

Guide to Engaging Consumer Advocates in AF4Q Alliances

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Introduction

The premise of the Robert Wood Johnson Foundation’s Aligning Forces for Quality (AF4Q) project is that no single person, group or profession can improve health and health care throughout a community without the support of others. Therefore, AF4Q asks key stakeholders—health care providers, employers, consumers, and health plans—to work together to achieve better care in their communities. The purpose of this *Guide* is to help AF4Q Alliance leaders and staff ensure that one of the key stakeholder groups—consumers—is engaged in their Alliance.

Consumers are a unique stakeholder in that, historically, they have not been primary drivers of health care quality improvement efforts. Furthermore, while they are impacted by health care costs, their livelihoods don’t come from the health care system, like some stakeholders. As a result, it can be challenging to identify the best consumer representatives to include in your Alliance, and to activate and maintain their engagement over time. However, given the fact that a key AF4Q consumer engagement goal is consumers accessing and using health and comparative performance information at key decision points, the inclusion of consumer advocates is crucial to ensuring that your Alliance’s efforts and end-results benefit all stakeholders, including consumers.

This *Guide* defines consumer advocates, provides examples of consumer advocacy organizations, and details a consumer engagement process. It outlines specific strategies the Alliances can undertake independently to achieve an authentic consumer voice in their Alliance as well as areas in which the National Partnership for Women & Families (National Partnership) can offer assistance.

The AF4Q initiative recognizes that consumers have important roles to play in their health and health care, including accessing and using health and comparative performance information to make health care decisions, communicating with their physicians, and committing to changing their personal behaviors. An effective consumer engagement strategy recognizes that when motivating consumers to take these actions, the “source” matters. Trusted entities in your community—consumer advocates—should be identified and enlisted to participate in Alliance efforts. In short, consumer advocates have much to offer Alliances:

- **The ability to represent and give voice to the needs and wants of consumers.** Consumer advocates are in regular contact with their constituents. They understand their constituents’ experiences and views and can offer a perspective that is informed by a diversity of patient experiences—from the underserved to seniors to patients with specific diseases—as well as their own personal encounters with the health care system.
- **The ability to reach consumers.** Consumer advocates can be highly effective trusted distributors of information to consumers. They typically have a variety of ways in which they communicate with their constituencies, including websites, newsletters, broadcast e-mails, conferences, and mailing lists. Additionally, the advocates can also connect you with their constituencies to solicit input on Alliance projects, products, and activities—you can then refine and tweak your Alliance work based on that feedback.

- **The trust of consumers and, therefore, the ability to educate and influence.** Consumer advocates and their organizations—like health care providers— are often a trusted source of health care information whereas, according to a California HealthCare Foundation report, other entities such as health plans and employers are typically not viewed as a trusted 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 nearly 1 in 5 did not trust employers at all.¹

Even fewer people trusted health plans: only 18 percent trusted plans “a lot,” and more than one quarter did not trust them at all. Voluntary consumer organizations focused on specific diseases, on the other hand, seem to have the confidence of consumers: more than 65 percent of consumers indicated that they have “a lot” of trust in these organizations. Engaging advocates in your Alliance can help you achieve the credibility you will need before many consumers will seek out and use your Alliance’s health and performance information.

- **Credibility with decision leaders.** Many consumer advocates have earned the respect of community members and established relationships with stakeholders including the media, policy makers, and elected and appointed community leaders. They may be able to leverage these relationships in ways that benefit the Alliance, including securing media coverage for Alliance events or convincing community leaders to provide monetary or in-kind support for Alliance initiatives.
- **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—for example, accessing and using performance reports and self-management tools.
- **An understanding of the community.** Because they are integrated into the community they serve, advocates can help ensure that the output of the Alliance is useful to the community. They also can function as a “translator,” in that they can promote the work of the Alliance in ways that are meaningful to the public.

How to Define a Consumer Advocate

Generally speaking, the term “consumer advocate” refers to an individual who works at a nonprofit, mission-oriented organization that represents consumers or patients. Some consumer groups operate at the state, regional, or even national level; others work at the community level; some work at both. Every group may have a unique focus, but they all share a single mission: to improve the quality of life for their constituencies.

The focus of consumer advocates and organizations 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.

Examples of organizations include faith-based groups, which typically address a variety of issues. Another relevant category is consumer advocacy groups that focus on policy, particularly health care reform, from the consumer perspective. Additionally, groups like Citizen Action have 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.*

Another distinguishing characteristic of consumer organizations is that they do not have a financial stake in the health care system. Unlike other stakeholders who depend on the health care system for their livelihoods, the consumer's health care agenda isn't largely influenced by economic interests.

Alliances should 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 consumers. The National Partnership can help you make these distinctions and identify the most appropriate advocates to engage in your Alliance.

Examples of Consumer Advocacy Organizations

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

- AARP
- AFL-CIO
- The Arc
- Area Agency on Aging
- NAACP
- YWCA

Faith-based organizations, such as:

- Churches
- Mosques
- Synagogues
- Association of Professional Chaplains
- PICO- Faith-based community organizers

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

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

Consumer Engagement Process

The process for engaging consumer advocates consists of four main stages:

1. Identifying likely collaborators
2. Initiating and building relationships
3. Involving and activating
4. Supporting the activated advocates

➤ Identify Likely Collaborators

Research

To identify appropriate consumer advocate stakeholders to involve in your Alliance, start by researching your community's consumer groups to learn more about them and determine whether they are a good fit. Groups' priorities and programs evolve over time; you might find that an organization you passed over at one point might actually be a very good fit for your Alliance.

Spend some time learning about the major policy issues that impact the advocates' priorities, their challenges, and the environment in which they operate. This research will help you articulate how your Alliance activities relate to the immediate concerns of the advocates and their organizations. Consider things like:

- The level of knowledge about health care, generally, and quality, specifically, and where these issues fit into the organizations' priorities.
- The number of paid staff, availability of resources, and constraints that may impact the advocates' ability to engage.
- The organization's reach, communication capabilities and interest in collaboration.

Don't assume that organizations with limited resources or other constraints will not want to participate in the Alliance. As you build your relationships with the various consumer groups you can work with them to determine the best way to engage them. In some cases their level of engagement will be lower because of these constraints. Other advocates will overcome their organizational barriers because they are highly vested in the Alliance's objectives.

Consumer Core Competencies

Once you have identified potential consumer groups for Alliance involvement, it's time to find the right people. Try to identify advocates with these groups who will provide meaningful input, rather than the ones who will "rock the boat." Be careful not to choose people who are likely to be consistent "naysayers." That said, you do want to have diverse perspectives and someone who is willing to speak up. Some good core competencies to look for:

- Experience advocating the patient viewpoint;
- Background in health care or understanding of the health care system;
- Communication skills and ability to "tell a story";
- Experience serving on multi-stakeholder groups; and
- Baseline knowledge of the technical components of health care quality.

Most consumer advocates won't possess all of these competencies. Your primary goal is to find the people who will support your mission and will help move your Alliance forward meaningfully. Many consumer advocates will be effective members of your Alliance even if they don't have all the core competencies and others will attain them over time and with some training.

➤ Initiate and Build Relationships

Engagement

Once you've identified a pool of potential advocate stakeholders, it's time to start the relationship-building process.

Even if you think you have enough information from your research, hearing from the consumer advocates directly will provide more insight and clarity around their priorities, focus areas, and capabilities. Consider organizing a community listening session; invite advocates from consumer organizations you've researched and get to know them a little better.

A listening session is an opportunity to increase your understanding of factors that may impact the consumer advocates' ability and willingness to partner with you, for example:

- What do they know about the issue of health care quality, and what is their interest in working to improve quality?
- What constraints might the consumer advocates face in engaging in health care quality work? (e.g., a fundraising objective, a legislative platform that does not include health care)
- What is their experience with and interest in partnership and/or collaboration? What other organizations have they worked with? To what end?
- What is their organization's "reach" (i.e., their membership, their constituency)? How many people do they communicate with via their website, 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 research holds true and to assess how your Alliance could benefit from each organization's knowledge and focus.

A listening session also provides an opportunity for you to share information about the Alliance's goals and objectives and to cultivate interest in your work. There are three main topic areas to address:

1. Explain why the work of the Alliance concerns them and the community.
2. Make the connection between their organization's priorities and the work of the Alliance.
3. Talk about potential advocate involvement.

Segmentation

As you get to know the advocates, keep in mind that your intent is to grow a pool of advocates who you can turn to for some level of engagement with the Alliance. The pool of advocates should be diverse and should reflect the population of your community as well as your target audience. Keep in mind that not everyone in the advocate pool has to engage with the Alliance in the same way. Create a list of all of the potential ways for advocates to engage in Alliance work—Leadership Team, list-serv, media events, Alliance Workgroups, outreach to policy makers and other stakeholders, vetting of materials, outreach to consumers, etc.—and then work with the advocates to determine the best roles for them to take on.

➤ Involve and Activate

Invitation

After you've learned as much as possible about the consumer advocate pool in your community, you should have a good sense of which advocates will be the best fit for your Alliance. Consider how you will approach these consumer advocates to invite them to participate in the Alliance. It can be helpful if a fellow consumer group or third-party extends the invitation to participate in the Alliance. The National Partnership is available to reach out to consumer organizations in your community and can provide technical assistance on relationship-building such as the timing of recruitment, the right constituency representation, and the required resources and expansion of relationships.

Activation

Once you have approached the consumer advocates and invited them to participate in the Alliance, it is time to “activate” them. Think about the best role for specific consumer advocates and refer back to the segmentation you did of your consumer pool. Some advocates will be prepared to take on a leadership role within the Alliance while others will offer to promote the Alliance's performance report among their membership. Some advocates will volunteer to be featured in media stories about the Alliance initiatives and others will offer to recruit consumer members to an advisory panel.

Whatever role the consumer advocate assumes should be decided upon collaboratively. And, it's important to clearly articulate expectations once the roles have been decided.

Think about answering the following questions:

- Are they being asked to join a multi-stakeholder committee? What will their role be?
- What is the time commitment and how will the advocate's skills be utilized?
- What is the committee or work-group charged with? How will the consumer advocate's perspective be accounted for?
- What kind of preparation should the consumer advocate do to participate effectively? What resources are available to support the consumer advocate?

Decision-Making

Consumer advocates do not want to feel like their role in the Alliance is to serve as a rubber stamp or to fulfill a dashboard objective. Their involvement will be sustained only if they are offered leadership and decision-

making opportunities. Ensuring that the advocates' participation is meaningful can help facilitate adoption of patient-centered innovations, and ultimately, enhance the quality of health care provided in a community.

As you engage consumer advocates in your Alliance, identify and implement best practices in decision-making and consensus building for diverse multi-stakeholder groups. For advocates on the Leadership Team or a sub-committee or working group, part of being activated means being a member on equal footing with the other members. As described above, consumer advocates have unique and valuable perspectives and skills to contribute, just as other stakeholders do. One important means to ensuring equal footing is to outline member roles and responsibilities in a governing document, such as a committee charter. Such a document can make clear that each member, regardless of his or her stakeholder perspective, has a role (and a vote) equal to that of every other member.

Both consumers and advocates are more likely to remain involved in your Alliance if they don't feel isolated or outgunned. It's important that the consumer perspective is represented in proportionate numbers to the other stakeholders.

Link advocates to the activities of the Alliance as soon as possible. While they may still be getting up to speed on the intricacies of health care quality, getting involved will help them move up the learning curve more quickly; it also will ensure that you incorporate a consumer perspective from the outset.

➤ Support the Activated Advocates

Issue-Specific Information-Sharing

Providing resources to support the advocates who have agreed to participate in the Alliance may increase their understanding of complex health care quality issues and help them engage in the dialogue in a more constructive manner.

The National Partnership has developed numerous tools to keep the consumer advocates abreast of quality issues and can help to coordinate educational webinar and presentations. Topics include but are not limited to:

- 1.** *Health Care Quality 101*
- 2.** *Performance Measurement & Public Reporting Basics*
- 3.** *The Value of Race, Ethnicity, Language Data Collection*
- 4.** *Patient Experience Survey Basics*
- 5.** *Health Literacy and Plain Language Principles*

AF4Q's website also houses a resource library with fact sheets, presentations and guides on health care quality issues that can be tailored for a consumer advocate audience.

You should remember to avoid acronyms and encourage the advocates to ask for clarification of terms or concepts.

One-on-One Support

The advocates will serve most effectively as members of the Leadership Team and Work Group if they are informed and prepared for dialogue and interaction prior to meetings and conference calls.

Whenever possible, identify opportunities to provide individualized assistance to the consumer advocates in advance of stakeholder meetings to ensure the advocates are up to speed on the issues that will be discussed and are thinking about how to articulate their perspective. Make sure advocates know who among the staff or leadership they can contact for information or assistance. Check in with the advocates on a regular basis to gauge their understanding and engagement, and to learn how to support them more effectively.

The National Partnership is available to help Alliances provide individualized support to the advocates and can connect with the consumer advocates to review meeting agendas, discuss specific issues and perspectives, and debrief following meetings.

Cultivate Meaningful Advocate Participation

As your Alliance matures, consumer advocates will have many opportunities to shape the Alliance in ways that benefit the public—which is the ultimate goal of this initiative. Alliance leaders can also take steps in the early stages to help ensure that the consumer advocates function effectively as participants in the Alliance and remain involved.

- Recognize that the advocates, like any new stakeholder, can often feel like the “odd person out” among Alliance participants. You can help diminish that feeling by avoiding jargon and explaining acronyms clearly every time they are used.
- Help ensure that the advocates are seen as equal partners by highlighting what the advocates bring to the table, particularly with respect to their knowledge of—and work with—consumers. You can foster mutual understanding among stakeholders by communicating the advocates’ concerns to others in the group, briefing the advocates before meetings, and making time on agendas for a consumer viewpoint so that the advocates have an opportunity to be heard.
- Make sure you update consumer advocates regularly on discussions among the Alliance Leadership Team, the National Program Office, and the Robert Wood Johnson Foundation about Alliance initiatives, objectives, etc. Whenever possible, identify opportunities for the consumer advocates to contribute to those discussions.
- Offer ongoing encouragement and support. As with other stakeholders, assist the advocates in being informed and connected by distributing relevant articles about quality improvement and reporting as well as news of similar activities in other communities.
- Encourage consumer advocates to reach out to their peers in other Alliances. The National Partnership maintains a consumer advocate list-serve and website to facilitate peer-to-peer learning. Advocates can participate by sending a request to: NAIOn@nationalpartnership.org

Consumer Advocate Engagement Framework

1	Identify	<ul style="list-style-type: none">• Perform landscape analysis of community advocates• Research potential collaborators
2	Build	<ul style="list-style-type: none">• Coordinate listening sessions; articulate Alliance goals• Segment the advocates based on their capabilities
3	Activate	<ul style="list-style-type: none">• Invite advocates to participate in Alliance• Orient advocates to roles and responsibilities
4	Support	<ul style="list-style-type: none">• Build advocate knowledge-base of quality issues• Provide 1:1 support to consumer advocates

For More Information

The National Partnership for Women & Families (National Partnership) provides technical assistance for *Aligning Forces for Quality* (AF4Q), the Robert Wood Johnson Foundation's signature effort to improve the overall quality of health care in targeted communities, reduce racial and ethnic disparities and provide models for national reform. Each of the Aligning Forces communities has built its initiative around a core, multi-stakeholder leadership Alliance working to advance the goals and activities of AF4Q at the local level. These Alliances include participation from physicians, nurses, patients, consumers and consumer groups, purchasers, hospitals, health plans, safety net providers and others.

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ⁱ 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>