

# The Imperative to Promote Collaborative Consumer Engagement: Lessons From the Aligning Forces for Quality Initiative

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**T**ruth, justice, and fairness. Everybody is for them, which is why so many public policy proposals are described in those terms. But when it comes time to roll out the specifics, it turns out that exactly what is truthful, just, and fair is almost entirely in the eye of the beholder.

The same dynamic is at work with consumer engagement in healthcare. Almost everyone says it is essential, beneficial, needed, and overdue. Hardly anyone argues against it. However, what consumer engagement means in practice varies dramatically based on personal definitions.

One thing is very clear: achieving a meaningful definition and shared understanding of consumer engagement is a critical step in making real progress as the nation works to transform its healthcare system to make care more efficient, affordable, effective, and patient-centered. Put simply, we can't get to patient-centered care without engaging patients in a collaborative way. That's what consumer engagement is all about.

The experience provided by the Aligning Forces for Quality (AF4Q) initiative—the Robert Wood Johnson Foundation's signature effort to lift the overall quality of healthcare in targeted communities, reduce racial and ethnic disparities, and provide real models for national reform—has advanced the work to define consumer engagement. Developing a concept as revolutionary as this one doesn't happen in a straight line, of course. The experience gained through the AF4Q initiative has come in fits and starts because, inevitably, it was affected by broader confusion in the healthcare world about what defines genuine consumer engagement. Our understanding of what consumer engagement is, and how best to implement it, is still evolving. However, 6 years after the AF4Q initiative began, the National Partnership for Women & Families unequivocally recognizes that it has made valuable contributions in clarifying and building shared understanding of the concept. It positioned us to develop and advance a shared vision for this work and gave us real confidence that it can be done.

Despite a tremendous contribution, years of work lie ahead. True collaborative consumer engagement, implemented broadly, would amount to nothing less than culture change for our healthcare system—and culture change is never quick or easy. However, it can and must be done because, without it, our healthcare system will surely remain fragmented, inefficient, plagued by disparities, and ineffective in ways that cause real harm. There is an urgent imperative to continue this work.

## Viewpoint of the National Partnership for Women & Families

Most providers and healthcare stakeholders today say they are dedicated to creating a patient-centered healthcare system—that is good news. However, the bad news is that too often patients, family caregivers, and consumers are omitted from the process of designing, implementing, and evaluating change. If that continues, the best possible result of this work is a care system that may become more consumer-friendly or patient-focused. Although this may be an improvement, it will not bring the kind of systemwide transformation that the nation needs.

We need a common understanding that real engagement is more than getting consumers to do what providers and payers want. It's more than creating financial incentives, or providing the right information to steer consumer choices, convincing patients to adopt healthy behaviors, getting them to manage their chronic conditions, or getting them to interact more effectively with providers.

Although these are laudable goals, they may not genuinely engage consumers or help us achieve patient-centered care. True consumer engagement is collaborative. It makes consumers equal partners in defining, designing, and assessing the care practices and systems that serve them. It engages consumers at all levels—from policy to governance, to redesign of care practices, to individual/family engagement, to community involvement.

That kind of engagement has transformational power. At the national level, for example, consumer advocates have

become a game-changing force that is shaping policy around payment, quality improvement, and care delivery.

We need that kind of consumer-driven transformation at the community level. It can and must be done, because only by engaging patients, families, and consumers in designing care that meets their needs—giving them a voice, really hearing what they say, and taking it as seriously as the voices of other stakeholders—will we achieve the change we need. Just as it would be unthinkable, perhaps even laughable, to gather untrained consumers in a room to decide how to fix the physician payment system, it must become unthinkable for other stakeholders to decide what consumers and patients need without engaging them in the conversation from the very start.

Existing mind-sets and practices can be hard to break, and the National Partnership for Women & Families is advocating for real transformation. That means no longer allowing others to represent consumers. It means no longer putting a token consumer or two in the proverbial room late in the process, after key decisions have been made. It means no longer allowing providers, purchasers, and other stakeholders to design the system without the voices of those it is intended to serve. It means that consumers and patients are given the support they need to contribute in a meaningful way. It means a whole new way of thinking, a whole new way of working, a whole new kind of respect.

It means a whole new kind of healthcare system that works for all who count on it.

### Lessons From Aligning Forces for Quality

The concept of collaborative consumer engagement is now reasonably well developed, and support is growing. The AF4Q initiative has contributed to its development and evolution, and to the distillation of numerous lessons and best practices. My colleagues and I believe that the 6 years of work on this project have offered critically important lessons.

#### *Lesson 1: You Can't Achieve What You Can't Define*

Like the healthcare community around it, at several points, the AF4Q initiative changed the way it defined consumer engagement and the goals it set to evaluate community work in this area. As is often the case, the first goal was to convince consumers to change their behavior and become more adherent to provider recommendations. In response, many alliances organized public education campaigns and created consumer brochures designed to make consumers “better” patients who would manage their conditions more effectively. For the most part, these campaigns achieved little change in consumer behavior. Consumers were not involved

in the decision to change their behavior nor asked what strategies would help them do so. While some consumers were trained separately to be more empowered in their healthcare interactions during this period, many of them expressed skepticism and even fear that exercising their new skills would generate few or only negative responses from their providers and care system.

The AF4Q initiative then shifted its engagement goals to encouraging consumers to use the public performance reports that the alliances produced. In a positive step, most alliances involved consumers in designing the reports to be accessible and consumer-friendly. Nonetheless, consumers were generally not at the table in discussions of whether such reports would be useful, or what information would be measured and publicly reported.

Over time, the AF4Q initiative made a full evolution to focusing on ensuring consumers were involved in real leadership and had genuine decision-making roles in the alliances. Some alliances have even begun to integrate consumers into quality improvement efforts. The alliances now doing this will be generating important lessons about the process and results of including consumer experience and perspectives in efforts to improve quality and care delivery.

#### *Lesson 2: Put Real Consumers at the Table*

Some AF4Q alliances resisted engaging consumers in leadership positions. Others were confused about how to define the consumer role, and they assumed individuals with other stakeholder orientations could represent the consumer perspective. This is not an uncommon practice, but it's one that inevitably fails because these stakeholders carry perspectives, experience, and sometimes financial interests that vary significantly from those of consumers.

From the AF4Q initiative, my colleagues and our partners learned that patients and consumer advocates play different roles, and both are needed. Patients and family members bring their experience of care to the table, while consumer advocates are skilled at representing the needs and interests of a broader community. This is not unlike the difference between a practicing doctor and the chief medical officer of a health plan or professional association. The perspectives and experiences of both are needed.

#### *Lesson 3: Change Doesn't Happen Without Accountability and Rewards*

Even when the AF4Q alliances had a clear definition and goals for consumer engagement, had the right people at the table, and the pieces were in place, there was more work to do. Quality improvement requires change, and change

doesn't happen unless it is supported and nurtured and there is real accountability. The right people need to be engaged and there must be a climate in which they are heard and their input is respected.

The AF4Q initiative experience confirmed the need to put in place specific goals and requirements that prevent consumers from being marginalized, such as being placed in positions where the deck is stacked against their successful and effective participation or on advisory bodies with no real power. It also requires guidance, training, and ongoing support—not just for consumer participants, but also for the alliance leaders and other stakeholders. Fostering effective multi-stakeholder collaboration requires real skill and knowledge, and should not be assumed. For most leaders and stakeholders—including consumers—it also requires a significant shift in cultural mind-set and ending the behaviors described above.

### ***Lesson 4: Real People Need Real, Meaningful Work***

Consumers need meaningful engagement and the chance to shape strategies, provide leadership, set priorities, and engage at all levels rather than being directed to—or isolated in—select discussions or decisions. Going forward, AF4Q communities will need to engage consumers in leadership and setting priorities, giving them the chance to shape the direction of projects, involving them in design of quality improvement initiatives and the way care is delivered, and inviting them to help develop and implement strategies to engage people in their own care.

In the years to come, we look forward to more consumers playing these roles in the alliances. If this happens, we believe the alliances will benefit from new insights and perspectives that will move them out of familiar paradigms, but also help them achieve their goals in ways that meet the needs of both patients and providers. My colleagues and I believe that the lessons from this kind of collaboration will be rich, and the transformation it produces will be deeper

and faster than if we continue the business of redesigning healthcare in the usual way.

## **Conclusion**

Culture change is hard. It doesn't happen overnight and it doesn't happen without determination and a real willingness by all stakeholders to bend and change. Sometimes, that means listening and learning. Sometimes, it means sharing platforms and power. Just about always, it means staying at the table through the rough spots.

Patients and consumers can be a game-changing force if they are equal partners when new care delivery models are implemented and operationalized. However, consumers need help attaining the skills and ability to be equal partners, and providers and other stakeholders need help attaining the mind-set and the skill set to engage consumers in this way.

Collaborative consumer engagement is worth the work. It truly has the power to transform. My colleagues and I are convinced that the AF4Q initiative has made enormous contributions, offered critical lessons, and pointed us toward some of the solutions our nation's healthcare system urgently needs. If we realize the full promise of collaborative consumer engagement, we will put patients and families first and finally begin to turn the promise of patient-centered care into reality.

**Author affiliation:** National Partnership for Women & Families, Washington, DC.

**Funding source:** This supplement was supported by the Robert Wood Johnson Foundation (RWJF). The Aligning Forces for Quality (AF4Q) evaluation is funded by a grant from the RWJF.

**Author disclosure:** Ms Ness reports board membership with the AF4Q National Advisory Committee. She also reports receipt of grants and honoraria from and meeting/conference attendance for the RWJF.

**Authorship information:** Concept and design; drafting of the manuscript; critical revision of the manuscript for important intellectual content; and supervision.

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