



# COMMUNITY VOICES FOR HEALTH

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A guide for bringing people together to build networks, solve problems and make decisions



A resource from Public Agenda

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# 1

## What is this document for?

### **Better engagement infrastructure for better health**

This guide is for people who are interested in strengthening, deepening and diversifying consumer engagement to make the health care system work better for the people it is meant to serve. It is a product of the Community Voices for Health project, which works to amplify community voices to achieve better health policies, better health care systems and, ultimately, better health. To accomplish these goals, the project aims to increase the quantity and quality of opportunities for people to engage, particularly for marginalized communities whose voices are rarely heard on health policy issues.

The guide is a product of the work by Public Agenda, Altarum and the Pennsylvania Health Access Network in Pennsylvania Voices for Health, an ongoing effort that also served as the planning phase for the larger Community Voices project.

The foundation of any engagement infrastructure is local, regularly occurring meetings and exchanges. These can take many forms (described in Section 4 of this guide). In Pennsylvania, and in every state, people are already engaging with one another on health and other issues in numerous ways.

#### **A few Pennsylvania-specific examples include:**

-  Members of the Somali Bantu Community Association of Pittsburgh meet regularly to discuss local issues and community projects.
-  There are 59 Pennsylvania chapters of the National Alliance on Mental Illness, organized by town or by issue area, that meet monthly.
-  Over the past several years, more than 1,000 people have attended monthly potlucks, with a different issue or theme each month, at the same house in State College.

Local, regularly occurring engagement, where people meet, face-to-face and online, throughout the year



In some places, where there are not enough opportunities to engage, people may want to start new meetings, especially ones that are regular, convenient, social and organized around food. One example is the “Meet and Eat” lunches that occur in many West Virginia towns.

Regularly occurring, local engagement is also happening online, in the form of online discussions, networks and the Nextdoor forums that can be found throughout the state. In Philadelphia, hundreds of people have engaged through BeHeardPhilly, a process in which participants answer short surveys on community issues to provide input to officials on policy decisions.

Whatever form it takes, ongoing local engagement is important because it can improve the health of:

- Individuals:** Research shows our health depends a great deal on whether we are connected to family, friends, neighbors and health professionals – are other people looking out for us and providing help when we need it?
- Communities:** Public health improves when people work together to solve problems, either by getting information, volunteering or working with decision-makers and health professionals (see Section 2).

By connecting these local, regularly occurring engagement opportunities, you can also realize benefits at a third level:

- Your state:** Helping people understand health issues while giving them a meaningful voice in health policy decisions will make it more likely that the policies benefit the people they are intended to serve.

To attract people who have traditionally been ignored, marginalized or underserved, it is particularly important to build relationships with groups and networks that can reach those communities. One-on-one interviews, focus groups, “meet and eat” discussions, booths at street fairs and other kinds of strategies can be helpful for engaging members of these communities on their terms (three examples are described in Section 6).

The strategies described in Section 5 of this guide can help you to connect local engagement opportunities, so that people have meaningful ways to weigh in on important statewide policy discussions. When large, diverse but connected groups of people talk about the same issue as part of a structured process in which they weigh policy options and other potential actions, the ideas and recommendations they generate are more likely to influence legislators and other state decision-makers (see Section 2). For example, if groups of Pennsylvanians statewide used a shared set of discussion materials to examine problems and assess laws and regulations to make prescription drugs more affordable, their collective input could shape how state officials ultimately attempt to address the issue.

**Statewide issue: Prescription drug affordability discussions happen in October**

The graphic includes a map of Pennsylvania with several orange stars marking various locations across the state, including Allegheny City, State College, Harrisburg, Lancaster, and others. The map is titled 'Pennsylvania' and shows the Allegheny Plateau and Appalachian Mountains. To the right of the map is a sidebar titled 'POLICY TOPIC: PRESCRIPTION DRUG COSTS' for the state of Pennsylvania. The sidebar contains three questions and their answers:

- How Much Does the U.S. Spend on Prescription Drugs?**  
Prescription drugs currently account for 15 percent of overall health spending, or about \$482 billion in 2016. This includes drug purchased from the pharmacy—sometimes called the “retail” setting—as well as drugs administered in doctors’ offices and hospitals.
- Are Prescription Drug Prices Too High?**  
New innovative drugs have helped patients live longer, healthier lives. However, many new drugs come with shocking price tags, and many drugs that have been around for years have had steep price increases that defy explanation. In 2015, Americans spent more than double, per person, on retail pharmaceuticals than comparable countries.<sup>1</sup>
- What Causes High Drug Prices?**  
Most drug manufacturers are for-profit companies that often face little competition for their products. Barriers to competition in the pharmaceutical market include patent protection, market exclusivity and natural monopolies for drug-making biotech with patient populations that are too small to attract multiple manufacturers.<sup>2</sup> As a result, drug companies can set high prices to fund future research and development (R&D) but also to maximize their profits. Drug manufacturers were able to maintain average profit margins of between 18 and 22 percent for the period 2008 through 2015.<sup>3</sup> For the sake of comparison, average profits among non-pharmaceutical Fortune 500 companies fluctuated between 8 and 9 percent during the same time period.<sup>4</sup>

Section 5 describes some of these connector strategies, such as online crowdsourcing platforms, meeting-in-a-box kits for community conversations, systems for identifying and training delegates and texting-based approaches like Text, Talk, Engage.

## Statewide issue: Prescription drug affordability voices heard in Harrisburg



The more these engagement opportunities are supported and leveraged to help people learn about, think about and voice their opinions on policy decisions, the healthier our states and communities will be.

Other complimentary resources produced for the Community Voices for Health project include:

- **A Pennsylvania-specific "engagement scan"** that lists many of the existing engagement opportunities throughout the state, including local engagement opportunities and connector strategies like the ones described above. Similar versions of the scan can be created for other states.
- **Pennsylvania-specific policy explainers** to inform Pennsylvanians of potential solutions to health-related issues they think are important. Topics include prescription drug affordability, surprise medical bills and access to health care in rural areas. Accompanying glossaries explain key terms. Again, these kinds of resources can be replicated for other states.
- **Case studies** highlighting different ways communities can influence state and local policy processes and examples of how the academic research community can help.

To help find, create, and connect local engagement opportunities...

**Engagement Scan**

**Community Voices Guide**

Research to help inform the discussions

**Policy Topic: SURPRISE MEDICAL BILLS**

*State: Pennsylvania*

**What is a Surprise Medical Bill?**  
Any medical bill for which a health insurer paid less than the patient expected. Surprise bills can come from in-network or out-of-network providers and can take many forms.

**How Do Surprise Medical Bills Occur?**  
There are many reasons surprise bills occur: providers not fully understanding the terms of their health coverage versus an insurer health plan's "network" of in-network doctors and hospitals, insufficient network adequacy and restrictive coverage policies, inadequate disclosure about out-of-network providers, and poor protections for consumers.

**What's the Consumer Hike from Surprise Medical Bills?**  
For most families in Pennsylvania, affording the out-of-pocket costs associated with healthcare is very difficult. Even more so when these families cannot budget for the expense because of bills they did not expect. A 2018 survey found that 35% of privately insured Pennsylvania adults reported receiving a medical bill that included an unexpected expense in the prior 12 months. More than one-third indicated that the issue was not resolved to their satisfaction.

**Surprise Bills from Out-of-Network Providers More Prevalent Among Those with Private Health Insurance**  
One type of surprise medical bill is a surprise out-of-network bill. These bills can affect anyone but they are particularly prevalent for those with private health insurance. Unlike traditional in-network, with almost all

**Research Poster**

**Policy Topic: PRESCRIPTION DRUG COSTS**

*State: Pennsylvania*

**How Much Does the U.S. Spend on Prescription Drugs?**  
Prescription drugs currently account for 11 percent of overall health spending, or about \$480 billion in 2016. This includes drugs purchased from the pharmacy—sometimes called the "retail setting"—as well as drugs administered in doctors' offices and hospitals.

**Are Prescription Drug Prices Too High?**  
New innovative drugs have helped patients live longer, healthier lives. However, many new drugs come with shocking price tags, and many drugs that have been around for years have had steep price increases that defy explanation. In 2015, Americans spent more than double, per person, on retail pharmaceuticals than comparable countries.<sup>1</sup>

**What Causes High Drug Prices?**  
Most drug manufacturers are for-profit companies that often face little competition for their products. Barriers to competition in the pharmaceutical market include patent protections, market exclusivity and natural monopolies for drug treating diseases with patient populations that are too small to attract multiple manufacturers.<sup>2</sup> As a result, drug companies can set high prices to fund future research and development (R&D) but also to maximize their profits. Drug manufacturers were able to maintain average profit margins of between 15 and 23 percent for the period 2006 through 2015.<sup>3</sup> For the sake of competition, average profits among non-pharmaceutical Fortune 500 companies fluctuated between 4 and 9 percent during the same time period.<sup>4</sup>

**How are Consumers Halted from High Drug Prices?**  
High drug prices lead patients to make the difficult choice between their health and their wallet.

*A Philadelphia Inquirer story described how every three months John Neenan's*

## 2

# Examples of how engagement can improve health

To understand the ways in which engagement can improve health, we can look at examples of impacts at the state, local and individual levels.

At the state level, large-scale engagement projects that reach a critical mass of participants have impacted policies for several reasons:

-  **People become more informed about public issues.** One example among many: Research on deliberative forums in South Dakota found that 72 percent of participants reported gaining new insights about issues, 79 percent reported discussing aspects of the problem they had not previously considered and 37 percent found they were thinking differently about the issue afterwards.<sup>1</sup>
-  When engagement processes bring together citizens on different sides of a policy debate, **they can often find common ground, which can break a legislative deadlock.** In Oklahoma, a process called Balancing Justice in Oklahoma helped the state legislature shift from an aggressive prison construction policy to becoming one of the leading states in community corrections.<sup>2</sup>
-  **Engagement can strengthen relations between citizens and public officials** and inspire better communication afterward. For example, after the CaliforniaSpeaks process on health care, 40 percent of the 3,500 participants contacted a public official.<sup>3</sup>

At the community level, some of the same kinds of policy impacts have occurred, for the same reasons. Engagement can also prompt citizen action in the form of volunteer activities and new initiatives, focused either on health directly or on social determinants of health such as promoting safe streets or encouraging people to exercise.

1. Elena Fagotto and Archon Fung, "Embedded deliberation: entrepreneurs, organizations, and public action." (Boston, MA: Taubman Center for State and Local Government, 2006).

2. Matt Leighninger, *The Next Form of Democracy: How expert rule is giving way to shared governance—and why politics will never be the same.* (Nashville, TN: Vanderbilt University Press, 2006).

3. Archon Fung, Taeku Lee, "The Difference Deliberation Makes: A Report on the CaliforniaSpeaks Statewide Conversations on Health Care Reform." (CaliforniaSpeaks, 2008).

There are several ways in which engagement leads to action by people who are not public employees and organizations that are not part of government:

-  **Engagement creates settings where people come up with ideas for new activities or initiatives.** Researchers studying local forums in West Virginia were able to quantify this effect: they found that 88 percent of the participants felt that the forums had given them new ideas of possible actions to take.<sup>4</sup>
-  **Engagement can help people find the resources and allies they need** to implement their ideas, in part by allowing people to form relationships with other participants. In a large-scale participation process in several Southeastern states called Turning the Tide on Poverty, the vast majority of participants indicated they had joined an action team. Moreover, 15 percent indicated this was their first time taking action in the community.<sup>5</sup>
-  **Engagement experiences provide spaces where new leaders can emerge.** The Horizons project, which has involved people in over 300 towns across seven states in dialogue and action on rural poverty, provides empirical data that goes beyond anecdotal stories.<sup>6</sup> Over 75 percent of the Horizons communities reported that after the project, decisions about what happens in the community involve more people, and 77 percent reported there are now more partnerships among local community organizations. In 39 percent of the communities, more people have joined local boards, clubs, service or other organizations. This leadership development may also encourage more government-initiated problem solving. For example, 34 percent of the Horizons communities reported that people new to leadership roles have been elected to public office. For more on Horizons, see Section 6.
-  There are also many instances in which **people inside and outside government work together** to solve problems.<sup>7</sup>

4. Elena Fagotto and Archon Fung, "Sustaining public engagement: Embedded deliberation in local communities." (East Hartford, CT: Everyday Democracy and Kettering Foundation, 2009).

5. Bo Beaulieu and Rachel Welborn, "Turning the tide on poverty: Measuring and predicting civic engagement success." (Mississippi State, MS: Southern Rural Development Center, 2012).

6. Diane L. Morehouse, "Horizons sustained effects: A report on continuing leadership and poverty reduction activities and outcomes in Horizons alumni communities." (Minneapolis, MN: Northwest Area Foundation, 2009).

7. Peter K. Spink, Naomi Hossain, and Nina J. Best, "Hybrid public action." Institute of Development Studies Bulletin 40, no. 6 (2009): 128.

At the individual level, expanding grassroots engagement opportunities helps build a stronger “culture of health,” which “places well-being at the center of every aspect of life, with the goal of enabling everyone in our diverse society to lead healthier lives”.<sup>8</sup> To achieve a stronger culture of health, we need to strengthen our social networks, social cohesion and community resilience, especially among groups of people who have historically been underserved.<sup>9</sup>

Increased engagement benefits individual health in many different ways. For instance:

- ❑ People with stronger relationships to friends and neighbors are at less risk of serious illness and premature death.<sup>10</sup>
- ❑ Cities and towns that have higher levels of “community attachment” have higher rates of economic growth and employment, which is one of the social determinants of health.<sup>11</sup>
- ❑ Neighborhoods where people work together and have a higher sense of “collective efficacy” also have lower crime rates – another social determinant of health.<sup>12</sup>
- ❑ Towns and neighborhoods with stronger social networks are better able to plan for natural disasters, better able to deal with these disasters when they happen and better able to reduce the risk of injury and death.<sup>13</sup>

Because engagement can strengthen health at all three levels – state, community and individual – and work at one level complements and supports work at the other levels, Community Voices for Health is designed to help people build, step by step, a more comprehensive, multi-level infrastructure for engagement.

8. Anita Chandra et al, “Building a National Culture of Health: Background, Action Framework, Measures, and Next Steps.” (Santa Monica, CA: RAND Corporation, 2016). [https://www.rand.org/pubs/research\\_reports/RR1199.html](https://www.rand.org/pubs/research_reports/RR1199.html).

9. Alonzo Plough. Interview with Alan R. Weil, “Building A Culture of Health.” *Health Affairs* 35, no. 11 (2016): 1953-958. doi:10.1377/hlthaff.2016.0913.

10. Jessica Olien, “Loneliness is deadly. Social isolation kills more people than obesity does—and it’s just as stigmatized.” *Slate.com*, August 23, 2013. [http://www.slate.com/articles/health\\_and\\_science/medical\\_examiner/2013/08/dangers\\_of\\_loneliness\\_social\\_isolation\\_is\\_deadlier\\_than\\_obesity.html](http://www.slate.com/articles/health_and_science/medical_examiner/2013/08/dangers_of_loneliness_social_isolation_is_deadlier_than_obesity.html).

11. Knight Foundation, “Soul of the community 2010. Why people love where they live and why it matters: A national perspective.” (Miami, FL: Knight Foundation, 2010). <http://www.hartfordinfo.org/issues/wsd/neighborhoods/SoulofCommunity.pdf>

12. Dan Hurley, “Scientist at work -- Felton Earls; On crime as science (A Neighbor At a Time)”. *New York Times*, January 6, 2004. <http://www.nytimes.com/2004/01/06/science/scientist-at-work-felton-earls-on-crime-as-science-a-neighbor-at-a-time.html>. See also Michael Davis, “The purpose of police.” Video presentation in at the Annual Frontiers of Democracy Conference, Jonathan M. Tisch College of Citizenship and Public Service (Medford, MA: Tufts University, 2013). <https://youtu.be/uw1scT1HvAY>

13. Daniel P. Aldrich, “Fixing Recovery: Social Capital in Post-Crisis Resilience.” *Department of Political Science Faculty Publications* 3, (2010). <http://docs.lib.purdue.edu/pspubs/3>. See also Monica Schoch-Spana et al., “Community Engagement: Leadership Tool for Catastrophic Health Events.” *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science* 5, no.1 (2007). <http://doi.org/10.1089/bsp.2006.0036>

# 3

## What does strong engagement look like?

There are three kinds of engagement happening in most communities today. “Conventional” engagement is by far the most common, but “thick” and “thin” engagements are both on the rise.

Conventional engagement is what happens in most official public meetings today. Citizens and officials are separated from one another, there are no breakouts or small group discussions and citizens have brief opportunities (typically limited to two or three minutes) to address the whole group. This is generally not a strong form of engagement, and it tends to be frustrating for everyone.

Thick engagement is more intensive, informed and deliberative. Most of the action happens in small group discussions. Organizers assemble large and diverse numbers of people and give the participants chances to share their experiences, present them with a range of views or policy options and encourage action and change at multiple levels.

Thin engagement is faster, easier and more convenient. It includes a range of activities that allow people to express their opinions, make choices or affiliate themselves with a particular group or cause. It is less likely to build personal or community connections. One way of understanding the difference is to say that thick engagement empowers small groups and thin engagement empowers individuals.

Thick engagement opportunities are more likely to be face-to-face, and thin ones are more likely to happen online. However, many thick engagement strategies include both online and face-to-face elements and some examples of thin engagement (signing a petition, for example) certainly existed long before the internet.

Thick and thin engagement have different strengths and limitations, and they complement each other well. Both of them – along with some conventional engagement opportunities – should be part of a stronger infrastructure for engagement.

## Attributes of strong engagement

There are a number of key attributes to strong engagement, both thick and thin:

-  **Giving people a chance to tell their stories.** The chance for people to explain why they care about an issue, and to hear and understand others' stories, is one of the most fundamental missing ingredients in conventional engagement formats. When people have a chance to relate their experiences, they are much more likely to learn from each other, be civil toward one another, form stronger relationships and make the connection between their individual interests and the public good. Over the last 20 years, this kind of storytelling has been a core component of successful face-to-face engagement.
-  **Building trust among citizens and between citizens and decision-makers.** Sharing stories and experiences builds relationships, not just among citizens but between citizens and public servants, especially when those public servants are part of the process. This may be one of the reasons why some forms of engagement lead to higher levels of trust between citizens and government. People who took part in the CaliforniaSpeaks deliberative forums on health care reform were over 55 percent more likely to agree, after the process, with statements like "We can trust our state's government to do what is right".<sup>14</sup> In one North Carolina project, external political efficacy (the extent to which people feel that government is responsive to their interests) increased by 31 percent.<sup>15</sup>
-  **Providing factual information – as much as people want.** In an era when information – and disinformation – circulates more quickly and widely than ever, providing user-friendly basic information about public problems, budget expenditures, public services and other data is an essential component of engagement. Information can be shared in numerous ways, including simple printed handouts, information briefs, infographics, interactive online maps, machine-readable datasets, presentations, discussion and issue guides and access to subject matter experts. Some kinds of engagement, such as community-engaged research<sup>16</sup> and online crowdsourcing platforms like SeeClickFix, PublicStuff and Ushahidi, rely on citizens to help gather and analyze the data.

14. Fung, Lee, Harbage, "Public impacts: Evaluating outcomes of CaliforniaSpeaks"

15. Tina Nabatchi, "Addressing the Citizenship and Democratic Deficits: The Potential of Deliberative Democracy for Public Administration." *The American Review of Public Administration* 40, no. 4 (July 2010): 376–99. doi:10.1177/0275074009356467.

16. Kiran Cunningham and Matt Leighninger, "Research for democracy, and democracy for research." In *Educating for deliberative democracy*, ed. Nancy Thomas (San Francisco, CA: Jossey-Bass, 2011): 59–66.

-  **Using sound group process techniques.** Process skills and techniques have emerged as a critical factor in the development of productive engagement. We have learned, often by trial and error, that thinking carefully about agendas, formats and facilitation, rather than accepting conventional formats or not thinking through the process at all, can mean the difference between success and failure. This is true of online as well as face-to-face forms of engagement.
-  **Providing choices.** Though they do so in different ways, both thick and thin forms of engagement give people choices. Rather than trying to sell participants on a particular policy, these good engagement opportunities allow citizens to decide for themselves what they think.
-  **Making it clear to participants that their voices are being heard.** In almost every public engagement setting, people want to know whether what they say really matters. They often ask for some kind of formal or informal legitimacy, a sense that decision-makers are listening and will respond to their input. Participatory budgeting is perhaps the fastest growing form of engagement because it goes one step further, allowing participants to vote on how to spend public funds as part of the process.<sup>17</sup>
-  **Supporting people to take action in a variety of ways.** Engagement processes can encourage and support citizens to take action in numerous ways, from clicking a link to joining a task force to cleaning up a park. Some projects result in higher levels of voluntarism, others steer people toward trying to influence public officials. Still others support the formation of committees and task forces to tackle specific, more advanced tasks. All of these opportunities for action recognize citizens as problem solvers, capable of making their own contributions to finding solutions.

17. Brian Wampler, "Participatory budgeting: Core principles and key impacts." *Journal of Public Deliberation* 8, no. 2 (2012): 1-13. <https://www.publicdeliberation.net/jpd/vol8/iss2/art12>. See also Ernesto Ganuza and Gianpaolo Baiocchi, "The Power of Ambiguity: How Participatory Budgeting Travels the Globe," *Journal of Public Deliberation* 8, no. 2 (2012): 1-12. <https://www.publicdeliberation.net/jpd/vol8/iss2/art8>

 **Making engagement enjoyable.** Because people have many options for how to spend their time, making engagement enjoyable can help encourage engagement while also enriching the process. In the 2014 book “Making Democracy Fun,” Josh Lerner not only documents the increasing use of games in public engagement, but also unpacks the ways in which the experience itself can be gratifying to participants. Surrounding engagement activities and opportunities with food, entertainment for kids and culture can add to the enjoyment.

 **Making engagement easy and convenient.** Most people have busy lives so they value engagement opportunities that fit easily into their schedules, in addition to opportunities that are more powerful but also more time consuming. They need engagement opportunities that eliminate barriers to participation, which can include a lack of transportation, lack of child care, language barriers and others.

It is important to note that the involvement of a large, diverse number of participants is usually a key factor in the success of engagement, especially when the engagement is intended to inform policy. Engaging a critical mass of people maximizes the power of volunteer action by bringing more problem solvers to the table. It also maximizes the social capital or culture of health benefits that accrue from sustained engagement. Finally, the presence of a critical mass of participants will tend to more easily capture the attention of decision-makers and the media. It can also help participants feel empowered. For example, being part of a large cross section of the community may give people a sense of political legitimacy even when public officials have been unable or unwilling to confer the expectation that citizen opinions will “matter” in the policymaking process. When it comes to influencing a policy decision, anecdotal evidence suggests that a large, diverse number of participants is critical.<sup>18</sup>

18. Fagotto and Fung, “Sustaining public engagement”; Will Friedman, *Deliberative democracy and the problem of scope*. *Journal of Public Deliberation* 2, no. 1 (2006): 1-29. <https://www.publicdeliberation.net/jpd/vol2/iss1/art1>; Leighninger, *The Next Form of Democracy*, 2006.

# 4

## Building blocks of local engagement: Meeting people where they are

When you consider the wide variety of ways that engagement is happening at the state, community and individual levels, and the different benefits people achieve by engaging, and you decide you want to capitalize on that energy to achieve a coherent statewide voice, you may feel excited – but you will probably also feel overwhelmed. The sheer diversity of people’s interests, backgrounds, activities, needs and skills is both a tremendous asset and an intimidating challenge.

To help break down what you might do into manageable chunks, consider the basic building blocks of your strategy: the sustained engagement opportunities you can build on, construct and connect. Start by mapping the ways in which people are already engaging, through an “engagement scan” if possible, and decide how to support and connect with people in those settings.

It doesn’t have to happen all at once. As long as these opportunities to engage are designed to be sustained and people are likely to continue participating, then you have time to build. It also doesn’t mean you have to reach a huge percentage of the population right away. Consider that today, the number of people who are intensively engaged in most policymaking processes is still fairly small. In most cases, only a few hundred attend meetings or other thick or conventional kinds of engagement, and the number who participate thinly by signing petitions or showing their preferences on social media is still only in the thousands. As a percentage of the overall population this is a drop in the bucket, and yet it sometimes still has a big impact on policymaking. Using the building blocks described below may allow you to reach these kinds of numbers in relatively short order, and in a way that grows over time rather than evaporating once an issue or policy has been decided.

This is especially true if the people participating are diverse. Public officials find it easier to dismiss citizens when they seem to all belong to the same political party, or if they are all members of the same organization or network that already has a clear advocacy position. The impact of the numbers is also lessened if they appear only as signatures on a petition or likes on Facebook. It makes a world of difference to be able to say to a policymaker, “Among the people who have participated, there are a good number in your district and they are willing to talk with you about this issue further.”

Achieving this kind of critical mass, therefore, is not only about the size of the turnout. It also helps if you can reach people in a variety of ways (see below), if you know where they live and if you can aggregate their ideas and input easily (see Section 5).

## Thinking strategically about networks and building blocks

Start with the list of networks in the engagement scan, or that you have mapped informally. Prioritize which ones you want to reach out to first, based on the following questions:

-  Do you, or someone close to you, know a person who is in a leadership position (or is influential in some other way) in that network? These kinds of existing relationships tend to make outreach and collaboration easier and faster. But while this is a good starting point, it will be important to move beyond your personal network if you want to gain a critical mass of truly diverse participation.
-  Does this network include people you particularly want to engage? Would this set of people make the overall turnout more diverse in some important way? Do they include people whose voices are rarely heard on public issues?
-  Would including this network be especially helpful in informing the policy questions at hand (they are affected by the problem and/or its solutions, they will be key to the implementation of solutions, etc.).
-  Would including this network be helpful as far as influencing policymakers?
-  What would the leaders of this network gain by working with you? How is it in their interest to participate?
-  What would the people who belong to this network gain by participating? How is it in their interest?

The building blocks graphics below include more information about some of the kinds of networks you might reach out to.

## Existing Meetings: Health-related Networks

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### How do they work?

- Chapters meet monthly, in most cases
- Format: small group discussion, sometimes a presentation
- Members usually connected through an email list, sometimes through social media

### Why are people participating?

- Get information about services
- Get information about a health condition or issue
- Support one another
- Work together on common concerns
- Sometimes to advocate with decision-makers

### Why work with them?

#### You get:

- More participants
- People who might be motivated to move on to other engagement opportunities

#### They get:

- Greater chance to influence policy
- Connections to other groups

### How to reach out to them?

- Find a connection, starting with statewide leadership or with a person who seems influential in that network
- Send materials, discuss what's in it for them/their network
- Pilot connector strategy (see Section 5) with key contact(s).

## Existing Meetings: Other Statewide Networks

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### How do they work?

- Chapters meet monthly, in most cases
- Format: small group discussion, sometimes a presentation
- Members usually connected through an email list, sometimes through social media
- Sometimes a process for making collective decisions about statewide issues

### Why are people participating?

- Get information about an issue
- Socialize or support one another
- Work together on common concerns
- Sometimes to advocate for an issue or cause

### Why work with them?

#### You get:

- More participants
- People who might be motivated to move on to other engagement opportunities

#### They get:

- Greater chance to influence policy
- Connections to other groups

### How to reach out to them?

- Find a connection, starting with statewide leadership or with a person who seems influential in that network
- Send materials, discuss what's in it for them/their network
- Pilot connector strategy (see Section 5) with key contact(s).

## Existing Meetings: Common Grassroots Groups

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### How do they work?

- Groups meet monthly, in most cases
- Format: small group discussion, sometimes a presentation
- Members sometimes connected through an email list or social media

### Why are people participating?

- They care about the place they live (a neighborhood or town), the institution they're connected to (a school) or a community of people
- Get information about any of the above
- Socialize
- Work together on common concerns
- Often to work with or put pressure on local decision-makers

### Why work with them?

#### You get:

- More participants
- People who might be motivated to move on to other engagement opportunities

#### They get:

- Greater chance to influence policy
- Connections to other groups

### How to reach out to them?

- Find a connection, starting with statewide leadership or with a person who seems influential in that network
- Send materials, discuss what's in it for them/their network
- Pilot connector strategy (see Section 5) with key contact(s).

## New Meetings: “Meet and Eat”

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### How do they work?

- Groups meet weekly or monthly
- Centered on food, typically lunch at the same restaurant or a potluck dinner
- Format: open space (people sit at tables depending on what they want to discuss)

### Why are people participating?

- Socialize
- They care about the place they live
- Get information
- Work together on common concerns

### Why work with them?

#### You get:

- More participants
- People who might be motivated to move on to other engagement opportunities

#### They get:

- Greater chance to influence policy
- Connections to other groups

### How to reach out to them?

- Find a popular location
- Reach out to individuals in charge of the location
- Find two to three people with strong social networks, enlist their help
- Start meeting, and stick to a weekly schedule.

## Existing Connections: Local Online Forums

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### How do they work?

- Via email lists, Facebook groups or platforms like Nextdoor
- Must live in the area served by the forum
- Format: regular emails, usually threaded according to topic
- Ground rules to encourage civility

### Why are people participating?

- Get information about what's happening in their neighborhood or town
- They care about the place they live
- Socialize
- Work together on common concerns
- Sometimes to work with or put pressure on local decision-makers

### Why work with them?

#### You get:

- More participants
- People who might be motivated to move on to other engagement opportunities

#### They get:

- Greater chance to influence policy
- Connections to other groups

### How to reach out to them?

- Find a connection, starting with statewide leadership or with a person who seems influential in that network
- Send materials, discuss what's in it for them/their network
- Propose questions to ask online, leading to one of the connector strategies (see Section 5).

# 5

## Connectors: Combining conversations into a statewide voice

The previous section on building blocks lists ways in which people are already engaged or could easily be engaged – it is a guide for meeting people where they are. This section focuses on how to connect people in those different locations and spaces and the avenues you can offer people to help them solve problems and influence policy decisions on a larger scale. It is about bringing people together, either physically or by combining their input, stories and data, in ways that can make an impact.

A strategy that combines engagement building blocks with connectors is far more likely to be successful than a disconnected group of meetings or discussions. The building blocks make it easier to include a wide range of people and sustain their engagement long enough for it to affect policy (and achieve the other benefits of a culture of health), while the connectors make it possible to achieve a common, coherent statewide voice. Furthermore, these two types of activities provide complementary incentives for participation. Some people are more interested in being part of a community or working with other residents, while others are focused on state and national issues. By linking the two experiences, you can get a better turnout for both.

### Thinking strategically about connectors

Connector strategies are helpful because they:

- Provide a consistent experience so that people in different places receive the same information, options and structure for their participation;
- Aggregate the input received so that organizers, public officials, researchers and the participants themselves can see where people stand on a given question or issue; and
- Give people a sense that they are part of something larger than themselves.

The connectors described in this section vary in some important ways. Some of them require more work by you, the organizer at the state level. Others place more of the burden on the people participating at the building block level. Some are highly scalable – you could conceivably have millions of participants – while others would likely include only a few hundred people. Some are thicker forms of engagement, while others are thinner. Finally, some are more likely to get people who have different perspectives to find common ground, while others would not.

The list of connector strategies below is organized into two categories. The first tier includes activities that can take place within the building block settings described in the previous section; they can be used in a face-to-face meeting or online discussion, either as a part of the agenda or as the whole agenda. The second tier consists of activities that would bring together people after they've engaged at the building block level.

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## Potential Connectors: Tier 1

### Activities that take place within building block settings

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#### Community Conversations

##### What is it?

A format for small group dialogue, deliberation and action planning by groups of eight to 10 people.

##### How to do it?

Develop a discussion guide that includes information on the issue they are addressing, sample views or policy options, discussion questions and guidelines for structuring the conversation. The guide should invite people to share why the issue matters to them and provide background information and policy options. You may want to recruit and train facilitators to help guide the process, not by providing information on the issue but by helping the group set ground rules, manage their time and use the material in the guide. You can gather input from the groups in a variety of ways, including paper surveys, online polling (see below) or by selecting delegates to represent the group at subsequent forums (see below).

##### What does it take?

One key requirement is the discussion guide, which can be developed in partnership with researchers and advocacy groups. The guide can be delivered to building blocks as part of a “meeting-in-a-box” kit that also

includes facilitation suggestions and instructions for communicating the group's input. However, for more complicated or divisive issues, trained facilitators will be important. In this case, facilitator recruitment and training is the other key requirement that organizers face.

Scalability	Find Common Ground
Medium	High
Thick-Thin	Best With
Thick	Any of the building blocks in Section 4

## Text, Talk, Engage

### What is it?

A strategy that uses texting to inform and facilitate face-to-face discussions among large numbers of very small groups and to aggregate the results in real time.

### How to do it?

Invite people to form groups of three to four and text "start" to a pre-assigned number. You can recruit participants through social media as well as through the Section 4 building blocks. From the texting platform, participants receive a series of polling questions, links to show how other respondents answered the same questions, discussion prompts and questions about what action steps they want to take. Each response from the group triggers the next question from the texting platform. You need to create the full module of questions, which typically takes 30 to 45 minutes for the group to work through.

### What does it take?

There are a number of texting-based polling platforms, such as OneCounts or Poll Everywhere. Many are free for small numbers, but charge a fee for larger numbers of respondents. In addition to the technology, you need to create a module that includes background information, polling questions and discussion prompts (similar to the content in a community conversation guide but adapted for the brevity required by texting and smartphones).

### Organizing tip:

Hold the text-enabled discussions all on the same day to create a sense of momentum. While the platforms allow people to participate whenever they want, if you point people toward a single day they are more likely to feel a part of the larger effort.

Scalability	Find Common Ground
High	Medium
Thick-Thin	Best With
Both	Any of the building blocks in Section 4

## Crowdsourcing

### What is it?

Crowdsourcing encompasses a variety of web-based tools that allow people to contribute, edit, rank and vote on proposals.

### How to do it?

Different platforms work in different ways, but they all allow participants (working in groups or on their own) to develop ideas, priorities or solution statements. People then have the chance to propose edits or changes to ideas developed by others. Finally, everyone can rank or vote on the proposals they like best. You can adapt the process to fit a face-to-face meeting by adding a bit of structure, such as instructions for the process and a few discussion questions to get things going.

### What does it take?

Platforms and organizations that support crowdsourcing include AllOurIdeas, IdeaScale and Ethelo.

### Organizing tip:

You can recruit people to participate in crowdsourcing on social media or through email blasts but you are likely to get a higher turnout, especially among people who wouldn't normally engage online, if the building blocks listed in Section 4 commit to participating together as part of their regular activities.

Scalability	Find Common Ground
High	Medium
Thick-Thin	Best With
Thin (for most participants)	Local online forums

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## Potential Connectors: Tier 2

### Activities that take place outside building block settings

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#### Action forums

##### What is it?

A large group event open to all the people in a community or region who have been participating in community conversations, Text, Talk, Engage or crowdsourcing.

##### How to do it?

Invite all the people who have participated so far to the action forum and encourage them to bring the main conclusions or action ideas they have discussed. The action forum should also include officials, staff, researchers and others who deal with the issues in a professional or public capacity. The event should be at least two hours. The first step can be an introductory small group or paired conversation where people explain their ideas and motivations. Then you form groups according to themes or issues, with professionals mixed in with other participants. Each group should plan out what they want to do and agree on next steps. You can also use instant polling to allow everyone to vote on policy options or other questions for the whole group.

##### What does it take?

A large space, an organizing team to design and facilitate the event and an instant polling platform and script.

Scalability

Medium

Thick-Thin

Thick

Find Common Ground

Medium

#### Delegates

##### What is it?

A system in which participants in Tier 1 activities select someone in the group to represent them at the next level. This can be a regional or statewide meeting in which delegates report on the conclusions reached in the groups they are representing and decide together how to carry those ideas forward.

### How to do it?

Create a clear protocol for the selection of delegates and distribute it to all the building block activities. Decide whether to bring delegates together in each region or at a single statewide event. Reach out to experts, including researchers, agency staff or consumer advocates, who can work with the delegates. Use small group discussions (like the community conversations described above) to help delegates address differences in their views and to find common ground. To help delegates influence state-level decisions, organize policy breakfasts or other statewide events at which delegates report to legislators on the conclusions reached by delegates and the participants as a whole.

### What does it take?

An organizing team to design and facilitate the delegate meeting(s), travel stipends for delegates.

Scalability	Thick-Thin	Find Common Ground
Medium	Thick	Medium

# 6

## Amplifying the voices we rarely hear

There are many groups of people whose voices are almost never heard on major decisions and policy questions, even though they are often the ones most affected by those decisions. The list of marginalized populations or historically underserved communities is long and varied, and includes recent immigrants, people from low-income households, people of color, people living in rural areas, the homeless, people suffering from addiction or mental illness, members of LGBTQ communities, young people and senior citizens.

People in all these groups might benefit if their input had a greater influence on policy decisions. They might also benefit from more opportunities to engage in ways that build their social networks and help them solve problems in their communities. The lack of a strong infrastructure for engagement impacts everyone, but it probably impacts these communities the most.

This section consists of examples of projects in which people from marginalized populations had the chance to engage meaningfully in decision-making and problem solving. You'll notice that many of the principles and practices described in the first five sections appear in these stories. Being able to engage different sets of people successfully is, of course, valuable in its own right, but it will also help build the credibility of your engagement work.

### Recent Immigrants

#### The Jane Addams School for Democracy in St. Paul, Minnesota

The Jane Addams School for Democracy was a community-based education and action program located in St. Paul, Minnesota, that ran from 1996 to 2016. Named after the pioneering 19th century social reformer Jane Addams, who invented the concept of the settlement house, it was not a school so much as a recurring activity that engaged thousands of people, many of them very recent Somali, Hmong and Latino immigrants.

Between 50 and 200 people took part in the Jane Addams School for Democracy meetings, which occurred twice a month from 1998 to 2016. Each meeting began with a social hour, featuring cultural exchanges and interaction around food, crafts and storytelling. During the second hour, neighborhood residents and college students worked together in a community conversations format. Each of these small groups was called a learning circle.

The Jane Addams School for Democracy activities were designed to help people learn about each other's languages and cultures, and also to help recent immigrants attain the knowledge and English skills needed to pass the U.S. citizenship exam. The learning circles were organized according to languages (at least four languages were spoken at the school in any one evening), with English translation in each circle. Bilingual college students served as translators, to allow people to discuss issues of concern in their native languages. "Valuing the knowledge resources that come from all cultures is key to the Jane Addams School philosophy," says Nan Kari, one of the school's founders. "Students and other non-immigrants learn about their own cultures, and new immigrants teach college and high school participants lessons that are not offered in the academic setting".<sup>19</sup>

Engagement through the Jane Addams School for Democracy also contributed to a number of other projects and outcomes, as participants compared experiences and generated ideas for improving St. Paul's West Side neighborhood. Hundreds of participants passed the federal citizenship exam. Participants also created a community farming project, a mural, a parent involvement partnership with the local schools, a health project and an annual community-wide celebration known as the West Side Freedom Festival. Even though most of the emphasis of the circles was on improving the local situation, Jane Addams participants have not stopped there. Concerned about human rights abuses in Laos, they successfully petitioned the Minnesota legislature to pass a resolution urging Congress to negotiate with the Laotian government for more humane treatment of the Hmong population. Participants also acted on their concerns with the way the U.S. citizenship test is administered. They forged a partnership with the regional director of Immigration and Naturalization Service, who agreed to allow English-speaking partners accompany Hmong applicants during the citizenship exam and interview.<sup>20</sup>

19. Nan Kari and Nan Skelton. *Voices of Hope: The Story of the Jane Addams School for Democracy*. (Dayton, OH: Kettering Foundation Press, 2007).

20. Margaret Post, "Building Relational Culture at the Jane Addams School for Democracy." *Family Involvement Network of Educators Forum: Harvard Family Research Project 5*, (Fall 2002). <https://archive.globalfrp.org/family-involvement/publications-resources/university-community-partnerships?print=1>. See also Ruth Ann Bramson and Matt Leighninger, "Engaging the Community in Productive Public Conversations about Immigration." *International Journal of Economic Development* 5, no. 4 (2003).

The initiative started with unpaid staff and no supply budget but grew to include one full-time and two part-time paid staff members. There was also an ongoing rotation of AmeriCorps members as well as 10 to 15 work-study students. However, the “heart of the school were the 200 or so community residents, high school students, college students and adult volunteers from the wider community who participated in the learning circles each week”.<sup>21</sup>

## The Homeless

### Engagement to improve services for the homeless in Philadelphia

Over the last three years, the City of Philadelphia’s Office of Open Data and Digital Transformation, PHL Participatory Design Lab and Office of Homeless Services have worked with other agencies and nonprofits to engage members of the homeless population to improve services provided by the Office of Homeless Services.

To get input on how to improve services, the project partners conducted one-on-one interviews with homeless people on the street and in shelters and intake centers. They interviewed a total of 121 people, including people who had refused services and those who had accepted them. The project partners also interviewed staff and shadowed them as they worked with service recipients. Finally, they held small group discussions with staff and recipients in shelters and intake centers.

A key aspect of the project has been to establish clear expectations with homeless people and the staff serving them on how people’s input would be used. Some of the conversations were explicitly about brainstorming solutions to challenges faced by the homeless, some were for sharing information and others were focused on making decisions together.

### The resulting changes can be grouped into three categories:

-  Increasing access to information, including redesigning and simplifying signage, forms and service descriptions and ensuring that all information is available in Spanish and English;
-  Making spaces safer and more welcoming – at different service centers they introduced a child’s play area, a resource center connecting participants to support, more comfortable furniture and “de-stress zones;” and
-  Improving interactions between participants and staff, including a new strategy informed by research on how people deal with trauma and new services for staff facing trauma in their work.

21. Nicholas Longo and John Wallace, “Creating Democratic Spaces: Jane Addams School for Democracy.” CURA Reporter (June 2000). 10-14 <http://www.cura.umn.edu/sites/cura.advantagelabs.com/files/publications/30-2-Longo-Wallace.pdf>.

The project is still ongoing. The Office of Homeless Services is now establishing an advisory board, including people who are currently homeless and who were homeless, in order to guide future stages of the work.

## **Residents of rural areas with high poverty levels**

### **The Horizons project in seven states**

The Horizons project, which took place between 2003 and 2010, in seven states (Washington, Montana, Idaho, North Dakota, South Dakota, Minnesota and Iowa), was designed to engage residents of rural areas in addressing poverty and economic development. Over several years, it involved over 100,000 people in over 300 small towns. Most of the towns had poverty rates over 30 percent, with the highest at 78 percent.<sup>22</sup>

Each of the small towns followed a sequence of deliberative public meetings, a structured community leadership program and a broad-based action planning phase. In most cases, the local activities were led or supported by extension agents working under the auspices of the state extension services, which in many states maintain strong connections with community leaders in rural areas.

Most of the Horizons communities showed a range of outcomes, including more inclusive decision-making processes, participants who won election to public office and a wide variety of citizen-driven activities. Evaluator Diane Morehouse found that 63 percent of participating communities reported that more people took individual actions to help those living in poverty and that 40 percent of communities were working on systemic poverty reduction efforts (e.g., jobs creation, skills training, micro-enterprise or business development). Moreover, 34 percent of participating communities reported that people new to leadership roles had been elected to public office and in 39 percent of the communities more people had joined local boards, clubs, service or other organizations. Seventy-five percent of the Horizons communities reported that decisions about what happens in the community now involve more people and 77 percent reported that there are now more partnerships among local community organizations.

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When asked to name the “most significant continuing activity,” [respondents] could seldom confine themselves to one, and named 77 activities they considered significant, including community gardens and farmer’s markets, parks, trails (one with a \$1.2 million grant) and recreational opportunities, community and community resource centers, scholarships for low-income children and families for day care, after-school programming and recreation, including Boys and Girls’ clubs, car repair and home maintenance programs and, in at least five communities, the establishment of community foundations.<sup>23</sup>

22. Diane L. Morehouse, “Northwest Area Foundation Horizons Program 2003 – 2010 Final Evaluation Report.” (Minneapolis, MN: Northwest Area Foundation, 2010). <http://msucommunitydevelopment.org/pubs/Report2010.pdf>

23. Morehouse, Horizons sustained effects, 2009.

One anecdotal finding that emerged from Horizons was related to how the organizers framed the issue. The Northwest Area Foundation, which supported the process in all of the states, named rural poverty as the problem they were trying to solve. However, when extension agents and community leaders in the small towns tried to engage residents, they found that people were uncomfortable coming to conversations about poverty, especially if they themselves were living in poverty. So, in most cases the engagement activities were organized under a broader heading, such as “Making [name of town] Stronger for the Future” or “Improving Our Local Economy for Everyone.”

### Common Threads

In each of these examples, there are common threads that reinforce some of the ideas presented in Section 3. All three efforts were or are:

-  Centered on the immediate needs and goals of the participants. They focused on providing things like language skills for people wanting citizenship or better services for people who use them. From there it is possible to build engagement around larger questions or decisions, such as how the Immigration and Naturalization Service administers the U.S. citizenship test.
-  Capitalizing on the fact that there are people who are already leading engagement work – such as neighborhood leaders, university partners, local government staffers and extension agents – or who have the connections and interests to engage others. Funding and organizational support was critical in each case, but those existing relationships formed the foundation of the strategy.
-  There may be particular engagement techniques, such as the one-on-one interviews with the homeless population in Philadelphia, that are especially helpful for working with a particular group. But working successfully with marginalized groups still relies on some fundamental principles of good engagement, including figuring out where people are or where they can easily be assembled (building blocks) and connecting those settings in ways that are meaningful for the participants and help produce a statewide voice (connectors).

# 6

## Conclusion: Staying focused on what people want

When more people participate, more intensively and more often, engagement usually becomes more powerful. But building and maintaining high levels of engagement is difficult if we treat it only as a legal requirement (governments must engage in order to “check the box” and comply with an open-meetings law) or a matter of civic duty (people must engage in order to think of themselves as “good citizens”). Both of these assumptions treat engagement like a bad-tasting cough medicine.

Engagement can, however, be enjoyable. In fact, when you look at some of the best examples of sustained engagement, it becomes clear that these models work because people find them convenient and fun. The city of Decatur, Georgia, hosts “Budgets and Beer” nights at a downtown bar where city employees bring poster boards to help explain public finance issues and surveys to gather citizen input. The residents and employees of Jun, Spain, use Twitter to communicate about everything from replacing streetlights to matters of European Union policy – along with advertising social events, booking doctor’s appointments and finding lost cats. On the Table, an initiative in Chicago that brings people together to discuss public issues over dinner, has engaged over 100,000 people and expanded to 15 other cities.

In these regular settings for engagement people keep coming back not only because the experience gives them a chance to provide input on policy decisions, but because of some more down-to-earth incentives: friends, food and lost cats. Following this line of innovation can be very simple – just follow the advice of Gloria Rubio-Cortes, former president of the National Civic League, who said “Sometimes you need a meeting that is also a party, and sometimes you need a party that is also a meeting.”

Democracy can’t survive on bad-tasting cough medicine. By using old ideas like the neighborhood potluck and new technologies like SMS platforms, we can support “anytime, anywhere” engagement that fits better into the rhythm of everyday life – and that offers a broader array of incentives to participate. This is the kind of engagement, embedded in the culture of communities and states, that can best promote health even as it helps inform and shape specific policy questions.

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