



Engaging Consumers in Improving the Health Care System

Building consumer demand for health care transparency and accountability in outpatient care

SUMMARY

From 2004 to 2010, the [National Partnership for Women & Families](#) organized a network of consumer advocates at the state and national level to promote transparency and accountability in the health care system through performance measurement and public reporting.

In 2007, the National Partnership shifted the focus of its efforts to the 16 communities participating in *Aligning Forces for Quality (AF4Q)*, the \$300 million Robert Wood Johnson Foundation (RWJF) program to advance health care quality in these communities. The Partnership identified, recruited and engaged a cadre of consumer advocates and then facilitated introductions between the consumer advocates and many of the *AF4Q* leadership teams and staff.

In September 2010 the National Partnership became a technical assistance contractor to *Aligning Forces* and is helping the initiative's regional alliances engage consumers and advocates in meaningful ways.

Results

The National Partnership for Women & Families:

- Established a core group of 200 grassroots consumer leaders well versed in, and committed to, health care quality issues and supported their engagement in national and local quality activities
- Strengthened the consumer voice in the *Aligning Forces for Quality* alliances. Most of the alliances have increased the participation of consumers and consumer advocacy organizations, and created new roles for them
- Created a health care quality coalition that engaged national consumer organizations in efforts to promote health care quality and transparency at the federal level. Among other activities, coalition members advocated for consumer interests as federal health

information technology—a key platform for quality measurement—was developed, and served on national panels and committees that addressed quality issues.

Funding

The Robert Wood Johnson Foundation (RWJF) provided:

- Four grants totaling \$4,439,431 to the National Partnership for Women & Families, over the course of four years¹
- One grant of \$249,932 to the Association for the Study and Development of Community to conduct an assessment²
- One grant of \$128,400 to Lake Snell Perry & Associates for facilitating focus groups³

CONTEXT

There is little hard evidence to support the oft-repeated claim that the U.S. health care is the best in the world.

A 2003 RAND study found that U.S. adults fail to receive recommended health care nearly half the time. The researchers noted that deficiencies in care pose "serious threats to the health of the American public" that could contribute to thousands of preventable deaths in the United States each year.⁴

"We really pay for volume, we don't pay for value," said Christine Bechtel, project co-director at the National Partnership for Women & Families.

Measuring the quality and price of care, and then reporting those findings to the public, is a core component of improving health care. A strong consumer voice helps to drive the demand for performance information, and to ensure that the information is meaningful and usable to those receiving care, but that voice has been largely absent in the health care quality enterprise or landscape.

"A lot of people think we have the best health care in the world, but one research study showed that people get the recommended care only 50 percent of the time. So we have a long way to go in terms of improving quality."

RWJF Program Officer Lori Grubstein

¹ Grant ID#s 51192, 52755, 58858, 61146

² Grant ID# 63956

³ Grant ID# 51561

⁴ This study, funded by RWJF, was published in the *New England Journal of Medicine* (McGlynn EA, Asch SM, Adams J, et al, "The Quality of Health Care Delivered to Adults in the United States." 348(26): 2635–2645, 2003) and is available [online](#).

Consumer advocates have not been engaged in quality discussions partly because they have tended to focus on other parts of the health care agenda, especially cost and access, and partly because they have not historically been welcomed.

"A lot of people assumed consumer organizations did not have the technical knowledge in terms of quality and clinical care and guidelines needed to sit at the table and weren't able to develop it. We had to change that mindset," said Bechtel. Consumer stakeholders also had to be persuaded that they could benefit from participating.

The [National Partnership for Women & Families](#), a nonprofit, nonpartisan organization in Washington, has undertaken a number of projects in the area of health care quality and transparency.

For example, with a grant in 2004 from RWJF, the National Partnership funded a team of consultants to research business models capable of supporting physician performance reporting systems.⁵ The team identified eight existing models and used their strongest components to design two models aimed at accelerating the implementation of physician performance measurement and reporting in outpatient settings. See [Program Results](#).

RWJF's Interest in This Area

RWJF's Quality/Equality Portfolio is committed to improving the quality of health care for all Americans. Specifically, the portfolio aims to help communities across the country set and achieve ambitious goals to improve the quality of health care in ways that matter to patients and their families. The team's approach is shaped by what staff has learned through extensive investments in improving chronic care and the knowledge that everyone who gets care, gives care and pays for care must work together to achieve meaningful improvement.

The approach has four major components, each representing significant investments and multiple partners:

Aligning Forces for Quality. This is the portfolio'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. The \$300 million program seeks to improve health care in a group of communities that together cover 12.5 percent of the U.S. population in the largest effort of its kind ever undertaken by a U.S. philanthropy.⁶

Measuring Progress. A substantial portion of the portfolio is devoted to research, tracking and evaluation, including:

⁵ Grant ID# 51755

⁶ The *Aligning Forces* communities are Albuquerque, N.M.; Boston; Cincinnati, Ohio; Cleveland; Detroit; Humboldt County, Calif.; Kansas City, Mo.; Maine; Memphis; Minnesota; Puget Sound, Wash.; Oregon; South Central Pennsylvania; West Michigan; Western New York; and Wisconsin.

- Using existing research investments to assess progress in *Aligning Forces for Quality* communities
- Issuing targeted solicitations to the field to garner ideas for new interventions and tools to help spur the pace of quality change and transformation

Transparency. Improving quality requires sharing information about what is happening inside the health care system with everyone who gets, gives or pays for care. The portfolio supports greater collaboration at the federal and local levels to standardize measurement and reporting activities, and to create measures that are more meaningful to patients, providers and others.

Communications. Improving health care quality begins with giving stakeholders access to timely, accurate information that they can use to make informed choices and implement change. The portfolio supports communications activities at multiple levels, including:

- Targeted assistance with messaging, advocacy and engagement for local communities
- Sharing stories and lessons learned from regional work at the national level

Recent funded projects focused on transparency and a patient focus include:

Consumer–Purchaser Disclosure Project: With almost \$3 million in support from RWJF, the Consumer–Purchaser Disclosure Project (ID# 058867), a coalition of more than 50 leading employer, consumer and labor organizations, works to give consumers and health care purchasers a greater voice in deliberations over performance measures. Traditionally, hospitals, physicians and other providers have played the dominant role in developing performance measures.

Among other results, the Consumer–Purchaser Disclosure Project has strengthened the voice of consumer and purchaser representatives on more than 80 decision-making bodies, including the National Quality Forum, that are developing or considering performance measures. See [Program Results](#) for more information.

National Quality Forum: During 2007–09, staff at the National Quality Forum created a measurement framework for evaluating efficiency across patient-focused episodes of care. The measurement framework is intended to "help key stakeholders move toward a high-performing health care system that is patient-centered, focused on quality, mindful of costs and vigilant against waste."

The measurement framework "proposes a patient-centered approach to measurement that focuses on patient-level outcomes over time—soliciting feedback on patient and family experiences; assessing functional status and quality of life; ensuring treatment options are

aligned with informed patient preferences; and using resources wisely. It will require fundamental change in the health care delivery system."

The forum described the framework in a 43-page report, *Measurement Framework: Evaluating Efficiency Across Patient-Focused Episodes of Care* (2009). See [Program Results](#) for more information.

THE PROJECT AND ITS RESULTS

From 2004 to 2010, the National Partnership for Women & Families organized a broad-based network of consumer advocates at the grassroots and national levels to bring the consumer perspective to health care quality activities.

The goal, said Project Co-Director Bechtel, was "to build a network of advocates that were knowledgeable enough and savvy enough to sit at multi-stakeholder tables alongside health plans and hospitals and ask for what is meaningful to them in quality improvement."

Other Funding

In the early phases of the National Partnership's work, the project received additional funding from Pfizer (\$85,000) and the Cigna Foundation (\$50,000).

Grassroots Outreach and Organizing

In 2005 and 2006, RWJF and the National Partnership selected four states and four metropolitan areas in which to conduct outreach activities to grassroots consumer advocates: Illinois; Minnesota; Tennessee; Washington State; Atlanta; Madison, Wis.; Raleigh/Durham/Chapel Hill, N.C.; and Trenton, N.J. The sites were selected partly on the basis of how much public reporting of health care quality and related legislative activity they already had underway.

Project staff then conducted a "scan" of consumer advocacy groups at each site and held approximately 16 focus groups in eight states to explore advocates' knowledge of health care quality issues and their willingness to become engaged in related activities. Under a separate RWJF contract, Lake Research Partners worked with staff of the National Partnership and RWJF to create an interview guide and to conduct the focus groups.⁷

Based on this information gathering, project staff identified a diverse "starter set" of advocates representing organizations focused on particular diseases or populations (such as women, children, minorities and seniors), faith-based organizations and unions. The recruits were not required to have experience with quality issues, but did need to be able

⁷ Grant ID# 51561

to devote sufficient time and staff power, and to have a constituency prepared to engage in efforts to promote health care quality and transparency.

"There are lots of consumer groups in health care, whether it is disease-specific work or helping patients navigate the health care system. But there are far fewer focused on health care quality and delivery," Project Co-Director Jennifer Sweeney said. "If they resonated with the goals of the project, and had a willingness to engage in health care quality activities, those are the type of folks we were targeting."

Once the starter set of advocates was identified, a select group participated in two-day capacity-building workshops in Washington (one held in 2005 and another in 2006), where they enhanced their content knowledge of health care quality issues.

Results: Grassroots Outreach and Organizing

According to its reports and interviews with RWJF, the National Partnership for Women & Families:

- **Established a core group of 200 grassroots consumer leaders well versed in, and committed to, health care quality issues.** These leaders represented state-level affiliates of national organizations, including AARP and the American Cancer Society, and other state and local consumer advocacy groups, such as Voices for Children, Memphis Healthy Churches and York County Hispanic Coalition.
- **Identified opportunities to engage grassroots advocates in national and local quality activities.** Project staff:
 - Nominated advocates to sit on state and national bodies engaged in quality issues.
 - Promoted activities that allowed consumer advocates to engage with providers and purchasers in their communities. For example, project staff encouraged advocates to promote the use of a standardized patient experience survey in their local hospitals.
 - Encouraged advocates to offer consumer perspectives on national quality activities. For example, advocates participated in a focus group developed by the National Committee on Quality Assurance⁸ and commented on educational materials drafted by the Surgical Care Improvement Project.⁹

⁸ The National Committee on Quality Assurance (NCQA) is a nonprofit organization that works with large employers, policy-makers, providers, payers and consumers to decide what's important in health care, how to measure it, and how to promote improvement.

⁹ The Surgical Care Improvement Project is a national partnership of organizations focused on significantly reducing surgical complications.

- Encouraged advocates to promote Leapfrog Regional Roll-Outs,¹⁰ which encourage hospitals to publicly report their progress on measuring quality and safety.
- **Provided ongoing technical assistance to advocates.** For example, project staff helped advocates:
 - Determine how best to raise their constituents' awareness of health care quality issues
 - Begin developing state-specific plans for their ongoing advocacy activities
- **Built a database that profiles grassroots consumer advocacy organizations and their health care quality activities.** This comprehensive repository of information also tracked the technical assistance project staff provided.

"We want to help providers and employers and health plans measure things that matter to consumers and then publicly report them in a way that makes sense. What consumers want to know is often a little bit different than what health plans and providers want to measure."

Jennifer Sweeney, National Partnership for Women & Families

National Outreach and Organizing

In July 2005, the National Partnership convened a meeting in Washington to engage policy-focused national consumer groups as advocates for health care quality and to identify specific opportunities in which they could become involved. Twenty organizations were represented, including AARP, the Consumers Union, the National Consumers League and the Service Employees International Union.

Results: National Outreach and Organizing

In 2005, National Partnership for Women & Families created a health care quality coalition and listserv that involved approximately 35 national consumer organizations. See the [Appendix](#) for a list of coalition members.

According to reports and interviews with RWJF and the staff at the National Partnership, the health care quality coalition:

¹⁰ Leapfrog Regional Roll-Outs are local efforts to increase the transparency of quality in individual hospitals, in line with the broader mission of the Leapfrog Group, a member-driven national initiative designed to mobilize employer purchasing power on behalf of health care safety, quality and customer value. The Leapfrog Group managed the RWJF program, *Rewarding Results*. See [Program Results](#) for more information.

- **Advocated for consumer interests in the development of federal health information technology (HIT) policies, a key platform for quality measurement.**

Project staff:

- Developed "Consumer Principles for HIT," sharing them with President George W. Bush's "health information czar" and the American Health Information Community¹¹
- Provided materials, talking points and analyses to the consumer representative of the American Health Information Community
- Worked with the federal Agency for Healthcare Research and Quality (AHRQ) to create a private consumer portal on its information technology website with information, resources and an online discussion forum for consumer advocates

- **Analyzed policy proposals and informed discussions on health care quality, value-based purchasing¹² and public reporting of quality and performance information.** For example:

- Coalition members participated in health care quality briefings hosted by the Consumer–Purchaser Disclosure Project.¹³
- Project staff testified at a U.S. Senate Health, Education, Labor and Pensions Committee Roundtable in January 2007 about the consumer stake in improving health care quality.
- The National Partnership was the sole consumer voice at a 2007 Joint Commission Roundtable on improving efficiency in the health care system.
- In 2007, the project introduced children's health advocates to the need to improve pediatric care and helped develop a set of principles for improving quality and adopting health information technology in the State Children's Health Insurance and Medicaid programs.

- **Served on national panels and committees engaged in quality issues.** These include the Health Information Technology Standards Panel¹⁴ and various committees and panels of the National Quality Forum.¹⁵

¹¹ The American Health Information Community is the federally chartered commission that provides input to the Department of Health and Human Services on the development and implementation of national interoperable HIT standards.

¹² Value-based purchasing brings together information on the quality of health care, including patient outcomes and health status, with data on the dollar outlays going towards health. It focuses on managing the use of the health care system to reduce inappropriate care and to identify and reward the best-performing providers. This strategy can be contrasted with more limited efforts to negotiate price discounts, which reduce costs but do little to ensure that quality of care is improved.

¹³ The Consumer–Purchaser Disclosure Project, established with a grant from RWJF in 2003, is a coalition of more than 50 leading employer, consumer and labor organizations working to give consumers and health care purchasers a greater voice in deliberations over performance measures. See [Program Results](#).

- **Engaged national advocates on the issue of reducing racial and ethnic disparities in health care quality.** The National Partnership and the NAACP co-chaired the Leadership Conference on Civil Rights' Health Care Task Force, which is exploring the role of measurement, public reporting and changes to the payment system in addressing health disparities.

Collaborating with *Aligning Forces for Quality (AF4Q)*

In 2007, RWJF asked the National Partnership for Women & Families to refocus its efforts to recruit, educate and engage consumer advocates exclusively in the *Aligning Forces for Quality* communities. Because the National Partnership's work pre-dated the *AF4Q* project, its consumer engagement work had not been wholly connected to the overall *AF4Q* initiative. The National Partnership's scope of work was not to provide technical assistance to the *AF4Q* alliances, but to do consumer engagement in the *AF4Q* communities and make connections with the alliances whenever possible.

To meet those goals, the National Partnership staff:

- Analyzed the landscape in the *AF4Q* communities to identify potential consumer representatives.
- Conducted "listening sessions" with some 10 consumer representatives from each *AF4Q* community to introduce them to the issue of health care quality.
- Provided an array of tools and training to strengthen the capacity of consumers to advance quality. For example, project staff:
 - Offered workshops and other training sessions to help consumer leaders enhance their content knowledge of health care quality issues and augment their leadership, communication and health literacy skills.
 - Developed a train-the-trainer module to help consumer and employer groups explore with consumers the roles they should play in their own health care
 - Produced fact sheets, webinars and other educational resources for consumer advocates. Topics include health reform, performance measurement and reporting, and collecting data on race, ethnicity and language
 - Established a consumer-only listserv that includes consumers and advocates in the *AF4Q* communities to encourage relationship-building and peer support.

¹⁴ The Healthcare Information Technology Standards Panel, a strategic partnership established in 2005 under the auspices of the U.S. Department of Health and Human Services, brings together public and private sector partners to advance the use of interoperable standards for a local, regional and national health information network.

¹⁵ The National Quality Forum is a nonprofit organization that endorses performance measurement standards and builds consensus on priorities for performance improvement.

Many of these resources are available on the project's website, which was redesigned to focus on the links between consumer representatives and the *AF4Q* alliances. See the [Bibliography](#) for details.

Assessment of This Work

In 2008 RWJF contracted with the Association for the Study and Development of Community in Gaithersburg, Md.,¹⁶ to assess the National Partnership's performance in assisting *Aligning Forces for Quality* communities to achieve their objectives of engaging with consumers. The assessment was based on interviews with grantees, project stakeholders, and local consumer advocates, and on information gained from site visits to selected *AF4Q* communities.

The assessment concluded that the funding and technical assistance provided by the National Partnership had varying degrees of effectiveness in meeting the objective of engaging consumers in *AF4Q* alliances. One stumbling block was a "perceived lack of clarity regarding roles and responsibilities," the assessment noted. The National Partnership's scope of work was to engage consumer advocates in promoting better quality health care, with a particular focus on consumer advocates in the *AF4Q* communities. However, RWJF also expected the National Partnership to provide technical assistance to the leaders of the *AF4Q* alliances, though that was not clear from the National Partnership's scope of work.

The assessment helped to clarify these differing expectations so that both parties could make adjustments. "In conversations with RWJF, we all agreed it made sense to adapt the focus of our technical assistance from working solely with the consumer leaders to providing technical assistance both to the consumer and to the alliance leaders," Jennifer Sweeney said. The National Partnership continues to work with the *Aligning Forces for Quality* alliances, as described in [Afterward](#).

Key Findings

According to the assessment:

- **The National Partnership established a good working relationship with most *Aligning Forces* grantees.** More than half the *AF4Q* grantees reported having a "strong" or "good" relationship with the National Partnership and being satisfied with the level of support received.
- **The National Partnership was generally perceived as having the capacity to identify, recruit and engage consumer groups and advocates.** However, *AF4Q*

¹⁶ The Association for the Study and Development of Community is a research and development organization focused on building community capacity and solving social problems.

grantees did identify capacity gaps, particularly the need for more staff presence at the local level.

- **Engaging consumers is complex, and may require a longer time commitment and more significant funding than was allocated.** Community-based advocacy organizations need to be educated about how health care access, which is often their first priority, is related to a quality agenda. Sustaining the participation of advocates requires meaningful engagement, which was difficult since most *AF4Q* grantees were still in a planning mode and much of the planning did not include consumers.
- **The concept of consumer engagement and its role in the *Aligning Forces* initiative was either not communicated clearly or not well understood by the grantees.** This made it difficult for the National Partnership to implement aggressive efforts to identify and recruit consumer advocates in some communities.
- **Most *Aligning Forces* grantees were in the early stages of efforts to improve outreach to minority consumers but *AF4Q* staff members believe the National Partnership can provide meaningful support to their efforts.** However, it was not clear if the National Partnership had the resources to assist grantees in all areas where such support is needed.
- **The National Partnership has a solid reputation among *AF4Q* participants for its national work on consumer engagement, which can be leveraged at the local level through community partnerships.** In general, grantee staff members believed that the National Partnership did relatively good work in implementing the consumer engagement model and could become more effective if its role was clarified to both consumers and the *AF4Q* alliances.

Recommendations

The assessment report included these recommendations:

- **Resources: Increase the National Partnership's resources to deliver technical assistance to *Aligning Forces* grantees.** In particular, the *Aligning Forces* grantees need tailored assessment and feedback on their "action plans" and more guidance on recruiting and engaging advocates from minority communities.
- **Effectiveness: Assist *Aligning Forces* leadership to focus on strategic planning and implementation processes that will enhance their capacity to engage minority communities.** To accomplish this, the National Partnership should have a better-defined and more direct role with *AF4Q* leadership teams.
- **Communication: Define what is meant by "consumer engagement."** RWJF should define this concept sufficiently to guide how *AF4Q* grantees prioritize planning, management and program implementation activities to align with *Aligning Force's* desired outcomes.

Results: Aligning Forces for Quality

Based on the assessment's findings, the National Partnership for Women & Families modified the scope of its work in 2009. According to its reports and interviews with RWJF program staff, the National Partnership strengthened the consumer voice in the *Aligning Forces for Quality* alliances, with the following results:

- **Most of the *AF4Q* alliances have expanded the role of consumer groups and individual consumers.**
 - Most *AF4Q* alliances have at least two consumer groups represented on their leadership team. These groups include the local or state affiliates of membership organizations, such as AARP, and disease-specific organizations, such as the American Cancer Society; organizations aimed at reforming health care, such as Health Care for All; faith-based groups; and organizations that serve racial and ethnic minorities. There is also at least one individual patient/consumer represented on each leadership team or workgroup.
- **Most *Aligning Forces* alliances are engaging consumer representatives in meaningful ways.** For example:
 - Consumer advocates trained in health literacy assessed the written materials created by the alliances for readability, and helped to develop materials appropriate for public audiences.
 - Consumer leaders are providing feedback to the alliances on the types of performance measures that are most meaningful to their constituents.
 - Many alliance leaders say they will recruit additional consumers and support their full partnership in the governance and decision-making of the alliance.
- **Many of the alliances are working to make performance reporting and health information aimed at the general public more consumer-friendly.** These efforts are partially in response to the input and advocacy of *AF4Q* consumer representatives.
- **The alliances are beginning to engage consumer organizations and their constituents in the redesign, ongoing practice and evaluation of new models of care.** For example:
 - In Humboldt County, Calif., where some medical practices are implementing the patient-centered medical home,¹⁷ patients are "at the table ...examining and evaluating the care of patients from their perspective and providing input into changes in processes and procedures to insure that their practice is patient centered," Sweeney said.

¹⁷ A patient-centered medical home is a health care setting with comprehensive primary care, a whole-person orientation and a commitment to coordinated, integrated care that emphasizes quality and safety.

- Maine has created a regional patient and family leadership team to advise implementation of patient-centered medical homes in the state.
- **The alliances are helping consumers develop skills and get information to become informed and empowered patients.**
 - Using a patient-empowerment training module, consumers groups have trained thousands of consumers in the *AF4Q* communities to take a more active role in their health care by seeking out information about their health condition and provider performance.

LESSONS LEARNED

Challenges

Recruiting and engaging consumer advocates in health care quality proved challenging for a number of reasons:

- The general public does not believe health care quality is a problem, making it difficult for consumer advocates to engage their constituents.
- Grassroots health advocates traditionally focus on issues related to cost and access to care, not quality.
- Most quality activities are taking place at the regional or national levels, giving consumer advocates relatively few local quality activities in which to participate.

Working With Consumer Advocates

1. **When the goal is to recruit grassroots consumer groups, make sure the group is a bona fide consumer organization.** "In some places, a disease group is consumer focused and in another place, it may be more aligned with a physician perspective," Project Co-Director Sweeney said. "That is an important distinction. We were looking for consumer groups interested in articulating consumer perspectives. That understanding allowed us to dig a little deeper during the recruitment calls. If it was our sense during those calls that the organization was not the right fit, we could have that conversation early."
2. **In recruiting grassroots consumer groups, be sure to have support at high levels of the organization.** "We looked for decision-makers," Sweeney said, "somebody who had the ability to commit the time and resources of the organization. It might be the director of programs or the director of advocacy. Then we had the conversation: 'Can your organization commit to this work?' You have to have the commitment of the people at the top to dedicate time and resources to an activity."
3. **Make a strong case to the public that health care quality is an important issue.** Advocates want to work on issues that they understand to be problematic and that

have a sense of urgency for their constituents. Project staff used multiple strategies to make a convincing case that health care quality affects their constituents. (Report to RWJF, Program Officer Grubstein, Project Co-Director Sweeney)

4. **Consumer advocates need knowledge, expertise, and resources to work effectively on health care quality.** Project staff created an array of tools to enhance the content knowledge of the consumer advocates and make it possible for them to work more effectively on these issues. (Report to RWJF)
5. **Link consumer advocates' work on quality to current policy debates.** Many local and national advocacy organizations were focused on health care reform, especially cost and access issues. To gain traction on quality, project staff had to find ways to connect it to reform efforts.

"The learning is you have to meet consumers where they are," Sweeney said. "We wanted to jump into measures, transparency and public reporting. But in 2004 and 2005 there was not a whole lot going on at the federal level in terms of policy-making [on these issues]. The initial opportunity really lay in health information technology, as a platform for quality measurement."

Engaging consumer advocates in health information technology "was a way to get them involved quickly while their interest was high. And once the other issues became more available, they were primed and ready to become engaged." (Report to RWJF, Project Co-Director Sweeney)

6. **Stakeholder groups who have not worked together previously may need help building relationships.** Purchasers and providers typically have little experience working with advocates, and advocates have not traditionally been included in multi-stakeholder groups. Project staff had to work with all parties to facilitate those relationships.

"You can't just go out and create the supply of people who can fill the consumer role," the National Partnership's Bechtel. "You also have to do the hard work of cultivating these bodies so that they understood the value of engaging consumers and embrace that role. They need some help in figuring out how to operationalize it."

7. **Building and maintaining trust with consumer advocates is an ongoing effort.** When consumer-driven health plans¹⁸ became popular, some advocates were concerned about engaging in quality improvement efforts that appeared to be focused more on shifting costs to consumers than on improving quality. The project team had to gain the trust of advocates and reassure them that project activities were aimed at true quality improvement and transparency. (Report to RWJF)

¹⁸ A consumer-driven health plan uses a variety of mechanisms to provide health insurance or fund health care costs, all of which encourage individuals to become actively involved in making their own health care decisions (e.g., designing their health insurance coverage, choosing their service providers, selecting healthcare services, and managing their own fitness and wellness).

8. **Be aware that staff turnover can affect the vitality of a state coalition.** In Illinois, for example, several consumer advocates changed jobs, which meant project staff had to cultivate other advocates at those organizations and recruit new organizations to shore up the state's efforts. (Final Report)

Working With the *Aligning Forces for Quality* Alliances

9. **Create accountability metrics for the alliances so they move toward the goal of consumer engagement.** Some stakeholders were slow to recognize the value of engaging the general public and the importance of including consumer representatives in alliance governance and decision-making. Project staff worked with the national program office and RWJF staff members to develop ways to assess the alliances' progress on the *AF4Q* goals, particularly in the area of consumer engagement. (Report to RWJF)
10. **Ensure that consumer leaders have the same opportunities to shape alliance activities and deliverables as other stakeholders.** One consumer leader said she wanted to help "drive the train, not just be a passive passenger along for the ride." (Report to RWJF)
11. **Prepare consumer representatives to participate meaningfully in multi-stakeholder alliances.** Toward that end, the project team helped consumer leaders understand the perspectives of the various *Aligning Forces* stakeholders and look for common ground. This enabled the consumer representatives to advocate in ways that furthered both consumers' needs and *Aligning Forces* goals. (Report to RWJF)
12. **Prepare *Aligning Forces* alliances to support the involvement of consumer advocates in *AF4Q* work.** The project encouraged the alliances to provide individualized support to consumers, including preparing them before and after key meetings. If the alliances were unable to provide this support, the project staff filled the gap. Such support can solidify consumer commitment to the alliance, especially for those new to the health care quality arena. (Report to RWJF)
13. **The *AF4Q* alliances required tailored technical assistance, not a "cookie cutter" approach.** Though tailored assistance is resource-intensive in terms of staff time and travel costs, the alliances told the National Partnership team and the national program office that the investment was critical. (Report to RWJF)
14. **When a project hinges on building good relationships, it is important to interact in person.** Communicating in person allowed the project team to build trust with consumer and alliance leaders and that trust encouraged the leaders to turn to the National Partnership for technical assistance. In-person meetings also allowed the project team to observe the unique context and character of each alliance in order to provide the most appropriate technical assistance. (Report to RWJF)

AFTERWARD

RWJF's Quality/Equality team has updated its indicators to clarify the Foundation's expectations around consumer engagement.

The National Partnership for Women & Families is working under a subcontract to provide technical assistance to *Aligning Forces for Quality* from 2010 to 2011. The Partnership's goals are to:

- Assist the *AF4Q* alliances in achieving meaningful consumer representation.
- Build the capacity of individual alliances to support consumer leaders and support the consumer leaders to engage effectively in the alliances.
- Facilitate relationship building to ensure that consumer leaders are engaged in shaping the activities of the alliances, including the content and direction of public reports, quality improvement initiatives, and health information technology and payment reform efforts.

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Program area: Quality/Equality

APPENDIX

Participants in National Consumer Coalition

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

AARP

Washington, D.C.

AFL-CIO

Washington, D.C.

**American Federation of State, County
and Municipal Employees**

Washington, D.C.

Bazon Center for Mental Health Law

Washington, D.C.

Center for Medical Consumers

New York, N.Y.

Consumers Checkbook

Washington, D.C.

Consumers Union

Yonkers, N.Y.

**Department for Professional Employees,
AFL-CIO**

Washington, D.C.

Health Privacy Project

Georgetown University
Washington, D.C.

March of Dimes

White Plains, N.Y.

Markle Foundation

New York, N.Y.

National Breast Cancer Coalition

Washington, D.C.

National Consumers League

Washington, D.C.

National Council of La Raza

Washington, D.C.

National Health Law Program

Washington, D.C.

Service Employees International Union

Washington, D.C.

BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Reports

Fact Sheets

The following fact sheets on consumer engagement are available [online](#) at the "Quality Tool Box." Scroll down to the individual Fact Sheets.

- *Creating a Consumer Advisory Council*. Aligning Forces for Quality, 2011.
- *Four Stages of Consumer Engagement*. Aligning Forces for Quality, 2010.
- *Alliance Stakeholder Perspectives*. Aligning Forces for Quality, 2010.
- *OnBoarding Materials*. A collection of documents designed with assistance from the AF4Q communications firms and the South Central Pennsylvania Alliance for recruitment and orientation of consumer representatives to AF4Q, 2010.
- *Consumer Engagement Best Practices*. Aligning Forces for Quality, 2010.
- *Improving Health Care Quality: A Shared Responsibility*. Aligning Forces for Quality, 2010.
- *Consumer Engagement Survey*. Aligning Forces for Quality, 2010.
- *Consumer Engagement Process*. Aligning Forces for Quality, 2009.
- *Effective Consumer Advocacy in a Multi-Stakeholder Setting*. Aligning Forces for Quality, 2009.
- *Overuse, Underuse and Misuse of Medical Care*. National Partnership for Women & Families, 2009.
- *Payment Reforms: What Consumers and Patients Should Know*.
- *Consumer Definitions*. Aligning Forces for Quality, 2009.
- *Health Literacy Overview*. Aligning Forces for Quality, 2009.
- *FRY Readability Formula: An Overview*. National Partnership for Women & Families, 2009.
- *Sample Letter to the Editor on Quality Issues*. Aligning Forces for Quality, 2009.
- *Alliance Stakeholder Best Practices*. Aligning Forces for Quality, 2009.
- *Collaborating with Consumer Advocates to Disseminate Public Reports*. Aligning Forces for Quality, 2010.

- *The Role of Consumer Organizations in Disseminating Health Information*. Aligning Forces for Quality, 2010.
- *Health Quality Thesaurus*. National Partnership for Women & Families, 2009.

The following fact sheets on quality improvement are available [online](#):

- *Ensuring High Quality Affordable Health Care*.
- *Patient-Centered Medical Home Toolkit*. 2009.
- *Foundational Principles for Gaining Consumer Trust and Acceptance of HIT*. Consumer Partnership for e-Health, 2006.
- *Meaningful Use of Health Information Technology*. Consumer Partnership for e-Health.
- *Health Information Technology (HIT) and Health Information Exchange (HIE): What Do Consumers Stand to Gain?* 2009.
- *You Can Help Reduce Health Care Disparities*. 2009.
- *Medical Errors: Not Just a Headline*. 2009.

The following fact sheets on performance measurement and public reporting are available [online](#):

- *Consumer Principles on Measurement and Public Reporting*. 2009.
- *Patient Experience Survey*. 2009.
- *Transparency: Shedding Light on Health Care Quality*. 2009.
- *Using Electronic Data for Performance Measurement*. 2007.
- *A Pocket Guide to Seven Key Quality Measurement Issues*. 2007.

Education or Toolkit

Curricula

Cost, Quality and Access. Americans for Quality Health Care project, 2008.

Guide to Engaging Consumer Advocates in AF4Q Alliances. National Partnership for Women & Families, 2009. Available [online](#).

Patient Empowerment Training Module. National Partnership for Women & Families. Available [online](#). Scroll down to get to it and its components.

Performance Measurement 101. Americans for Quality Health Care project, 2007.

Performance Measurement & Public Reporting. National Partnership for Women & Families, 2009. Available [online](#).

Performance Measurement Orientation. National Partnership for Women & Families, 2008. Available [online](#).

Public Reporting Orientation. National Partnership for Women & Families, 2008. Available [online](#).

Meeting or Conference

Testimony

Jane Loewenson, "Testimony of Jane Loewenson, Director of Health Policy, National Partnership for Women & Families," to the U.S. House of Representatives Energy & Commerce Subcommittee on Health, June 9, 2005, Washington. Written request from Subcommittee Chair Nathan Deal, June 7, 2005.

Debra Ness, "Testimony of Debra Ness, President, National Partnership for Women & Families," to the U.S. 110th Congress Senate Health, Education, Labor and Pension Committee, January 10, 2007, Washington. Written request of Committee Chair Edward Kennedy.

Communication or Promotion

Grantee Web site

www.qualitycarenow.org. Americans for Quality Health Care Web site, National Partnership for Women & Families, Washington.

ASSESSMENT BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Report

Assessment of Consumer Engagement Technical Assistance by the National Partnership for Women & Families Interim Report. Gaithersburg, MD: Association for the Study and Development of Community, 2008.