

The Community Quality Collaborative Leader's Guide to Engaging Consumer Advocates

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Introduction

The Agency for Healthcare Research and Quality (AHRQ) envisions Community Quality Collaboratives as communitywide partnerships of diverse stakeholders focused on improving health care quality and managing costs. For purposes of this guide, we will use the Institute of Medicine’s definition of health care quality: “*The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.*”¹ The Community Quality Collaborative stakeholders include purchasers, health plans, providers, and representatives of consumer organizations.

When some of you formed your Community Quality Collaborative, you may not have been clear about the role and potential of consumer advocates. Why should you include them, and how will they contribute to the goals of the Community Quality Collaborative? What types of consumer advocates should you seek out and what role should they play in the Community Quality Collaborative? Equally important, how are you supposed to make this connection happen? This guide is designed to answer these questions for Community Quality Collaborative leaders.

The inclusion of consumer advocates is key to ensuring that your Community Quality Collaborative’s efforts and end-results benefit all stakeholders, including consumers. In transforming the health care system and improving quality, consumers have important roles to play, including seeking out high-performing health care providers, communicating with their physicians, and committing to changing their personal behaviors. Also, they may act as stimulants for the system to become more patient-centered and might even offer specific quality improvement strategies to health care providers. The bottom line is that your Community Quality Collaborative’s processes must include consumer representatives to achieve the goal of improving health care, and ultimately improving care for individuals. This concept is discussed in greater detail below.

The First Question: Why Consumer Advocates?

AHRQ has specified that Community Quality Collaboratives include consumer advocates because these representatives can play an important role in the success of your initiatives. One basic reason is that your Community Quality Collaborative will have greater influence if all stakeholders are on the same page and working together. If consumer advocates are not included, there is a chance that, despite the best intentions, the Community Quality Collaborative may develop and implement a strategy that is contrary to the goals and interests of consumers, thus not effecting change in the community it is meant to help. Having representatives of consumers at the table early in the process is important to ensure that your Community Quality Collaborative’s efforts to increase transparency and improve health care quality are relevant to the patients whose health and lives are at stake.

Consumer advocates have much to offer your Community Quality Collaborative:

- **The ability to voice the needs and wants of consumers.** Consumer advocates are in regular contact with their constituents. They are aware of their constituents’ experiences with and thoughts on specific issues, which may include health care. Advocates also offer

¹ K.N. Lohr, Ed. (1990). *Medicare: A Strategy for Quality Assurance*. Washington DC: National Academy Press. 21.

a broader perspective than the average consumer because they draw from the experiences of their membership rather than just their personal experiences with health care.

- **The ability to reach consumers.** Consumer advocates can be highly effective distributors of information to consumers. They typically have various channels in place to communicate with their constituencies, including Web sites, newsletters, broadcast e-mails, conferences, and mailing lists.
- **Credibility with decision leaders.** Many consumer advocates have earned the respect of other community members and established relationships with these stakeholders including the media, public policy makers, and elected and appointed community leaders.
- **The trust of consumers and, therefore, the ability to educate and influence.** Consumer advocates may be viewed as a trusted source of health care information. According to a California HealthCare Foundation report, other entities, such as health plans and employers, may not be viewed as an objective source of information. A 2000 survey that asked California consumers whether they trust different organizations as a source of information about health care and medical needs found that only 34 percent trusted employers “a lot,” and 18 percent did not trust employers at all.² Even fewer people trusted health plans: only 18 percent trusted plans “a lot,” and nearly 26 percent did not trust them at all. Voluntary consumer organizations focused on specific diseases, on the other hand, seem to have the confidence of consumers: over 65 percent of consumers indicated that they have “a lot” of trust in these organizations. Advocacy organizations are often perceived as having a mission that is consistent with the best interests of those they represent.
- **The ability to empower and mobilize consumers.** Because of their relationships and ability to communicate quickly and effectively with consumers, advocates can assist in mobilizing them to take action when appropriate—whether with their providers of care or their legislators—to push for better information and improved quality.
- **An understanding of the community.** Because they are integrated into the community they serve, advocates can make sure that the output of the Community Quality Collaborative is pertinent and useful to the community. They also can function as a sort of translator, in that they can talk about the work of the Community Quality Collaborative in terms that are meaningful to the community.

Next Question: How to Involve Consumer Advocates?

Involving consumer advocates in your Community Quality Collaborative will require an organized ongoing approach. First, you will have to identify the advocates in your community who will be a good fit and provide broad representation of local needs and interests. Every community has a variety of advocacy groups; homing in on the ones that will benefit—and

² Sandra H. Berry, Julie A. Brown, and Mark A. Spranca, *Consumers and Health Care Quality Information: Need, Availability, Utility*. California HealthCare Foundation. (October 2001).
<http://www.chcf.org/documents/consumer/ConsumersAndHealthCareQualityInformation.pdf>

benefit from—the Community Quality Collaborative will require some research and relationship-building.

Second, recruiting and cultivating relationships with key consumer advocates will take time and effort. While well-versed in the issues they address, consumer advocates are not likely to be familiar with all the goals and tasks of a Community Quality Collaborative. Education on quality issues and the role of the Community Quality Collaborative will be critical—both in the initial stages of recruitment and on an ongoing basis for those who agree to participate.

For some, getting new advocates fully engaged will require an investment of time and attention on your part. You will need to support the advocates in becoming part of the decision-making process and building relationships with other participants so that they feel like they have a real stake in the outcome of the Community Quality Collaborative’s work and in its future endeavors.

Overview of the Guide

- **Section 1: Understanding Consumer Advocates** – Who are advocates, what do they care about, and what are the best ways to ensure their involvement in the Community Quality Collaborative’s work?
- **Section 2: Getting the Lay of the Land** – What do you need to know about the advocates in your community? What are their primary concerns relating to local health care issues?
- **Section 3: Recruiting Advocates** – What do you need to tell potential participants in the Community Quality Collaborative? What messages are likely to be effective, and which should you avoid?
- **Section 4: Educating Advocates** – What do you need to impart to advocates so that they can participate fully in the Community Quality Collaborative, and what are effective ways to convey this information?
- **Section 5: Activating Advocates** – What can you do to integrate advocates into the Community Quality Collaborative’s projects and keep them engaged over the long term?
- **Section 6: Resources** – This section lists several useful resources for Community Quality Collaborative leaders as well as suggested reading for consumer advocates.

Section 1: Understanding Consumer Advocates

Although you may have heard and used the term “consumer advocates” before, you may not be quite sure who they are and how they operate. This section offers a brief overview of advocacy groups and their interests and constraints.

Defining Advocates

Research and focus groups with the general public in the Robert Wood Johnson Foundation’s 14 Aligning Forces for Quality communities in 2007 found that language is important in a health care context. Respondents preferred the term “people” when referring to the general public, “consumer” when referring specifically to people who are making choices about the best provider or institution, and “patient” when referring to people who are actively being cared for by a doctor.³

Generally speaking, the label “consumer advocates” refers to individuals who work at nonprofit, mission-oriented organizations that represent a specific constituency of consumers or patients. Some consumer groups operate at the state, regional, or even national level while others work at the community level. Every group may have a unique focus, but they all share a single mission: to improve the situation for their constituencies.

The focus of consumer advocates varies widely. Some center their work on the needs of specific populations, such as older adults and children. Others focus on a specific disease, such as asthma or cancer.

Another large category is faith-based organizations, which typically address a variety of issues. A smaller but potentially very relevant category is advocacy groups that focus on policy, particularly health care reform. These groups may be concentrated in state capitals. And, finally, there are groups like Citizen Action with broad-based constituencies and even broader missions that touch on a variety of issues in a community such as housing, health care, education, and employment.

For all these groups, the key distinguishing feature is their emphasis on the needs and interests of consumers, even if defined narrowly.

For the purposes of your Community Quality Collaborative, it is best to seek out groups that truly represent consumers. Sometimes the lines appear blurry and it may seem like a health plan, employer group, or even a provider organization could serve as a consumer representative. While they may aim to speak for consumers and patients, these representatives have additional interests to consider, as with any stakeholder group, and cannot be regarded as consumer advocates.

³ *Communicating About "Quality" Health Care: Messages to Support RWJF's Efforts to Improve the Quality of Health Care in Communities.* (November 2007). Robert Wood Johnson Foundation.

What Advocates Care About

While each consumer advocacy group has its own agenda, they may share the concerns of other participants in your Community Quality Collaborative. They care deeply about health care in their community, and they see value in engaging the public on health care issues. However, because many advocacy groups focus on the needs of populations that do not get sufficient care, many focus their efforts on access to care and may need some basic education on quality issues.

Many advocates care deeply about the public's "right to know." With a better understanding of the role that performance information can play in informing consumers' decisions and promoting improvements in care by providers, advocates are becoming more interested in publicly reported performance information and could play a critical role in facilitating use of this kind of information by consumers. When explaining your Community Quality Collaborative's goal of encouraging consumers to buy value, emphasize the right of consumers to know how well their health care providers deliver care.

It also will be important to acknowledge that until recently most performance information has been difficult to locate and understand. Be prepared to explain how the work of your Community Quality Collaborative will likely improve the state of public reporting.

Typical Constraints That Advocates Face

To work effectively with consumer advocates, it is important to recognize the challenges they face and the likely implications for their ability and/or willingness to partner with you. First and foremost, you can expect that many of the advocates you approach are working with a limited budget. With some exceptions, these people are not in organizations with resources to spare. This will affect how much you can ask of them; staff time alone can constitute a major contribution.

A related concern for advocates is that their time and resources are devoted to their mission, which may or not be the same as the Community Quality Collaborative's mission. Some simply cannot take on additional work. Others may be interested and able, but will need to make sure that any activities they participate in have a clear benefit for the people they serve.

On a more substantive note, while you may be approaching consumer advocates with a health care focus, they may not necessarily know what you mean by health care quality or be aware that it is a problem. You may need to educate some of them about the issues and help them see how poor quality affects their constituencies. Other advocates may be acutely aware of the problems with quality to such an extent that they are convinced that the challenges cannot be overcome. For those advocates, it may help to emphasize the potential for change and the successes that others have achieved. For example, you may want to reference initiatives like the Institute for Healthcare Improvement's "100,000 Lives Campaign" in which 3,100 hospitals implemented quality improvement interventions and saved an estimated 122,000 lives in 18 months.⁴ Or, you may want to provide the advocates with information on a Wisconsin-based study that indicated that making performance information public stimulates quality improvement activities.⁵

⁴ Institute for Healthcare Improvement Web site: <http://www.ihl.org/IHI/Programs/Campaign/Campaign.htm?TabId=1>

⁵ Judith H. Hibbard, Jean Stockard, and Martin Tusler, "Does Publicizing Hospital Performance Stimulate Quality Improvement Efforts?" *Health Affairs*, (22) no. 2, 84-94. (2003)

Finally, for some advocates, access to care is a priority that outweighs all other concerns. You may be able to engage them in your Community Quality Collaborative efforts by helping them see how your initiatives to improve quality encompass improved access as a key element.

One final consideration to keep in mind is that some advocacy groups have a long history of successful collaboration with health care providers, local hospitals, or physician groups. Be prepared to describe the multi-stakeholder approach of your Community Quality Collaborative and how participating in the Community Quality Collaborative may enhance existing relationships and/or establish new connections for the advocacy group.

Section 2: Getting the Lay of the Land

Now that you understand more about consumer advocates, where do you start? And what else do you need to know to work effectively with advocates in your community? It is helpful to begin by doing a little research.

Identifying Likely Collaborators

The first step is to identify your community's advocates for health care consumers and patients. You can start simply by asking for recommendations from board members and staff, exploring Web sites for local organizations, and identifying local affiliates of national organizations. Possibilities include organizations that represent specific constituencies, such as AARP, the Area Agency on Aging, and local labor unions. Organizations that focus on the needs of people with specific conditions or diseases, such as the American Diabetes Association, the American Cancer Society, and the American Heart Association, are another good option. It's possible that your community includes organizations such as Citizen Action or the League of Women Voters that are working to reform health care generally, and may be interested in expanding into health care quality. Churches, synagogues, and other faith organizations provide other avenues to pursue because they are community gathering places and often have lay and professional health ministers on staff.

One of the most effective ways to find potential partners is to ask for referrals from people who work with advocates or who serve as members of the groups' boards of directors (e.g., legislators, leaders of provider organizations, your Community Quality Collaborative's other stakeholders) as well as any advocates you already know. Ask them who is active in your community or state and what kinds of populations they represent. In some communities, advocacy groups already have a coalition that they use to pursue shared goals. Partnering with representatives of an existing collaborative can be ideal for your Community Quality Collaborative, which would benefit from the multiple perspectives they can provide.

Some Community Quality Collaboratives may find that identifying advocates who can adequately represent consumers is a challenge. This is often because of socioeconomic factors that may crowd out the need to address health care quality. In the experience of the authors—who have worked at the grassroots level in communities around the country—a market like Memphis, for example, has a large population of people with chronic conditions, but its community of advocates is small and already has a full plate of obligations addressing deep and systemic problems, such as poverty and racial bias. And, because the city of Detroit is experiencing a significant economic downturn, the community's advocates are overwhelmed by issues related to housing and jobs. Situations like these should not discourage you from seeking out people to represent consumers, but they do mean that you will have to exercise some creativity to ensure that consumer groups are adequately represented.

Creativity also is called for in rural areas, many of which cannot support traditional advocacy organizations. However, these areas often have groups such as the Lion's Club or Kiwanis Club or individual leaders who play a similar role in the community. Community Quality Collaboratives that cover geographic areas with rural populations may want to identify people who serve as advocates in their communities even if that is not their official role. For example, a 2004 study by the Society for Public Health Education found that librarians in North Carolina

answer more than 10 health-related questions a week.⁶ In a region with few advocacy groups, librarians could be cultivated to serve as consumer representatives.⁷

Examples of Consumer Advocacy Organizations to Contact

Consumer advocacy organizations that serve women, children, older adults, minority patients, and labor members, such as:

- AARP
- AFL-CIO
- The Arc (the world's largest community-based organization of and for people with intellectual and developmental disabilities)
- Area Agency on Aging
- Easter Seals
- NAACP
- YWCA

Faith-based organizations that serve individuals with specific diseases, such as:

- Churches
- Mosques
- Synagogues

Broad-based or policy-focused organizations, such as:

- Citizen Action
- Consumer's Union
- Kiwanis Club
- League of Women Voters
- Lion's Club
- Literacy Council
- Neighborhood Associations

Doing Your Homework: Potential Partners

Once you have identified these possible partner organizations, learn more about them. To determine whether they are a good fit for your Community Quality Collaborative, you will need to find out what these organizations do, what they care about, and how they are funded.

You also need to assess the relative strengths and weaknesses of the individuals who would represent these advocacy organizations in order to determine their fit with your Community

⁶ Laura A. Linnan, Barbara M. Wildemuth, Claudia Gollop, Peggy Hull, Christie Silbajoris, and Ruth Monnig, "Public Librarians as a Resource for Promoting Health: Results From the Health for Everyone in Libraries Project (HELP) Librarian Survey." *Health Promotion Practice*. Vol. 5, No. 2, 182-90. (April 1, 2004)

⁷ Ibid.

Quality Collaborative. As you do in identifying any stakeholder representatives, consider the following:

- **Is the advocate ready to engage in the kinds of projects the Community Quality Collaborative will take on?** You can assume that the advocates you meet will fall along a broad spectrum with respect to their readiness to engage in the work of the Community Quality Collaborative, with some not at all interested, some unsure but intrigued, some interested but not quite ready, and some highly enthusiastic. While it may be ideal to help move all advocates along that spectrum, the more practical approach is to focus your attention on the “early adopters.”
- **Is the advocate able to see beyond his or her personal experience with health care?** Is he or she able to use personal experiences constructively to focus on what could be improved? Advocates may be passionate about health care issues because of their personal experiences with the health care system, but it is critical that they can speak for the organization’s constituency, not just themselves, and see how their concerns fit into the big picture.
- **Will the advocate be able to incorporate the work of the Community Quality Collaborative into their current job responsibilities?** Some advocates will be unable to participate in the Community Quality Collaborative because their organization is acutely understaffed. These organizations often will suggest that a volunteer, a retiree, or member of their organization fulfill the role. This person’s strengths and weaknesses should be assessed as well to determine whether they are a good fit.
- **Does the advocate have good people skills?** Can he or she participate effectively in a multi-stakeholder group? In the context of the Community Quality Collaborative, this person may have to deal with a number of people who have very different perspectives and priorities. Does he or she have the skills to engage diplomatically? Will he or she feel comfortable asking other stakeholders to explain jargon or concepts that are unfamiliar?
- **Does the advocate have good communication skills?** In addition to being able to listen well and absorb information, the advocate needs to be able to support and communicate your Community Quality Collaborative’s messages to his/her constituency.

The following worksheet is designed to help you keep track of potential partners. (See *Section 6: Resources* for a full-page version of this sample form.) As discussed later in this Guide, it is possible that participants in the Community Quality Collaborative will need to leave the group over time, so it will be helpful to Community Quality Collaborative leaders to be able to refer back to this record of your research and your reasons for selecting specific individuals to participate.

Consumer Advocate Contact List

Name of Organization	Focus/Priorities	Organization Representatives: Name, Position, Phone, Fax, E-mail Address	Assessment of Fit with the Community Quality Collaborative (Include brief	Status (Include record of meetings)
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Doing Your Homework: Key Issues

In addition to learning about the people, take some time to learn about the major policy issues in your community so that you can better understand the advocates' priorities, their challenges, and the environment in which they operate. This will help you articulate how your Community Quality Collaborative activities relate to the immediate concerns of the advocate and their organization.

- **What issues is your community struggling with?** Possibilities worth noting include hospital closures, housing shortages and/or foreclosures, access to healthy foods, the employment picture, and constraints on public transportation.
- **How do those issues intersect with health care?** For example, how does limited access to transportation affect access to care?
- **What is the quality profile of your community's health care system?** What are the quality improvement priorities in your state or community? These priorities may suggest the inclusion of particular consumer advocacy organizations in your Community Quality Collaborative. To help determine the quality profile of your community, Community Quality Collaboratives can tap information from the HCUPnet (<http://hcupnet.ahrq.gov/>), the National Healthcare Quality Report (NHQR) (<http://www.ahrq.gov/qual/nhqrfact.htm>), and the NHQR state snapshots (<http://statesnapshots.ahrq.gov/snaps07/index.jsp>).
- **What health care-related issues are current priorities for the state legislature?** The advocates are likely to focus attention on those issues.
- **What kinds of projects are foundations and other funders supporting in the community?** Those projects can offer insight into the local concerns that others have identified. Knowing who is doing what also can give you a sense of whether some advocates may already be over-extended.

Section 3: Recruiting Advocates

As you are investigating possible partners, you also will be starting the process of recruiting. This step encompasses cultivating relationships, communicating the mission and goals of your Community Quality Collaborative, and determining together the potential fit between the advocate and the Community Quality Collaborative. Your goals at this point are to identify the most suitable options among the ones available to you and make the case for their involvement.

What You May Want to Find Out

As with a budding relationship with any potential Community Quality Collaborative stakeholder, it helps to start out by learning as much as you can about the advocates you are interested in. Take the time to get to know them:

- What are their organizational priorities?
- Where does health care fit into these priorities?
- What do they know about the issue of health care quality, and what is their interest in working to improve quality?
- How many paid staff does their organization have?
- What constraints might the advocates face in engaging in health care quality work? (e.g., a fundraising objective, a legislative platform that does not include health care)
- What external factors influence their work? (e.g., legislative calendar, election year, business community if union)
- Do they ever work with other organizations? Which ones and for what purposes?
- What programs, tools, etc., do they provide to the people they serve?
- How do they communicate with their constituents? (e.g., Web site, newsletter, listserv, annual meeting)
- What is their organization's "reach" (i.e., their membership, the people they serve or their constituency)? How many people do they communicate with via their Web site, newsletter, listserv, annual meeting?
- What are their professional interests as individuals?
- What challenges do they face in their day-to-day work?

You can use this information both to gauge whether your initial assessment holds true (i.e., that this person and the organization they represent really will be a good fit with your Community Quality Collaborative) and to assess how your Community Quality Collaborative could benefit from this person's experience and knowledge.

Suggested Messaging: Engaging and Educating

As you cultivate relationships with the consumer advocates, as with any new stakeholder group, it is important to communicate several points so they clearly understand what they are agreeing to do.

1. First, you need to explain why the work of your Community Quality Collaborative concerns them.

Not all advocates are aware of the issues surrounding health care quality. You will need to brief them on the nature and extent of these problems. If possible, try to put the problems in a context that is meaningful to them. Helping them see how access is a key element of quality—and how poor access contributes to poor quality of care—can be particularly useful. To the extent that information on quality can be tailored to their constituents (e.g., by geography, payer, disease, age), all the better. (Resources from HCUPnet <http://hcupnet.ahrq.gov/> and NHQR <http://www.ahrq.gov/qual/nhqract.htm> noted earlier might be useful.)

Be careful not to overwhelm the advocates with detailed information. For example, you wouldn't want to start talking about quality measures with someone who is not already well-versed in quality issues. The purpose at this point is to engage more than it is to educate. Explaining the breadth of the quality problems—such as infections and medical errors—and the extent to which these quality deficiencies occur are compelling ways to help the advocates understand why improving quality is an important goal. Using personal consumer stories or patient vignettes about quality care also will resonate with many consumer advocates.

2. Second, it is important to make the connection for them between their organization's priorities and the work of your Community Quality Collaborative.

For example, if one of the priorities of an advocacy organization is to provide education, information, and support to people with diabetes, you can explain how the Community Quality Collaborative will gather and report information that enables consumers to choose a health care team that provides high-quality diabetes care. Additionally, most advocacy organizations will be interested in giving their constituents information about patients' experiences with health care providers and facilities, so if your Community Quality Collaborative will be reporting based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS), point this out to the advocates and explain how this information can assist consumers in making informed health care decisions.

A second key message involves the value to the advocates of participating in the Community Quality Collaborative's initiatives. It is natural for the advocates to want to know what's in it for them. While you may want to tailor what you say to the individual, there are a few points you can make:

- This is an opportunity to be involved in a fast-growing movement to improve health care quality. While the idea of assessing and reporting performance information to spur higher-quality care has been simmering for some time, in many communities it has only recently taken root. Participating in the Community Quality Collaborative puts advocates at the center of a promising initiative with national support.
- Participating advocates can tell their organization's members that their interests are being represented in a forum with diverse and important community stakeholders.

- Involvement in the Community Quality Collaborative enables the advocates to make sure that their colleagues in the Community Quality Collaborative understand the benefits and costs of the initiative from the perspective of the constituency that they represent.
- Participating advocates have access to a national network of advocacy organizations pursuing better quality and increased transparency.

3. *Finally, it will be helpful to spend some time talking about advocate roles.*

(See Section 4 for a discussion of the roles that advocates can play in the Community Quality Collaborative.) Some advocates may be better suited for certain roles than others, so discussing expectations up front can help minimize frustrations in the future and ensure that you recruit the best people for the tasks at hand. Similarly, Community Quality Collaborative leaders should be as explicit as possible about what will be required of participants in terms of time, resources, and/or staff. As noted earlier, the donation of the advocate’s time may be all the organization can afford.

Advice About Communicating With Advocates

Based on several years of experience recruiting advocates around the country, the staff of the National Partnership for Women & Families offers the following tips:

Selecting the Right People

- Get a feel for the politics of the advocacy community. If possible, expand your network beyond the “usual suspects,” and ask questions to learn who is respected and who to avoid.
- Whenever possible, begin the process at a high level in the organization. A senior leader is in the best position to commit the organization to your Community Quality Collaborative.
- Choose advocates who will provide meaningful input, rather than the ones who will not “rock the boat.” However, be careful not to choose people who are likely to be consistent “naysayers.” Your goal is to find the people who will support your mission and will help move your Community Quality Collaborative forward productively.

Communicating Effectively

- Frame the message as a win-win. Talk about how participating in your Community Quality Collaborative will benefit both the advocacy organization as well as the Community Quality Collaborative.
- Be positive—not critical—about the role of health care providers. Many consumer advocates have ongoing collaborations with the physician community.
- While your Community Quality Collaborative’s activities may be intended to benefit everyone in the community, advocates are acutely aware that quality problems faced by some populations will not be eliminated quickly or easily. Acknowledge the limitations of a “rising tide” argument and be prepared to point out the ways that the work of your Community Quality Collaborative will impact the advocates’ constituents positively.

- Be prepared to explain to the advocates the benefits of a more efficient health care system (e.g., reducing waste, such as duplicate or unnecessary tests). Advocates may be wary of the term efficiency and incorrectly associate the concept with limits on treatment, medications, etc., that could help their constituents.
- Anticipate that some topics, such as patient privacy, will be controversial for some advocates. It is not necessary to avoid those topics, but be prepared to address concerns that advocates are likely to raise, including how patient privacy is protected in your Community Quality Collaborative's transparency agenda.
- Let the advocates know who else will be at the table. Some advocates will be attracted by the opportunity to serve alongside their colleagues at other organizations.

Important Considerations

As you get to know various consumer advocates and move toward recruiting some more intensively, there are several considerations to keep in mind:

- **Timing.** Don't allow the recruitment of consumer advocates to lag behind that of other member types. Adding them at the end will reinforce any concerns they may have about being peripheral to your Community Quality Collaborative's main objectives. If you do ask advocates to participate in Community Quality Collaborative work after all the other stakeholders are assembled, be sure to emphasize how important advocate involvement is to ensuring that the end results of your Community Quality Collaborative efforts benefit consumers, patients, and the public-at-large.
- **Representation.** Ideally, the advocates participating in your Community Quality Collaborative will represent a broad swath of the community. This does not mean that you cannot recruit someone associated with a narrow focus (e.g., an uncommon disease), but that you should try to strike a balance so that multiple interests have a voice.
- **Resources.** Ideally, participating advocates have sufficient resources to support their role as a Community Quality Collaborative stakeholder, whether by participating in meetings or by telling consumers about your Community Quality Collaborative's initiatives. However, making the availability of resources a criterion for participating in the work of your Community Quality Collaborative may eliminate some advocates with significant strengths who can provide other important benefits to your Community Quality Collaborative. Some Community Quality Collaboratives address this issue by establishing a reduced dues rate for consumers and advocacy groups.
- **Initial Representation and Future Expansion.** It is important to strive to have a good balance among stakeholders in your Community Quality Collaborative, including consumer advocates. Over time, it may make sense to add advocates to your Community Quality Collaborative, or replace those who have to leave. You can use this initial recruiting process as a way to identify and cultivate possible future participants so that you have a pool of relationships to revisit.
- **The Messenger.** In some communities, advocates may have preconceptions about other stakeholders, or even certain members of your Community Quality Collaborative. You

may need to find a “trusted messenger” who can approach the advocates about the idea of participating in your Community Quality Collaborative. Ideally, this “trusted messenger” would be another consumer advocate, a representative from an organization that provides funding for advocacy initiatives, or a stakeholder who has a history of collaborating successfully with advocacy organizations.

Section 4: Educating Advocates

During the recruiting stage, Community Quality Collaborative leaders (or their proxies) started the process of educating consumer advocates about health care quality issues. Once they have agreed to participate in the Community Quality Collaborative, that education needs to shift to a deeper level so that the advocates can be fully involved.

The most important thing for Community Quality Collaborative leaders to keep in mind is that the education of the advocates will be an ongoing process. You can plant the seeds in the early start-up phase of the Community Quality Collaborative, but realistically, it will take some time for the advocates to build their knowledge base and become fluent in the language of quality. You also should remember to avoid acronyms and encourage the advocates to ask for clarification of terms or concepts.

Why Quality Should Concern Consumer Advocates

There is no way to generalize about what consumer advocates will already know about quality, but you can assume that there will be wide variation in their knowledge and in their views about the health care system. Some may have misconceptions about the health care system, such as the notion that more services and treatments are better than fewer and more expensive treatment is better than less costly care.⁸

While you may want to adjust your approach to account for what they may already know, there are several major points you will want to cover:

- **What you mean when you refer to the problems with health care quality.** To help advocates understand what you mean by quality problems, talk about the ramifications of underuse, overuse, and misuse of health care. (See the *Fact Sheet Series* included in the *Consumer Advocate Workshop Template* materials section of this toolkit.) In this conversation, you may have to tackle two common misperceptions about quality. First, there may be a misperception that more care is better care. Second, some people may not be aware that underuse is also a problem. To counter those beliefs:
 - Cite statistics on the variations in the delivery of care across the country. Whenever possible, use data from your state or even your community (e.g., AHRQ’s HCUPnet: <http://hcupnet.ahrq.gov/> and National Healthcare Quality

⁸ Dr. Carolyn Clancy, *Busting Myths About Health Care Quality*. Agency for Healthcare Research and Quality (February 19, 2008): <http://www.ahrq.gov/consumer/cc/cc021908.htm>.

Report (NHQR) and State Snap Shots:
<http://www.ahrq.gov/qual/measurix.htm#quality>).

- Explain that there is a growing body of evidence about what and how much care is most effective.
- Tailor the information you present to the advocates as much as possible by focusing on the aspects of health care that are important to them (e.g., diabetes care, or care for children.) Include information about patients' experiences with care and the CAHPS surveys. Information on CAHPS can be found here: <https://www.cahps.ahrq.gov/default.asp>.
- Discuss Community Quality Collaborative resources specific to consumer organizations such as the Agency for Research on Health and Quality's Questions Are the Answer Web site available at: <http://www.ahrq.gov/questionsaretheanswer/>. The Web site includes information directed at consumers on reducing medical mistakes, building a list of personalized questions to bring to doctor visits, and preparing for surgery.
- **Poor quality is a problem for everyone.** Many people mistakenly believe that only those who are poor are at risk for poor quality care. It is important to show how quality problems impact people of all socioeconomic levels. You may want to explain how people in a relatively wealthy community may be more likely to receive unnecessary care, putting them at risk of complications and errors in care that could have been avoided.

You also may want to use the following messages that have been tested with consumers in the Robert Wood Johnson Foundation's 14 Aligning Forces for Quality communities:⁹

"Getting good medical care is a worry for many people. There are too many choices and not enough clear, trustworthy information."

"Many people don't have close relationships with their doctors anymore. Finding the right doctor can be tough in a confusing health care system, and the journey can leave some people feeling uneasy about the care they receive."

"Most doctors are pressed for time these days, and patients feel like they don't have time to really ask their doctors questions. Rushed doctor visits can leave people with lingering concerns about their treatments or medications, or not having fully explained their symptoms."

- **Poor quality reflects problems with the system.** In the experience of the authors, advocates are often protective of health care providers and do not want individual doctors singled out. Explain that poor quality has many causes, such as inadequate communication and lack of coordination, that are a function of how the system works rather than the limitations of individuals and that your Community Quality Collaborative's efforts are aimed at improving the health care system. It may be helpful to say something like:

⁹ *Communicating About "Quality" Health Care: Messages to Support RWJF's Efforts to Improve the Quality of Health Care in Communities.* (November 2007). Robert Wood Johnson Foundation.

“In every community, both good and bad care is being provided in hospitals and doctors’ offices. There are too many mistakes and too much miscommunication in the health system that can negatively affect people’s lives.”¹⁰

- **Poor quality is a problem we cannot afford to neglect.** Advocates, like many of the people they represent, may believe that fixing the health care quality crisis will lead to even higher health care costs. It is critical to talk about the costs, financial and otherwise, associated with poor quality care, and how the savings achieved through higher quality could be used to expand access and achieve other worthy goals. Using messages that encourage the advocates to get involved and take action is important. For example, you may want to say:

“People can improve their care by learning more about their doctors and their own conditions—asking questions, sharing their medical history, making sure they understand their doctor’s recommendations, and taking the necessary steps to feel better sooner.”¹¹

What Others Are Doing

Consumer advocates need to know that the efforts of the Community Quality Collaborative are consistent with work being done across the country by many other multi-stakeholder collaboratives, including the other Community Quality Collaboratives. This context will help them see that they will be part of a large movement confronting the same challenges.

While you want to avoid overloading the advocates with information, you can touch on the various initiatives in place at this time:

- **Chartered Value Exchanges (Community Quality Collaboratives):** Your Community Quality Collaborative is part of a nationwide learning network organized by the Agency for Healthcare Research and Quality to promote transparency about the quality and cost of services delivered by health care providers. Each Community Quality Collaborative includes key stakeholders such as public and private payers, providers, plans, and consumer advocates. Community Quality Collaboratives focus on one or more of eight areas: collaborative leadership and Community Quality Collaborative sustainability, public at-large-engagement, quality and efficiency measurement, public reporting, provider incentives, consumer incentives, capacity for improving quality, and health information technology/health information exchange. Learn more at: <http://www.hhs.gov/valuedriven/communities/valueexchanges/exchanges.html> and <http://www.ahrq.gov/qual/value/localnetworks.htm>.
- **Aligning Forces for Quality (AF4Q):** This national program of the Robert Wood Johnson Foundation operates in 14 communities, and is sometimes referred to as “AF4Q.” These communities are funded to make progress in five key areas: performance measurement/public reporting, consumer engagement, quality improvement, reducing racial and ethnic gaps in care, and enhancing the central role that nursing plays in good health care. Learn more at: <http://www.forces4quality.org/default.asp>.

¹⁰ Ibid.

¹¹ Ibid.

Depending on your location, you also may want to share information about local, state, and regional initiatives related to or separate from the above initiatives.

Tips for Community Quality Collaborative Leaders Regarding the Education of Advocates

Getting any Community Quality Collaborative stakeholder, including consumer advocates, up to speed on quality issues is not a simple or one-time task. It will take time and repetition to get the advocates to a point where they feel engaged and knowledgeable. Community Quality Collaborative leaders need to view this up-front effort as an investment that will bear fruits later.

The following guidance is intended to help make this process more effective and efficient:

- Be wary of information overload; do not try to tell advocates everything at once.
- Use your time efficiently by meeting with as many advocates as you can at the same time. Provide lunch or dinner, as appropriate.
- Use a slide presentation, tailored to the advocates' constituencies, to break down your messages into manageable pieces. (See AHRQ slides on AHRQ's Learning Network for Community Quality Collaboratives Web site under the "Program Info" tab and the PowerPoint slides included in this toolkit.)
- Be prepared with more detailed materials that the advocates can review after the meeting.
- Leave a substantial amount of time for questions.
- Contact each advocate after the meeting to answer questions, reinforce the key messages about the importance of the Community Quality Collaborative's initiatives and how they'll benefit the advocate's constituents, and encourage their participation in specific activities.

Section 5: Activating Advocates

Community Quality Collaboratives have identified eight areas in which they are engaging, to varying degrees:

1. Collaborative Leadership & Sustainability
2. Public At-large Engagement
3. Quality & Efficiency Measurement
4. Public Reporting
5. Provider Incentives
6. Consumer Incentives
7. Capacity for Improving Quality
8. Health Information Technology (HIT)/Health Information Exchange (HIE)

Not all Community Quality Collaboratives are engaged in work in every focus area, and not all stakeholders are involved in every Community Quality Collaborative focus area.

Once the advocates are sufficiently engaged and comfortable with the work at hand, Community Quality Collaborative leaders can “activate” the advocates by helping them determine what aspects of your Community Quality Collaborative’s work are the best fit for them. Some advocates will be suited to participating in a leadership role. Other advocates will make a significant contribution to your Community Quality Collaborative by articulating the needs and concerns of consumers in decisions about public engagement, quality measures, public reporting, consumer incentives, and quality improvement priorities. For example, advocates can help you understand the best ways to engage the public on health care quality issues using their experiences working on other public health and public education campaigns. They also can provide input on the best way to publicly report performance measures to ensure that the information is accessible to consumers and may even help identify individuals to test messages. The advocates also may have suggestions on what kinds of incentives will result in sustained behavior changes among consumers. Many advocates also will play a major role in communicating with consumers about the goals and programs of your Community Quality Collaborative, and help to engage patients and consumers in quality issues.

Supporting Activated Advocates

Community Quality Collaborative leaders can take several steps in the early stages to help ensure that the consumer advocates function effectively as participants in your Community Quality Collaborative.

- Recognize that the advocates, like any new stakeholder, are likely to feel like the “odd person out” among Community Quality Collaborative participants. You can help diminish that feeling by avoiding jargon and explaining acronyms clearly every time they are used.
- Make sure that the advocates are seen as equal partners by helping other participants understand what the advocates bring to the table, particularly with respect to their ability to reach out to the public. You also can foster mutual understanding by communicating

the advocates' concerns to others in the group, briefing the advocates in advance of meetings, and making time on meeting agendas for the consumer's viewpoint so that the advocates have an opportunity to be heard.

- Link advocates to the activities of your Community Quality Collaborative as soon as possible. While they may still be getting up to speed on the intricacies of the health care quality issue, getting involved will help them move up the learning curve more quickly; it also will ensure that you incorporate the consumer's perspective from the outset.
- Incorporate advocates into planning and decision-making. Their role should not be limited to communicating with consumers about goals and activities, particularly ones they had no voice in developing.
- Develop a Community Quality Collaborative structure that supports consumer advocates. There are several potential options: 1.) Consider creating a consumer engagement committee that meets independently of the other Community Quality Collaborative initiatives to help advocates with limited time and resources participate in the Community Quality Collaborative work. If you do form a consumer engagement committee, be certain to integrate the work of the committee into the overall Community Quality Collaborative efforts and vice versa. 2.) Include at least one consumer advocate in each Community Quality Collaborative workgroup. 3.) Support the advocates in forming their own quality-oriented network, from the patient perspective, to learn from each other and possibly expand upon your Community Quality Collaborative's efforts. A network like this also can help to educate other advocates not involved in the Community Quality Collaborative, creating a pool of potential participants to draw upon in the future.
- Look for opportunities to involve the advocates in "small successes" (i.e., short-term projects that are highly likely to succeed). Some advocates may be unclear about the Community Quality Collaborative's goals and their role; a project focusing on a topic they can relate to, such as improving patient safety, can help them understand what your Community Quality Collaborative aims to do and how they can help. A "small success" also can address any skepticism they may have regarding your Community Quality Collaborative's ability to make an impact in the community.

Moving Forward

As your Community Quality Collaborative matures, consumer advocates will have many opportunities to shape your Community Quality Collaborative in a way that benefits the public—which is the ultimate goal of this initiative. To sustain them in this critical role:

- **Offer ongoing encouragement and support.** For example, you can assist the advocates in being better informed and connected by distributing relevant articles about quality improvement and reporting as well as news of similar activities in other communities. Be sure to check in with the advocates on a regular basis to ask how you could make the process work better for them.
- **Continue to cultivate your relationship with the advocates.** Talk to them about their role in your Community Quality Collaborative and whether they believe their

involvement is making a positive impact; if not, discuss how their role could change to ensure that they are involved effectively.

- **Encourage consumer advocates to reach out to advocates in other Community Quality Collaboratives.** The Community Quality Collaborative Learning Network Web site includes a membership feature to facilitate this networking.
- **Finally, anticipate turnover.** In some cases, their organization's priorities may shift over time, making their continued participation infeasible or inappropriate. Or, the individual advocates may need to leave your Community Quality Collaborative because they no longer represent the consumer organization. If this happens, be sure to ask the person who is leaving for recommendations; replacing the departing advocate with someone else in their organization can make the transition easier for everyone. If that is not possible, go back to the network of advocates you developed in the early stages and ask the other advocates participating in your Community Quality Collaborative for recommendations as well.

Section 6: Resources

This section provides resources that Community Quality Collaborative leaders can use with consumer advocates and suggests several books that can orient advocates to the issues the Community Quality Collaborative plans to address.

Resources for Community Quality Collaborative Leaders

- HCUPnet (<http://hcupnet.ahrq.gov/>). HCUPnet is a free, online query system based on data from the Healthcare Cost and Utilization Project (HCUP). It provides access to health statistics and information on hospital inpatient and emergency department utilization. HCUPnet's query system allows users to generate tables and graphs on national and regional statistics and trends for community hospitals in the U.S. In addition, community hospital data are available for those States that have agreed to participate in HCUPnet.
- *National Healthcare Quality Report* (<http://www.ahrq.gov/qual/measurix.htm#quality>). This report tracks the health care system through quality measures, such as the percent of heart attack patients who received recommended care when they reached the hospital or the percent of children who received recommended vaccinations. National and State-specific information is available via NHQRnet, an online query system at <http://nhqrnet.ahrq.gov/nhqr/jsp/nhqr.jsp>. NHQRnet provides data by subpopulations (i.e., age ranges) and tracks and displays trends over time for national estimates of nearly 50 measures.
- *The Dartmouth Atlas* (<http://www.dartmouthatlas.org/>). The Dartmouth Atlas is an interactive resource for identifying variations in the use of medical care across local markets. It was developed by researchers with the Dartmouth Institute for Health Policy and Clinical Practice.

Suggested Reading

Glossary of health care and quality terms:

<http://www.academyhealth.org/publications/glossary.pdf>

Shannon Brownlee. *Overtreated: Why Too Much Medicine Is Making Us Sicker and Poorer*. New York: Bloomsbury, 2007.

Atul Gawande. *Better: A Surgeon's Notes on Performance*. New York: Henry Holt and Company, 2007.

Atul Gawande. *Complications: A Surgeon's Notes on an Imperfect Science*. New York: Henry Holt and Company, 2002.

Rosemary Gibson and Janardan P. Singh. *Wall of Silence: The Untold Stories of the Medical Mistakes That Kill and Injure Millions of Americans*. Washington, DC: Lifeline Press, 2003.

Michael F. Roizen and Mehmet C. Oz. *You: The Smart Patient: An Insider's Handbook for Getting the Best Treatment*. New York: Simon & Schuster, 2006.

Robert M. Wachter and Kaveh Shojania. *Internal Bleeding: The Truth Behind America's Terrifying Epidemic of Medical Mistakes*. New York: Rugged Land, 2004.

National Health Care Quality Entities

- Agency for Healthcare Research and Quality (AHRQ)¹²—The Nation’s lead Federal agency for research on health care quality, costs, outcomes, and patient safety.
- National Quality Forum (NQF)¹³—Formed in 1999 based on the recommendations of a President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry. Serves as the national measurement endorsement entity and the primary forum for setting measurement priorities.
- National Committee for Quality Assurance (NCQA)¹⁴—Formed in 1990 and has been a central figure driving quality through its accreditation, certification, and recognition programs. Accredits health plans, disease management and managed behavioral health organizations; recognizes high-quality physicians; certifies other programs; develops and implements measures (e.g., HEDIS).
- The Joint Commission¹⁵—Formed in 1951 to provide voluntary accreditation of hospitals. Accredits hospitals, home health programs, nursing homes, etc.; develops and implements quality measures.
- Centers for Medicare & Medicaid Services (CMS)¹⁶—Instituted in 1964, CMS is an Agency within the Department of Health and Human Services. Medicare embarked on performance measurement reporting as a vehicle for promoting voluntary quality improvement in 2004. CMS is the payer for Medicare and Medicaid and also sponsors measure development and data aggregation.
- Quality Alliance Steering Committee (QASC)¹⁷—Formed in 2006 from two key health care quality alliances—the Ambulatory Quality Alliance (AQA) and the Hospital Quality Alliance (HQA)—to coordinate the promotion of quality measurement, and speed the adoption of the work of AQA and HQA.
 - AQA Alliance (AQA)¹⁸—Coalition formed in 2004 by physicians, health plans, and the Agency for Healthcare Research and Quality (AHRQ), which has evolved to be a multi-stakeholder group working on measure implementation for physicians and non-physician clinicians.
- Hospital Quality Alliance (HQA)¹⁹—Formed in 2002 to increase hospital participation in public reporting and expand use of quality measures. The HQA is a public-private

¹² Agency for Healthcare Research and Quality Web site: www.ahrq.gov/

¹³ National Quality Forum Web site: <http://www.qualityforum.org/>

¹⁴ National Committee for Quality Assurance Web site: <http://www.ncqa.org/>

¹⁵ Joint Commission Web site: <http://www.jointcommission.org/>

¹⁶ Centers for Medicare & Medicaid Services Web site: <http://www.cms.hhs.gov/>

¹⁷ Quality Alliance Steering Committee Web site: <http://www.brookings.edu/projects/qasc.aspx>

¹⁸ AQA Alliance Web site: <http://www.ambulatoryqualityalliance.org/>

¹⁹ Hospital Quality Alliance Web site: <http://www.hospitalqualityalliance.org/>

coalition of hospitals, nurses, physician organizations, accrediting agencies, government, consumers, and businesses that sponsor measure implementation initiatives.

Consumer Advocate Contact List

Name of Organization	Focus/Priorities	Organization Representatives: Name, Position, Phone, Fax, E-mail Address	Assessment of Fit With the Community Quality Collaborative (Include brief rationale)	Status (Include record of meetings)