to ensuring this work lives on (see blog for more details)
  - **Weaving into the fabric of the community/organization:** Building activities or providing tools as standard practice, part of culture
  - **Multiple and reoccurring touchpoints:** Ensuring a regular rhythm of sharing through recurring programming or media messaging
  - **Dedicated nurturing:** Establishing a position (within an organization) or team dedicated to this work
  - **Creating/supporting local champions:** Supporting others to take this forward (students to retirees, private and public sector, representing diversity of communities)
  - **Ongoing relationships/coalition building:** tapping strengths of each
  - **Upfront and reoccurring strategy setting:** to determine the right methods and people to keep this work going in any community (including funding)
  - **Recognizing this is a long runway**

Slide #15: Presenter introductions

### Presentation 1

Joan Gibson, Founder

#### **The Conversation Project in New Mexico**

**Slide #16:** The Conversation Project in New Mexico: Redefining Sustainability

- Or rather: WHAT needs sustaining? WHAT is it time to let go of?
- 6 years ago: my colleague Revathi A-Davidson (a retired senior administrator for New Mexico's largest health care delivery system and health plan) formed the all-volunteer New Mexico Conversation Project. National TCP was incredible generous: grant funds for materials, bringing Rosemary Lloyd to NM for a community-wide ACP project and training for our faith communities. This past summer we shut down our NMCP web site, we're referring everyone directly to the national TCP web site...
- How can this be seen as sustaining our local effort?
- This past year we realized we'd reached that predictable place where we were expending an increasing amount of energy to preserve the structure of the NMCP. Clearly, we couldn't sustain that, and were forced to confront the question: What if the very public face and focus of the NMCP were to go away? What would be left?

**Slide #17:** Advance Care Planning in New Mexico: Lessons Learned

- We asked ourselves:
  - How did we get this far?
  - Who is continuing to do this work as the formal NMCP sunsets?
  - What have we learned?
- As I answer these questions for New Mexico, you might think about your own answers and observations:
  - What does your journey look like?
  - Who are the players who continue to commit and be active?
  - **WHAT**, for you and your community or group or organization, needs to be sustained?

**Slide #18: New Mexico's Answers**

- NM ACP history:
  - 1977 Right to Die Law
  - Late 80s Values History Form
  - The first state to adopt the Uniform Health Care Decision Act, as our statewide legislative template
- 40 years of history, engagement, multiple groups and individuals
- Community: In taking a current inventory of our uniquely diverse community, we began to appreciate anew how many individuals and groups have been involved over the years...and how many continue to be active, in ways entirely appropriate to their constituency. Our recent focus on the NMCP had temporarily diverted our appreciation for this.
- Let me highlight 2 very different instances of this "sustainability in action."
  - **Presbyterian Healthcare Services**

- PHS Advance Directive: a national model, decades old
  - New Mexico MOST
  - ACP Volunteer Facilitator program
  - Online Advance Directive platform (went “live” last week)
- **Local and Personal**
  - TCP resources are embedded...alive and well and spreading throughout organizations, faith communities
  - We agree on effective steps for initiating and **sustaining** conversations.
- Two questions:
  - Who’s your health care companion/proxy, decision-maker? (ask at any age, no focus on serious or terminal illness)
  - How will people know? iPhones and Androids (see YouTube link), Wallet cards
- **Sustaining** the conversation may, in the end, start with and depend on our **own** experience and commitment to “having the conversation.”
  - Have you, personally, had the conversation?
  - Have you supported your friends and co-workers in doing so?
  - What you experience and learn may be your most reliable guide for next steps.
- Ellen Goodman’s initial insight:
  - The importance of **conversation**
  - Staying power of voice
  - Emotional memory (working w local NM neuropsychologists) is triggered by conversations and is more easily accessed than written documents in actual decision-making situations.
  - The wisdom of Goodman’s insight continues. What a **sustaining** gift.

**Slide #19:** Resources and contacts

- Feel free to e mail me with questions and requests for links and contacts.

**Presentation 2**

Mary Lou Infinito, Outreach Coordinator  
**Vidant Health, Eastern North Carolina**

**Slide #21** Who is Vidant Health?

- Serve Eastern North Carolina (eastern 1/3)
- 7 Community Regional Hospitals

**Slide #22** History of ACP At Vidant Health

- Vidant created an EOL work group made of patients, family advisors, and professionals in the healthcare system
- The goal was to create a culture in which ACP is important and normalized for patients, consumers, and health care teams

**Slide #23** A glimpse at the last two years

- The numbers look at in patients, consults, palliative care teams, and other interactions
- Number of documents is not their success measurement – they would rather have good documents rather than many documents

- They use a 5-step process – “you need to think about it yourself and then have a conversation with your family and friends”
- Multiple classes held with multiple participants so that anyone can have a conversation with a patient if it is brought up

**Slide #24** Moving conversations upstream

- Wellness clinics are examples of interactions outside the hospital
- Vidant says “we go wherever we are invited”
- We push for conversations to go upstream – when patients come in as in patient, it should not be the first time they’ve thought about their ACP
- Employees who have created their own ACP are better at talking to patients about their ACPs

**Slide #25** Normalizing conversations

- Normalizing the conversation takes a lot of effort on the community level
- Personal engagement includes employees who do it themselves first

**Slide #26** Ideas for supporting ACP

- We do not advocate one and done programs – prefer to do programs that are 2 or 3 sessions to keep conversations going
- Providers have been trained to teach other providers

**Slide #27** Sharing the necessary tools

- We have a variety of tools to share with people other than the TCP materials – DNR form, POLST
- Make these tools part of their charts
- Advocate for patients to talk to their doctors about them

**Slide #28** Networking with key community leaders and stakeholders

- Introduce topics to stakeholders
- Want documents in place – we go all over the place and talk to everybody

**Slide #29** Final thoughts

- Includes Mary Lou’s information
- Dr. Ira Byock’s quote highlights Vidant’s “what-if” framing

**Presentation 3**

Joe Greaves, Executive Director

**East Bay Conversation Project (EBCP)**

**Slide #31** ACCMA Snapshot

- Joe Greaves is the ED of the Contra Costa Medical Association in the San Francisco East Bay area
- Urban/suburban medical association with smaller medical societies (Napa and Solano)
- Mission is to provide a forum for the doctors in the community to address concerns of their own and their patients

**Slide #32** What is EBCP?

- EBCP is a community-wide coalition to champion ACP
- Provide resources for the community

**Slide #33** Origins in 2009

- Work began in 2009 around POLST when it became a legally recognized document
- POLST form symbolized an enhancement for ACP
- Doctors needed help with the conversation itself

**Slide #34** Steering Committees

- Steering Committees provide focus for the champions to come together in community to support one another

**Slide #35** Quarterly Trainings

- Quarterly trainings are half-day programs to provide information on ACP
- 30-40 per session from all walks of life

**Slide #36** Community Outreach

- Goal is generally 30 community outreach programs a year

**Slide #37** Film Screenings

- Combination of watching a film and then having an audience discussion

**Slide #38** Annual Summit

- 2 of them in 2017 and 2018 – third one planned for January 2020
- Daylong programs with a combo of keynote speakers and breakout sessions

**Slide #39** Communications

- The project website with a quarterly newsletter allows community to plug-in

**Slide #40** Other Info

- Leslie provides support on administrative tasks and handles nuts and bolts
- Able to function on a \$40,000 budget
- Partnership with CCCC

**Slide #41** Sustaining Our Momentum

- Have observed declining demand – lower attendance, audiences shifting to wider community members
- Observed health systems taking the work on more
- View it as a success of our efforts
- Funders have moved on to other priorities
- More educational programs, deep dives
- Revisiting how to best accomplish goals moving forward
- Likely moving into a new role as support or convening figure – fewer direct services

**Slide #42** Questions? Thank You!

**Slides #44-end:** Review of ways to keep connected with TCP, each other, and resources