



The Conversation Project

# Getting Started Guide for Communities



Institute for  
Healthcare  
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is a national initiative to ensure that everyone’s end-of-life wishes are both expressed and respected. Since 2012, we’ve worked to raise the profile of this issue by increasing awareness with the public and by creating tools, like our **Conversation Starter Kit**, to help individuals “have the conversation” with their loved ones.

To bring about national change, we need to reach people where they work, live, and pray — and many community leaders, like you, have reached out to us for help with introducing The Conversation Project in their communities.

This Getting Started Guide is intended to help you do just that. An individual, organization, or coalition of organizations can use the Guide to help figure out where to get started with engaging community residents in end-of-life care conversations, and how to think about engaging other community partners in this work. You can also find more resources and tools in the **Community Resource Center** to help spread The Conversation Project end-of-life care planning activities throughout your community.

**Note:** There is no “one way” to approach this work. Some groups will host public events or train speakers, while others will focus on a media-based initiative.

Many have found that it’s helpful to start by thinking about three basic questions:

- **Who** is the audience you’re trying to reach?
- **How** is it best to reach them?
- **What** actions do you want them to take?

Feel free to start by simply answering the questions on the next page, or by going deeper into the examples in the following pages. This Guide is meant to be a helpful resource and not overwhelming! We’ve collected years’ worth of experiences from around the US, and we don’t expect communities to take on all of this work at once. Different communities are at different points in their planning, have different resources available to them, and have different levels of acceptance of the idea of end-of-life planning. You know your community better than we ever could, and we hope this Guide will provide a helpful framework for you in planning next steps.



*The Conversation Project works in collaboration with the Institute for Healthcare Improvement, a not-for-profit organization that is a leader in health and health care improvement worldwide. This material was developed for The Conversation Project with funding from The Cambia Health Foundation. We would love feedback on whether you find this document and the Community Resource Center website to be a helpful model for your planning. If you have additional resources you’d like us to consider posting, please send them to [kdebartolo@ihi.org](mailto:kdebartolo@ihi.org).*



*Thanks to the Cambia Health Foundation for their generous support of our Community Resource Center.*

# Ten Questions to Get You Started

**1** *Who* do you want to reach? And *by when*?

**2** *How* do you want to reach them?

**3** *What* actions do you want people to take?

**4** *How* will your target audience respond to the topic of end-of-life care?

**5** *Who* else is already doing work on this topic in your community? *Who* else could you be working with?

**6** *Who are respected leaders or organizations that could help you advocate for the importance of this work?*

**7** *Who will be responsible for actually doing this work in your community?*

**8** *How will you measure successes and challenges?*

**9** *How do you plan to reach diverse groups of people in your community?*

**10** *What can you do by next Tuesday?*

# Here are additional ideas and examples to consider as you answer the ten questions.

## 1 Who do you want to reach? And *by when*?

The audience you want to reach can, and likely will, grow over time. It's helpful to set an aim early on — who you want to reach, and by when — to be clear about your plans, drive the pace of work, and establish a focus on outcomes. You don't want to take on too much — or too little — at the start. Thinking about the scope of your work helps clarify next steps.

### ■ Who are you interested in engaging in your community?

- Is this because of a noted need? Because you have connections with this group?

#### FOR EXAMPLE, ARE YOU TRYING TO REACH:

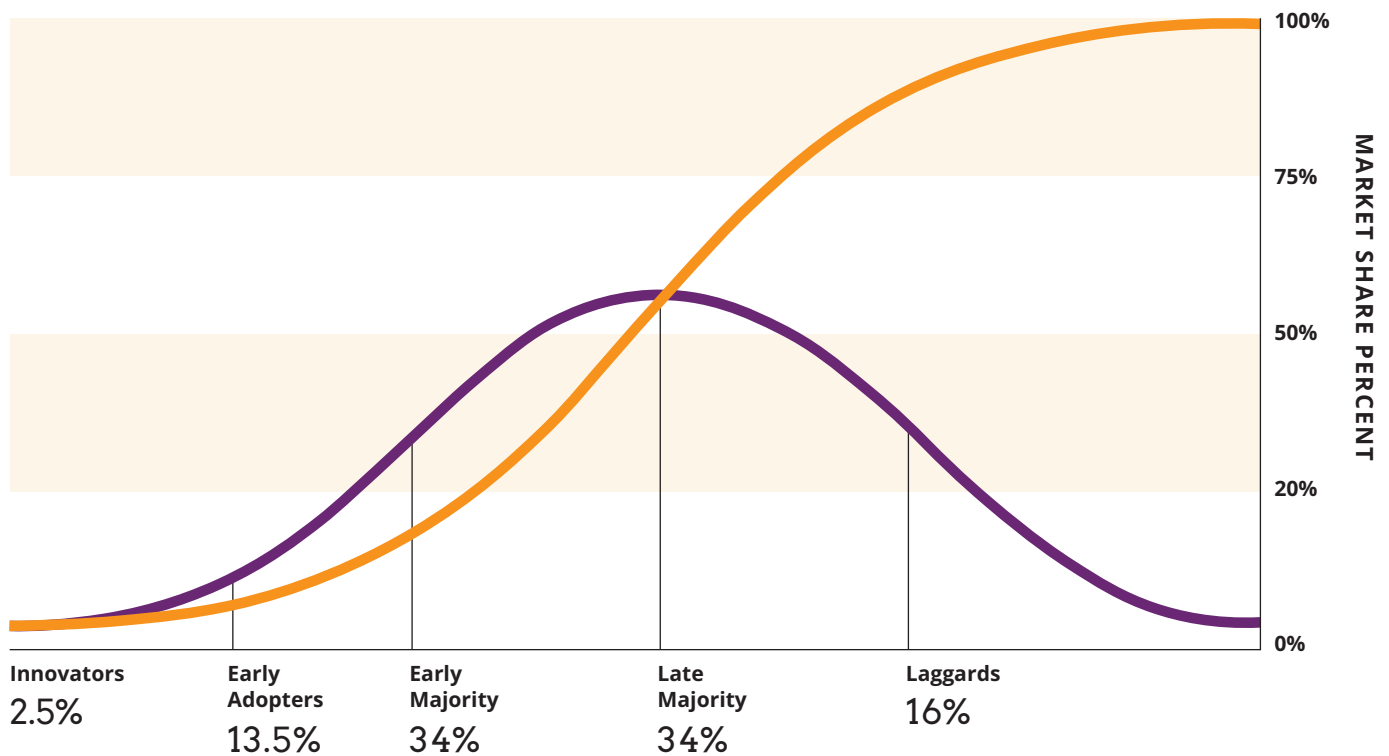
- Your employees?
- Everyone over age 75 in your community?
- Staff working in the local retirement communities?
- Everyone over age 18 in your county?
- A study group within your faith community?

### ■ We recommend first focusing your efforts on “early adopters” (in Everett Rogers’ terminology; see Rogers’ “*Diffusion of Innovations*” curve to the right).

Given the many people who are eager to start the conversation about their end-of-life care wishes, it's better to start with this group of early adopters than to spend time and energy trying to convince those who aren't yet ready. By engaging those who are interested, you'll work out some of the kinks in your process with a friendly audience. When you're ready, you can expand the focus to a larger group of people — those who might have been resistant early on.

**“Some is not a number, soon is not a time.”**

*Don Berwick, MD, President Emeritus and Senior Fellow, Institute for Healthcare Improvement, in his National Forum keynote address in December 2004, announcing IHI's 100,000 Lives Campaign*



Source: Rogers EM. *Diffusion of Innovations* (5<sup>th</sup> edition). Free Press; 2003.

■ **We recommend starting with a smaller region**

(for example, a city or county instead of an entire state) while you get your bearings and learn about others who might already be working on this topic in your region.

■ **If you find it difficult to estimate the number of people in your target audience,**

do a back-of-the-envelope calculation to determine the number of people you'd like to reach in order to start making an impact in your community. Whether that number is 15 or 1,500 or 15,000, it's good to have an idea of what you think success will look like.

**FOR EXAMPLE:**

- There are 12 long-term care and senior housing facilities in your community, and each one has 3 client services/education employees. Your goal might be to reach these 36 staff in the next 2 months.
- There are 20,000 people in your town and 5,000 are over 75 years of age. Your goal might be to reach 10% of them (500) over the next year — and an additional 10% the year after that.

## 2 How do you want to reach them?

Think about what motivates different groups of people. What is unique or special about the group you're trying to engage? For example, are they drawn to the idea of making sure someone knows what is important to them at the end of life? Or maybe they seek to provide better care for a loved one, or to give someone else the gift of preventing undue stress and burden at the end of life? Or maybe they are more interested in the cultural "pull" of knowing they are doing something they see others doing or heard they should do?

### ■ Describe a persona of someone you are trying to engage:

- What is their day-to-day life like?
- What do they care about?
- How can you design your outreach to meet the needs and current activities of your target population?

### ■ What are ways you could reach your target audience where they:

- Work?
- Live?
- Pray?

### ■ What activities might help you engage your target population? What do you think will attract your target audience in a way that will encourage them to take action?

#### FOR EXAMPLE:

- Writing op-eds for the local newspaper
- Speaking at conferences or educational events
- Hosting a conversation session that is open to the general public, with a goal to reach as many people as possible with a one-time event
- Training many champions/ambassadors to spread the word
- Hosting many training events in the community over the course of the year
- Creating a media and Public Service Announcement (PSA) campaign to raise awareness

### ■ Perhaps your target audience will not require any in-person events at all; how, then, will you reach them?

### ■ When creating your portfolio of activities, use stories, personal profiles, data, and other methods to engage people's hearts and minds.

### 3 What actions do you want people to take?

There are a lot of possible areas to cover in advance care planning. Simplifying your “ask” of people will make it easier for them to take action.

- **What do you want people to ultimately do? Know this early on so you can make “the ask” clear and concise.**

#### FOR EXAMPLE, DO YOU WANT THEM TO:

- Have the conversation with a family member or loved one?
  - Have the conversation AND talk to their doctor?
  - Have the conversation AND talk to their doctor *and* designate a health care proxy AND prepare an advance directive?
- **What tools will you use, and how can you help make sense of the many resources?**

#### EXAMPLES INCLUDE:

- [The Conversation Project Conversation Starter Kit](#)
- [Five Wishes](#)
- [Honoring Choices](#)
- State-specific advance care planning tools

Some community groups choose to focus on getting their target audience to have the conversation (the primary goal of The Conversation Project), while others focus on making sure people have medical or legal documentation (e.g., health care proxy and advance directive) on file.

#### FOR EXAMPLE:

- A group in Denver, Colorado, found that many people they spoke with had conversations about end-of-life wishes with loved ones but had not talked with their clinicians about end-of-life care, so this group chose to focus on that latter step of engaging health care providers.

- **Can you do a quick gap assessment to see what the biggest need is in your community?**

#### FOR EXAMPLE:

- Ask 20 seniors at the community center whether they’ve had the conversation about their end-of-life wishes or have completed an advance directive.
- Use one of the measurement tools in our [Community Resource Center](#) to poll attendees after an awareness-building event to learn more about whether they had a conversation with loved one or clinician.
- If you have access to patient medical charts, pull the charts of 20 patients in your target audience to see if they have a health care proxy or advance directive on file.

Your informal assessment will not be perfect, but it can provide a good indication about where the biggest needs are in your community.

If you’re going to work on “all of the above,” be sure to sequence the work so it is clear what next step an individual should take and doesn’t become more confusing. Because states’ rules and regulations may differ, it’s helpful to get familiar with the medical and legal requirements for end-of-life planning in your region. Those you connect with may have state-specific questions, and understanding your state’s regulations can help you clarify which documentation or resources will be medically or legally binding.



## 4 How will your target audience respond to the topic of end-of-life care?

How are you taking into consideration the local environment in which you are trying to spread The Conversation Project? The topic of end-of-life conversations seems to be highlighted in the national media more and more each week. That said, it is received differently in various regions of the country or types of settings. There are important variables to consider when assessing the context of how this topic is received in a community or region. Depending on the audience or region you've selected, there may be different ways to reach different people.

■ **Talking about end-of-life care is received in different ways around the country.** It may be easier in one community than another. How can you take this into account?

- A state's consideration of adopting the POLST Paradigm (Physician Orders for Life-Sustaining Treatment) may provide an opening to introduce the topic or cause some resistance, depending on the audience.
- What works in one community or setting will not always work in another. Make sure you consider the local context (religious beliefs, urban/rural differences, the number and type of health care institutions, etc.).

■ **Think about your target audience and how they usually receive information.** Don't use only one medium if that isn't the way your audience is used to receiving material.

### FOR EXAMPLE:

- Does your target audience use social media (Facebook, Twitter) and email? Or do they like receiving hard copies in the mail?
- Podcasts and Google Hangouts vs. newspaper and public broadcasting channels?
- When inviting undergraduates on a college campus to an in-person event, you would probably use different strategies than you would to connect with residents of assisted-living facilities in the county.

■ **Accept different approaches depending on the venue or host organization.**

### FOR EXAMPLE:

- The person introducing the topic at an employee event may take a very different approach than a faith leader with his/her congregation.

■ **Consider language translations or other settings that may help convey the message.**

### FOR EXAMPLE:

- Physicians who worked on the Russian translation of the Conversation Starter Kit suggested that Russian-speaking patients in Cincinnati would "hear" this message better from their Jewish Community Center rather than from doctors. The same thing happened in Providence, Rhode Island, when working on the Mandarin and Korean translations of the Starter Kit — current medical school students introduced the material at church health fairs rather than in a medical setting. Knowing where the messaging should come from is helpful.

■ **Think through any political, ethnic, or cultural systems in play in your community.** Have you accounted for the cultural diversity in the population you are trying to reach?

### FOR EXAMPLE:

- Leaders in New Mexico learned that the topic of end-of-life conversations was better received in the local Hispanic community when introduced to entire families at once and not only to individuals, who were then expected to bring the conversation back home on their own.

## 5 Who else is already doing this work in your community? Who else could you be working with?

Do a quick review of other organizations or informal groups in your community or region to see what work is already underway. Rather than adding more “noise” to a crowded field of helpful initiatives, see if there are ways you could assist those already in existence or select a theme that’s a bit different or in support of their work.

### FOR EXAMPLE:

There may be a group in your community particularly focused on education around the state’s MOLST/POLST project or legal documentation (e.g., advance directives). You could connect with them to learn more about ways you could work with them to help promote the idea of having the conversation in addition to their goal of completing the legal paperwork. Or perhaps both groups will agree that you’re targeting different audiences, but will establish monthly connections to bring each other up to speed on current work and areas of overlap.

When resources are limited, it’s important to leverage partnerships. Don’t operate in isolation; look for partners where you can both cooperate to advance this important work.

In addition to connecting with those who are doing similar work, you can also approach and partner with new groups and audiences. Below is a collection of possible partners to consider for outreach.

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### CHECK OFF THE GROUPS THAT MIGHT BE A GOOD FIT FOR YOUR INITIATIVE:

- |   |  |  |  |
|---|--|--|--|
| <input type="checkbox"/> Assisted living facilities   | <input type="checkbox"/> Estate/legal entities (e.g., elder law, legal aid offices, local bar association) | <input type="checkbox"/> Homeless shelter/ services  | <input type="checkbox"/> Prisons/jails   |
| <input type="checkbox"/> Businesses and local employers   | <input type="checkbox"/> Faith-based organizations, clergy, chaplains, ministerial associations            | <input type="checkbox"/> Hospice   | <input type="checkbox"/> Retirement communities and home owners’ associations  |
| <input type="checkbox"/> City employee retirement system  | <input type="checkbox"/> Family counselors and therapists  | <input type="checkbox"/> Hospitals/health systems  | <input type="checkbox"/> School District (employee benefits, Parent/Teacher Organizations)   |
| <input type="checkbox"/> Department of Public Health, Mental Health, Behavioral Health              | <input type="checkbox"/> Financial community (e.g., banks, CPA firms, financial advisors)                  | <input type="checkbox"/> Local community resources (e.g., libraries, book clubs, Chamber of Commerce, Lion/Rotary/Elks Club) | <input type="checkbox"/> Senior Advocacy Organizations/Elder Services (Area Agency on Aging, senior centers, transportation services, meals on wheels) |
| <input type="checkbox"/> Educational institutions (students, families, alumni, and faculty)         | <input type="checkbox"/> Foundations   | <input type="checkbox"/> Media channels (local, state, regional)   | <input type="checkbox"/> State hospital/medical/nursing/social work associations   |
| <input type="checkbox"/> Elected officials  | <input type="checkbox"/> Health plans/insurers   | <input type="checkbox"/> Nursing homes, rehab facilities, long-term care   | <input type="checkbox"/> Veterans Services   |
| <input type="checkbox"/> EMT providers  | <input type="checkbox"/> Home care/VNA   | <input type="checkbox"/> Physician office practices/primary care/ community health centers                                   |  |
| <input type="checkbox"/> End-of-life coalitions in your community or state (e.g., Honoring Choices) |  |  |  |

# Stakeholder Assessment

A stakeholder assessment can be a helpful tool for identifying partners. Think about the groups or individuals you want to engage (or that you think might be a hindrance to your efforts) and consider the larger context of this work.

**Ask yourself: Are these stakeholders going to stop, let, help, or make this happen?**

- Who will make sure this work gets done?
- Who is likely to help you with this work?
- Who may let the work happen, but won't be particularly helpful to the initiative?
- Who will work to actively stop you?
- And why?

Group Name	Make It Happen?	Help You?	Let You?	Stop You?	What Matters to Them?

**A TIP TO CONSIDER**

To begin, you may want to focus on what you can do to introduce your plan to the “make it happen/help you” partners *and* work with the “stop you” groups to shift them to “let you” partners. (They don’t have to become your biggest champions, but see if you can work to transfer their energy away from blocking your efforts.)

Pay attention to the balance of community partners you work with and how your collective message will resonate with your target audience. For example, if you’re working to engage young adults in your region, be sure to connect with the local universities and employers and not just home care and senior services.

## 6 Who are respected leaders or organizations that could help you advocate for the importance of this work?

Think back to your target audience. Is there anyone in your community who is well respected and could help promote the status of your initiative? Are there particular groups, agencies, or people that will strongly motivate others to join? Are there key thought leaders who need to be engaged — for example, a local political figure, employer, news anchor, or religious leader?

### BEFORE CONNECTING WITH THEM, THINK THROUGH “WHAT’S IN IT FOR THEM?”:

#### ■ How does your initiative align with the work a person or an organization is already doing?

- What is their day like? How much time might they be able to offer?
- Why is working with you in their best interest?
- What do they care about?

#### FOR EXAMPLE, PERHAPS...

- ... you could suggest the topic of end-of-life planning to local media outlets (TV, radio, newspaper) and offer to help pull together a panel of experts and speakers.
- ... a large local church needs topics for congregant educational programming and you can offer to present in a few weeks, encouraging their prominent faith leader to attend or say a few words.
- ... an influential individual has had this on their personal “to-do” list for a long time and wouldn’t mind being filmed or giving a quote after having their own conversation with a loved one.

#### ■ Think about what you want your specific “ask” of them to be: a letter of support? Space to host an event? Asking them to tell their story publicly? Remember not to request too much from any one person or group.

■ **Don’t make this an unpleasant obligation** — if you approach it properly, saying “yes” should be an easy decision that could lead to additional fruitful interactions or connections.

#### ■ Identify some light-touch opportunities for engagement. Many community partners have local leaders...

- ... kick off the agenda for public events with a personal story.
- ... share photos on social media with a copy of their Conversation Starter Kit or advance directive.
- ... provide a quote for a blog post or media opportunity.

Your request of these leaders doesn’t have to take a long time to complete, but can go a long way toward reaching and engaging your target audience.

## 7 Who will be responsible for actually doing this work in your community?

Is there an individual or organization who can “own” this initiative in your community? Whether you have a formal or informal structure, who will be responsible for the realization of this work: setting the pace, making decisions, allocating resources?

**There are many models that could work.**

### **HERE ARE A FEW EXAMPLES:**

- In multiple regions, recent retirees, many with a background in end-of-life work, start their “encore career” volunteering to lead The Conversation Project work in their community.
- Some groups have worked to fit The Conversation Project into their current structure and daily responsibilities. For example, the East Bay Conversation Project initiative in Alameda and Contra Costa County, California, is supported by grant funding and administered by the ACCMA Community Health Foundation, a charitable subsidiary of the Alameda-Contra Costa Medical Association. They coordinate the efforts of many partner groups and facilitate all steering committee meetings and website hosting responsibilities.
- In South Carolina they’ve created a large umbrella organization, The South Carolina Coalition for the Care of the Seriously Ill, which engages many groups within the state (SC Medical Association, SC Hospital Association, Carolinas Center for Hospice and End of Life Care, SC Healthcare Ethics Network, SC Society of Chaplains, SC Nurses Association, LifePoint, AARP). These groups all agree to provide staff time and resources to keep the work moving forward.

**Depending on the model you select, it can be helpful to develop a steering committee of interested partners who can help you with planning, execution, and dissemination.**

### **FOR EXAMPLE, YOUR STEERING COMMITTEE MIGHT INCLUDE THE FOLLOWING PEOPLE:**

- Chairperson responsible for setting the agenda and driving the work
- Community member from target audience
- Department of Health
- Health care entity (hospital/primary care/cancer center/hospice/home care)
- Large employer
- Member of Interfaith Council

### **Areas that will need to be addressed and owned:**

- Brokering relationship with high-level champions (governors, for example)
- Brokering relationship with interfaith community
- Measurement
- Media placement for PSA ads and social media
- Ties to health care institutions
- Training coaches/speakers and managing events
- Funding

**If you'd like to be the lead individual or organization, think through what you want your role to be and how much time you have to dedicate to this work.**

**HERE ARE A FEW QUESTIONS TO HELP YOU THINK THROUGH PLANNING AND EXECUTION ACTIVITIES:**

- What are you ultimately trying to achieve?
- What can you do or plan for today that will advance this work?
  - If you have four hours per week to dedicate to this project, how do you want to spend them to have the biggest impact in your community?
  - Speaking at events?
  - Training additional presenters?
  - Connecting with more partners to take on additional pieces of work?
- What feedback or data are you getting about your efforts?
  - What can you stop doing that would be time better spent elsewhere?
  - What are some low-risk “tests of change” you could do (with minimal resources) to learn what works best in your community?
- How can you create pace in your work?
  - What are some themes or core goals you could organize around each quarter?
  - How can you identify and link the work to key milestones?

As your work continues, think through how you want to be organized in your community or region to foster learning and increase the number of people involved. How will you plan for growth?

As some community initiatives have matured, they've garnered so much interest from the public that the demand for presentations and the interest from community members to volunteer have grown. Many of these groups have now developed trainings for “conversation champions” and “conversation coaches.”

**Conversation Champions/Speakers** are volunteers trained to educate and engage the general public and community stakeholders regarding the benefits of having conversations about end-of-life care with an individual's loved ones and caregivers. They are available to make presentations to community organizations, community groups, or any other interested groups and individuals. The Conversation Project team hosts regular virtual trainings for those interested in becoming speakers, and some community partners host their own in-person volunteer trainings. You can find out about upcoming speaker trainings by visiting the “Hosting Events” section of the resource center and clicking on “Speaker Training.”

**Conversation Coaches** are volunteers trained to work with individuals and families who request support with advance care planning and family end-of-life care conversations. This can be a great role for people who are more comfortable with one-on-one interactions than with public speaking. Many community leaders have invested in developing or providing these trainings. Additionally, our **Coaching the Conversation Guide** can be a helpful resource for future champions/speakers and coaches.

**A TIP TO CONSIDER**

**As your work grows and you engage various types of partners, think through ways you can help them share with each other. Perhaps host an interfaith meeting for religious leaders in the community to share questions and best practices. Or host a neighborhood event at which different local organizations share what they've been doing to advance this work in the same specific geographic area in your region.**

## 8 How will you measure successes and challenges?

It is always helpful to think about how you will measure your activities to identify successes or areas for improvement. This can be particularly useful for identifying trends in which types of events or engagements have been more or less successful, as well as for communicating with potential partners and the media about what you've accomplished.

Additionally, many funders are interested in evaluation and it can make for a stronger funding proposal if you can show the impact of the work and how you plan to evaluate your work going forward.

While we strongly believe measurement and data are important, we don't recommend collecting metrics just for the sake of collecting them. If you can't think about how you might use a particular measure, don't do it! If a particular method of data collection is too burdensome and the information could be captured in a different way, take the less resource-intensive route. Measurement and evaluation should always be in service to your work — something you look forward to capturing and analyzing, not something you dread.

Sample measures are listed in the [Community Resource Center](#).

## 9 How do you plan to reach diverse groups of people in your community?

Consider the diversity of your community (language, age, race, religion, culture, sexual or gender orientation, socioeconomic status). Take a look back at your notes for the questions above and reflect on whether this diversity is represented in your plan.

Do you notice a particular demographic of your community is not represented? If so, think through partners you could engage that may be able to join your steering committee or help you introduce this topic to a more representative audience. This may not happen seamlessly in the first phase of your work, but it should be accounted for as you move forward.

Here are a few examples of new target audiences some of The Conversation Project's community partners identified after reevaluating the demographics of their regions:

- Homeless population
- LGBT population
- Non-English speaking populations
- People with mental health or memory conditions
- Prisoners
- Young adults

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## 10 What can you do by next Tuesday?

There will always be more planning or research you could do. Instead, we invite you to get started! What is a small "test" you could do in the next week? Who are one or two people you can connect with or introduce the Conversation Starter Kit to?



## ! Bonus Question!

Let's be forward thinking and reflective. This can be a great question to ask at a steering committee meeting, or whenever you introduce The Conversation Project to a new group. Knowing your community...

■ In one year if you look back and have wild success with the introduction of The Conversation Project, what will have been the factors of success? What would cause this to succeed?

**FOR EXAMPLE:**

- In a region with a predominant faith community, the clergy and congregations could be very important allies.

■ In one year if you look back and the introduction of The Conversation Project has been a flop, what will have been the factors of that failure? What would cause this not to succeed?

**FOR EXAMPLE:**

- Lacking a driver of the work who will own the pace of the work and the operations in your region, or depending too strongly on someone without enough time to give.

While our natural tendency may be to think of all the resources we are lacking when starting an initiative like this, we strongly encourage you to focus on the assets you do have already available rather than on those you don't have. Our hope is that, with the assistance of this Getting Started Guide, you will think through the individuals, associations, institutions, physical assets, and connections you can access as you plan your next steps.

That said, you can always keep an eye on what resources could help you jump to the next level of community engagement (e.g., a website). Just be sure not to get deflated before you start! We've found it is far easier to ask for additional resources when you can show what you've been able to accomplish with few. By getting started, you'll identify what works for you and what has been a struggle and can then address these challenges with potential partners or funders — many of whom will be pleased to see what you've already started.

**We can't wait to hear what you design for your community, and we hope you'll keep us posted as you embark upon this work.**

**Here are a few ways to stay engaged with The Conversation Project going forward:**

- We host monthly webinars — on the 3<sup>rd</sup> Wednesday of the month from 3-4 pm ET — for community leaders to hear updates from The Conversation Project team and presentations from others.
- We also host quarterly speaker training webinars (with recordings and notes always available).
- Sign up for The Conversation Project newsletter and monthly regional communications.
- We can offer in-person trainings or community planning sessions for a fee.

For additional information on any of the above, check out our **Community Resource Center** or email us at [conversationproject@ihi.org](mailto:conversationproject@ihi.org).



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