Aligning Forces for Quality | Improving Health & Health Care in Communities Across America

Robert Wood Johnson Foundation

TOOL/UTILITY

Core Operations for AF4Q Consumer Engagement Staff

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Meaningfully engaging consumer leaders in the *Aligning Forces for Quality* (AF4Q) initiative helps ensure the community's patient, caregiver, and consumer needs are met. Genuine and effective consumer engagement (CE) in this multi-stakeholder initiative also is critical to AF4Q's long-term sustainability. Involving consumers in a meaningful way anchors the project in the community, resulting in an informed community committed to the AF4Q goals.

Meaningful consumer engagement is a term often used when describing multi-stakeholder organizations. It is a set of practices established to activate consumers in all aspects of a project's design, governance, implementation, and evaluation. Meaningful consumer engagement is:

- *Effective*—Consumers' participation has an impact on programs and is an integral part of achieving the organization's vision and mission.
- *Equitable*—All stakeholder groups are engaged, including consumers, and stakeholder representation is balanced; consumers are offered equivalent opportunities in activities and shaping decisions regarding the organization's work.
- *Purposeful*—Consumers feel the relationship allows them to achieve their respective goals; the organization respects consumers' interests and uses their expertise.

This document outlines key competencies and core operations for Alliance project staff, including the project director and CE lead, who work with consumers and on consumer engagement goals. Listed below is a set of operations critical to engaging consumers and advocates successfully in AF4Q. They include recruitment, strategic planning, relationship building, facilitation, support and retention, and evaluation. Each category includes sample resources and implementation methods. All AF4Q staff with consumer engagement responsibilities should be familiar with these strategies for involving consumers and advocates throughout the grantee organization and within the AF4Q initiative.

About Aligning Forces for Quality

Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in targeted communities, as well as reduce racial and ethnic disparities and provide real models for national reform. The Foundation's commitment to improve health care in 16 AF4Q communities is the largest effort of its kind ever undertaken by a U.S. philanthropy. AF4Q asks the people who get care, give care and pay for care to work together to improve the quality and value of care delivered locally. The Center for Health Care Quality in the Department of Health Policy at George Washington University School of Public Health and Health Services serves as the national program office. Learn more about AF4Q at www.forces4quality.org. Learn more about RWJF's efforts to improve quality and equality of care at www.rwjf.org/qualityequality/af4q/.

About the Author

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Recruitment

Recruitment is an ongoing process that includes identifying new consumers for AF4Q involvement, replacing consumers who are no longer active, and ensuring robust consumer representation as new workgroups and committees are formed. To operationalize the recruitment lifecycle effectively:

- Complete an environmental scan or community profile, identifying local consumer organizations and community leaders to understand better the interests, capacity, and resources of local consumers and advocates.

- Recruit patients by networking with existing partners, such as asking physicians to identify empowered patients interested in improving health care in their community and seeking members of consumer organizations that are part of AF4Q. The Laser Focus process, outlined in Leveraging Community Partnerships, is a guide to recruiting new consumers. Give prospective recruits and new Alliance members an overview of AF4Q goals, funding, activities, staffing and infrastructure, resources, etc., and outline concrete opportunities for consumer engagement. CE staff should recruit consumer leaders with specific roles in mind. Consider where opportunities exist to include consumers, such as in workgroups, quality improvement projects and pilots, and Alliance leadership.

- Orient new consumers to AF4Q focus areas, such as performance measurement and public reporting, reducing health disparities, quality improvement, and consumer engagement. The National Program Office (NPO) offers a number of "AF4Q 101" webinars throughout the year, which include an introduction to the project and can be helpful for newcomers. Contact the NPO regional support staff assigned to your community to ask about the schedule for these webinars. National websites for RWJF and AF4Q as well as local websites on AF4Q also are important resources to share with new consumer leaders. Be responsible for the continuing orientation process required to keep activated consumers abreast of new project developments and activities. A guide to developing AF4Q orientation materials can be found in Building an OnBoarding Toolkit.

- Match consumers with roles and activities that align with their interests, skills, and expertise. Each consumer should have clearly defined roles and responsibilities within the Alliance. For example, the role of a Consumer Engagement Workgroup member could include "solicit and organize consumer input into all aspects of AF4Q work and recommend strategies and develop plans to meet consumer engagement aims/targets." These responsibilities will differ depending on the role, but consumer members should be informed of expectations regarding time commitment, any activities outside of set meeting times, general rules of conduct, decision-making processes, and the goals associated with their work. For more examples of roles and responsibilities, see OnBoarding materials from South Central Pennsylvania.

- Identify and recruit consumer leaders to serve in governance and leadership positions. Serve as a resource for consumers and support them in these leadership roles by sharing materials such as fact sheets or helpful websites and pairing them with experienced stakeholders. For example, a consumer joining a subcommittee supporting a patient-centered medical home (PCMH) pilot would find the PCMH toolkit or the NCQA Guidelines for PCMH helpful in developing an understanding of this care delivery model. Details on additional support mechanisms can be found in the Tips for Success section of Building an Onboarding Toolkit as well as Consumer Engagement Best Practices.

- Identify local consumer leaders (including patients, caregivers, consumers, and consumer advocates) for speaking engagements that highlight the AF4Q initiative. Prepare speakers to articulate consumer perspectives as they relate to the AF4Q goals, etc. Preparation could focus on identifying concrete examples of consumer engagement activities and their results as well as linking consumer activities to AF4Q achievements.

Strategic Planning

Recognize the relationship between consumer engagement and the overarching goals of the AF4Q initiative and develop activities and work plans that reflect these connections. To operationalize strategic planning:

- Consider the AF4Q cost and quality goals as well as the quality/equality indicators and how consumers can help the Alliance achieve those goals. This process will help when identifying clear goals for consumer engagement that map directly to AF4Q's broader goals. Every activity should relate directly to these goals. For example, long term indicator 28, "Alliances will show improvement in identified disparities, as demonstrated by improvements in performance on publically reported quality measures or associated composite measures," could be achieved in part by recruiting consumers from organizations that represent diverse members of the community to help in program planning and provide input on the needs of their constituents. Another example would be creating a council of patients, advocates, and health care providers to collaborate on a care transitions initiative. Together the group could learn about health care experiences directly from those who have chronic conditions or care for someone who does, identify areas for improvement as well as potential solutions, and collaborate to test and evaluate interventions. Assess consumer engagement activities mid-course and after completion for evidence of success and lessons learned.

- Ensure consumer engagement activities receive appropriate allocation of Alliance resources and funds. Ensure that the resource needs of consumers are addressed including stipends for participation. This could include travel or mileage reimbursement, child care costs, meals, gift certificates, or modest monetary awards for time and participation.

- Work within the existing AF4Q structure as an advocate for meaningful consumer engagement in projects and decision-making. All staff should be familiar with the value of consumer engagement and the importance of meaningful engagement and CE staff, in particular, should be responsible for its incorporation into activities and programs throughout the Alliance. The benefits of meaningful consumer engagement are outlined in the Guide to Engaging Consumer Advocates in AF4Q Alliances.

- When starting new projects, consider how you can integrate consumer engagement into the initiative. Meaningfully integrating consumers into all workgroups ensures consumer perspectives are included throughout the Alliance. Generally, including more than one consumer leader on Alliance boards and bodies is ideal to support equality among stakeholders and prevent consumer stakeholders from feeling marginalized. For example, a sole consumer representative on a board of clinicians may feel outnumbered or as if his or her perspectives are not as valuable as others.' Balanced consumer representation increases the likelihood that group members will feel comfortable enough to participate actively.

- Determine with all stakeholders the value of a Consumer Advisory Council (CAC), a consumer-only group supported by Alliance staff. These councils provide recommendations to other Alliance boards and bodies regarding consumer engagement. CACs can formalize consumer perspectives, equalize power among stakeholders, improve communications between entities, and further integrate consumer needs into AF4Q quality improvement activities. For Alliances choosing to initiate a CAC, staff should facilitate planning meetings, inform other stakeholders of the Council's goals and responsibilities, coordinate with Council members to draft a charter, formalize a decision-making process, and outline concrete strategies for ensuring Council members are meaningfully integrated into all AF4Q activities. Some communities have used their Councils as a way to elicit consumer input on all Alliance activities, while others have assigned them specific tasks, such as selecting patient experience survey measures for improvement or serving as advisors for a PCMH pilot. Creating a Consumer Advisory Council outlines the process for forming a Council.

Relationship Building

Build trust and bonds with consumers, and between consumers and other stakeholders, to facilitate collaboration and achieve AF4Q goals and objectives. To operationalize relationship building within the consumer community:

- Articulate the value proposition for consumer engagement, with AF4Q staff, other stakeholders, and external entities, explaining why consumers should be included in quality improvement activities and offering examples of how consumers have positively influenced similar initiatives. When possible, identify concrete ways consumers have accelerated AF4Q's work and helped achieve AF4Q goals; highlight these examples with all stakeholders. There are many examples of these "Bright Spots" on the forces4quality.org website.

- Leverage opportunities for discussion between consumers and other stakeholders and staff (e.g., Care about Your Care, cost roundtables, town hall meetings, AF4Q workgroups). Highlight that patient perspectives in a multi-stakeholder group can have a strong impact on the outcomes, aligning them more closely with the community's needs and increasing the likelihood of sustainability. Emphasize that consumers are equal stakeholders and that their involvement is critical to AF4Q's success.

- Look for opportunities to partner consumer leaders with other stakeholders to plan and execute AF4Q activities and achieve AF4Q cost and quality goals. For example, if an AF4Q hospital is making changes to its discharge planning process, recommend consumer leaders to assist in planning, implementing, and evaluating the project. Other Alliances have included patients as members of physician practice quality improvement teams or as partners in implementing patient and family advisory boards in AF4Q hospitals.

Facilitation

Successful meeting facilitation can enhance the value of stakeholder interactions. To operationalize this important skill:

- Convene effective meetings (i.e., identify appropriate participants, create an agenda, share the agenda in advance, ensure there is an explicit decision-making process, and identify desired outcomes and discrete next steps). Consumer Engagement in a Multi-Stakeholder Group outlines some facilitation methods successful in AF4Q communities.

- Facilitate consumer-only and multi-stakeholder conversations. Each conversation has value; consumer-only conversations provide consumers with an opportunity to build strong relationships with their peers and identify areas of particular interest to patients and consumers; multi-stakeholder conversations may be challenging, but they allow stakeholders to share perspectives and find the common ground necessary for solutions that meet the community's needs. Helping consumers understand the perspectives of other stakeholders increases the effectiveness of these conversations, as outlined in the fact sheet Alliance Stakeholder Perspectives. Decision making tools and maintaining a standard decision-making process can be effective when working in a multi-stakeholder setting. Consumer Engagement in a Multi-Stakeholder Group outlines some examples of these methods.

- When working on specific projects, such as a care coordination improvement initiative, or a diabetes education campaign, work closely with consumers to ensure there is a shared vision for success and an understanding of expectations. Discussing project goals and activities up front with consumer leaders ensures their efforts will remain well aligned and within scope.

Support and Retention

The goal of support and retention is to increase the number of active and engaged consumers, build their capacity to engage in effective ways, and, ideally, secure their long-standing commitment to the effort. To operationalize support and retention:

- Describe clearly the AF4Q infrastructure, funding, and how to contact Alliance staff and other stakeholders. Make available a contact list and organizational chart, and update consumers regularly on Alliance activities.

- Use new and varying technology to meet consumer needs, including social media (such as Facebook groups or blogs), listservs, conference calls, and audio-video communication (Skype, etc.). Not all modes of communication are necessary, and consumers can help assess which methods work best in the community and for particular messages. Consider ways to engage consumers in the Alliance's communication channels, such as serving as guest writers or contributors to Alliance blogs, newsletters, and other social media outlets. For an example, see the Maine Alliance Case Study on Engaging Healthcare Consumers through Social Media.

- Help consumers enhance their understanding of health care topics that are pertinent to their Alliance involvement, such as accountable care organizations, value-based benefit design, patient-centered medical homes, and health information technology (including electronic medical records, etc. Highlight consumer roles in various quality improvement and health care models and how changes to the health care delivery system can better meet patient and family needs. Share this information through fact sheets, webinars, guest speakers, and group discussion. Assist consumer leaders in keeping up with health care trends by sharing periodicals and news articles of interest. Encourage consumers to research these concepts on their own time by providing a list of reliable health resources (see below) and ensuring they are aware of local events such as health fairs and briefings.

- Identify and disseminate reliable health information resources for consumers (and other stakeholders) to enhance their content knowledge. Examples include AHRQ (www.ahrq.gov), Kaiser Family Foundation (www.kff.org), Robert Wood Johnson Foundation (www.rwjf.org), Aligning Forces for Quality (forces4quality.org), and Centers for Disease Control & Prevention (www.cdc.gov).

- Identify ways to engage consumers in AF4Q activities, both within the organizational structure and in the greater community (i.e., governance, decision making, public outreach, consumer messaging, ambulatory and hospital quality improvement and practice redesign, performance measure prioritization, etc.). Individual patients, caregivers, and consumer advocates can be involved in Alliance programs in myriad ways. The list below provides a starting point for Alliance leaders' thinking around meaningful ways to include consumers.

    - Solicit the input of consumer advisory councils or CE workgroups when analyzing patient experience data, prioritizing improvement activities, and planning improvement interventions. Consumer advocates are in regular contact with their constituents and understand their experiences and views. They can offer a perspective informed by a diversity of patient experiences as well as their own personal encounters with the health care system, which is critical when redesigning care processes to better meet the community's needs.

    - Involve consumers in planning community events, including identifying agenda items, participating as speakers, reaching out to community groups to build awareness and promote attendance, and securing media coverage.

    - Engage consumers in developing and vetting patient information, educational materials, websites and portals, care planning, and support tools, including cultural and linguistic appropriateness.

    - Enlist consumers and community organizations in organizing and convening patient empowerment training sessions.

- Offer consumers opportunities to give feedback about their involvement in AF4Q, act on the results, and communicate those actions to consumers. Feedback mechanisms should include periodic formal surveys (such

as the Consumer Engagement Survey) as well as querying consumers informally on a regular basis, regarding their perceived successes and challenges with the effort.

- For more tips on consumer support and retention, see Leveraging Community Partnerships, under General Strategies for Consumer Stakeholder Retention.

Evaluation

Continuously monitor consumer engagement activities to identify areas of success and areas in need of improvement. To operationalize evaluation:

- When possible, define ways consumer involvement has accelerated work or improved a final product, and share this information with all stakeholders. Documenting consumer leader activities and collecting stories from project team members are ways to identify consumer contributions.
- Conduct regular assessments of perceived and actual successes of consumer activities to capture best practices. Staff can collect these anecdotes from consumers and other stakeholders as part of their efforts to document project activities. Communicate these best practices with consumers and AF4Q staff (such as through Bright Spots).
- When possible, complete exit interviews with consumers who end their AF4Q involvement as a means for understanding their perspectives on the project and why they are no longer interested in being involved. Staff can use this information to inform and improve their work with consumers.
- Summarize successful models of consumer engagement to share with other AF4Q and non-AF4Q communities for replication. Include elements around project impact and implementation, such as:
    - Project description and primary goals;
    - Entities or individuals involved;
    - How consumers, patients, and families were involved in planning, implementing, and evaluating the initiative, including tangible products on which they worked;
    - How buy-in from stakeholders for involving consumers/patients/families was achieved;
    - Resources (monetary or otherwise) required for implementing the initiative;
    - Facilitating factors and challenges in categories such as infrastructure, staffing, funding, stakeholder receptivity and readiness, achieving leadership and stakeholder buy-in, and preparation and support for involving patients/families;
    - Method for measuring and evaluating project success; and
    - How to expand or sustain the initiative.

For more information on the competencies described above, see:

- Supporting Consumers in AF4Q Alliances Through the Four Stages of Consumer Engagement;
- Consumer Engagement Best Practices;
- Guide to Engaging Consumers in AF4Q Alliances;

- Consumer Engagement in a Multi-Stakeholder Group;
- Creating a Consumer Advisory Council;
- Building an OnBoarding Toolkit (pending); and
- Leveraging Community Partnerships (pending)

The Aligning Forces for Quality website also provides a searchable database of Tools and Resources for Alliance staff and Alliance members, including a section on Consumer Engagement.

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