

**BACKGROUND****Successful Strategies for Building and Sustaining Partnerships with Patients and Families to Transform Primary Care: Lessons from Aligning Forces for Quality**

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**Background**

Health reform efforts have been a catalyst for some health care organizations to work with patients and families to redesign and improve the care experience. Numerous compelling stories link these partnerships to improved clinical outcomes and experience of care scores. Yet less than one-third of primary care practices have engaged patients and families as improvement partners.<sup>1</sup> Aligning Forces for Quality (AF4Q) communities have worked to support primary care clinics in developing authentic and meaningful relationships with patients and families as improvement partners. The experiences of these communities can offer insight to others who seek ways for the perspectives of patients and families to inform changes to care delivery.

The experiences of the ten AF4Q Alliances that undertook efforts to forge partnerships with patients and families were varied and provide insight into what is needed to effect lasting change. A patient and family advisor is any role in which those who receive care work together with health care professionals to improve care for everyone. Some sites created partnerships with patient and family advisors in their clinics and organizations. Others were unable to get started or to sustain their early efforts. Managing complex change has many moving parts, and when key components are missing, progress toward transformation can stall. A useful framework to understand the challenges of managing complex change was developed in 1991 by Knoster from Enterprise Group, LTD.<sup>2</sup> The

**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](http://www.forces4quality.org). Learn more about RWJF at [www.rwjf.org](http://www.rwjf.org).

**About the Authors**

The Institute for Patient- and Family-Centered Care (IPFCC) provides essential leadership to advance the understanding and practice of patient- and family-centered care. IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support by promoting collaborative relationships.

<sup>1</sup> Han, E., Scholle, S. H., Morton, S., Bechtel, C., & Kessler, R. (2013). Survey shows that fewer than a third of Patient-Centered Medical Home practices engage patients in quality improvement. *Health Affairs*, 32(2), 368-375.

<sup>2</sup> Knoster, T., Villa, R., & Thousand, J. (2000). A framework for thinking about systems change. In R. Villa & J. Thousands (Eds.), *Restructuring for caring and effective education: Piecing the puzzle together* (pp. 93-128). Baltimore: Paul H. Brookes Publishing Co.

framework emphasizes how important each of the following components is in successfully implementing change: vision, skills, incentives, resources, and an action plan.

Communities that struggled to make progress were missing one or more of the components Knoster identified. Alliances focused efforts on developing skills and resources, and on building an action plan to implement partnerships with patient and families. However, Alliances had limited ability to affect the levers of vision and incentives for a given health care organization. In some cases, transitions in leadership, mergers, and systemic barriers (e.g., primary care reimbursement structures) prevented clinics from engaging in transformation efforts. When an organization assessed its readiness and determined the timing was not ideal, or the clinic did not perceive the value of patient and family partnerships to its strategic aims, no intervention or technical assistance was sufficient to result in a successful change process.

The examples of communities that implemented successful partnerships illustrate that working with patient and family advisors to improve care is worth the effort. The collective experience of the AF4Q communities can inform others interested in creating collaborative partnerships with patients and families to improve quality and safety and transform primary care. This paper describes six strategies for building and sustaining effective partnerships within organizations and across communities. These lessons, drawn from Alliance representatives, physicians, staff, patient and family advisors and technical assistance provider, the Institute for Patient- and Family-Centered Care (IPFCC), are intended to be a resource for community leaders, health care professionals, and patient and family leaders interested in building authentic partnerships to bring about transformational change in health care.

## Strategies for Supporting Health Care Organizations to Build and Sustain Effective Partnerships with Patients and Families

The AF4Q Alliances served as convenors of diverse stakeholders to improve quality across a community. As such, some Alliance leaders exercised diplomacy and influence to encourage health care organizations to explore how partnerships with patients and families could improve care. The ideas below represent lessons learned and effective ways to encourage and support organizations in integrating patient and family advisors as part of their improvement strategy.

- **Capture and convey the value of partnerships with patients and families to generate buy-in from leaders.**

### Benefits of Partnering with Patients and Families

- Inspires staff and clinicians.
- Identifies simple, cost-effective solutions.
- Reveals possibilities health care professionals have not considered.
- The time and expertise of a few can help improve care for many.
- Advisors become vocal supporters of the clinic in the community and champions for improving the health of their community.
- Process improvements are often less complex and better meet the needs of all patients and families.

- **Highlight benefits and examples of existing efforts to make the case for the value of partnerships with patients and families.** Strong partnerships between health care organizations and patients and families have numerous benefits. They can inspire health care providers and staff and provide an ongoing means for collaborating through trusting relationships to achieve common goals. Bringing a unique perspective distinct from that of clinicians and staff, patient and family advisors often think of simple, cost-effective solutions to quality issues that had not occurred to health care staff. Described as a “refreshing change” by physicians and others, collaborative relationships with patient and family advisors create an environment where discussions explore possibilities rather than getting bogged down by barriers. Like health care professionals, patients and families are committed to improving the practice and the health of their community. Their energy and participation can reduce the burden felt by health care providers to solve the problems by themselves.

Advisors who learn from experience that an organization is sincerely committed to authentic and collaborative problem solving often become vocal champions of the organization within the community, and effective recruiters of new advisors. Organizations often cite these intangible benefits as strongly as they do other benefits such as costs saved, quality scores improved, and processes that have been simplified by the advice and suggestions of patients and families.

Although many AF4Q Alliances engaged consumers at the community level to promote public awareness of health care quality variation and educate consumers on how to use quality scores to make health care decisions, partnering with patients and families in health care redesign was a new concept to the majority of AF4Q communities. A few Alliances—Humboldt County, Maine, Oregon, and South Central Pennsylvania—started partnering with advisors at the practice level. As they shared their experiences and the outcomes of initial partnerships, other AF4Q Alliances began to see the potential impact collaboration with patients and families might have.

Articulating these benefits and providing examples to support them is an important strategy for gaining buy-in from health care organization leadership. Partnerships with patients and families are not an experiment; they are a strategy with evidence of effectiveness on multiple dimensions.

Effective use of storytelling and the use of concrete examples build momentum for change and can be used to launch, sustain, and expand partnerships or inspire other organizations. Presenting multiple examples helps illustrate that that there is no specific “cookie-cutter”

*“Our Patient Advisory Council (PAC), started as a formal entity in 2008, was a deliberate effort to engage patients in the operations and strategy of our medical group. What has occurred has actually been that the medical group has become engaged in the vision of our Patient Advisory Council, who has given us the understanding of what it truly means to be ‘Patient and Family Centered.’ They have driven change, giving the leadership of our group clear guidance, insight, and most of all, inspiration. We now have patients as members of our committees and governing structures, and it has been our patient leaders who have directed much of our Community Health Improvement Plan work. Woven into the fabric of our organization, the PAC has made us stronger, more flexible, and far more vibrant than we could have ever been without them. We are truly blessed.”*

— Physician Champion from Oregon

approach; every community must tailor strategies to respond effectively to its unique strengths and challenges.

➤ **Start Small and Learn from Success and Challenges.** While partnerships with patients and families can cultivate culture change, the first efforts need not be overwhelming. Encourage health care organizations to take small steps to implement change in the beginning. Starting with achievable projects allows both the practice and new advisors to become comfortable with a new culture of partnerships for improvement. Many clinics start with a discrete, clear project, such as creating or revising informational materials for patients and families. Look for the natural intersections with other initiatives being implemented, such as progression toward patient-centered medical home (PCMH) status or development of patient portals. These initiatives provide a springboard to integrating patient and family advisors into planned changes. Many practices reported that patient and family advisors were instrumental in bringing ideas forward that helped prepare and engage patients and families to be active members of PCMH care teams. Starting with small, concrete projects helps build trusting relationships among advisors, staff, and clinicians and confidence in the collaborative process. It paves the way for more in-depth advisor involvement that will sustain their interest and commitment over time.

➤ **Approach initiation of partnerships with patients and families with respect for the organization’s constraints and readiness.**

➤ **Recognize and respect context and barriers.** Health care organizations in AF4Q Alliances encountered the challenges facing most health care organizations today—overburdened health care leaders with multiple demands for their time and their attention, and pressures of new regulations such as those related to meaningful use and ICD-10 coding. Similarly, some expressed confusion or skepticism about the benefits and risks of forging partnerships with patients and families. Some providers and staff seek assurance that such partnerships would benefit the organization and align with strategic priorities. Providers expressed concerns that patient and family advisors would slow the improvement process. They also worried patient and family advisor involvement might distract from efforts to engage physicians—engagement that is key to substantive primary care redesign.

Many clinics believe the system-wide changes underway—such as implementation of new electronic medical records (EMR), new team roles for existing staff, and hiring of care coordinators—sufficiently reflect a model of care centered on patients and families. Thus, in the context of competing priorities, partnering with patients and families in health care redesign is sometimes seen as a time-consuming “nice to do,” rather than an essential element of an authentic patient- and family-centered system of care.

*“It is a scary proposition to most practices. Even if they are a champion of the idea, it is really hard to know how to get started and how to do it right...and get past the discomfort level. The materials have been so valuable.”*

— AF4Q Alliance Leader from Cleveland

- **Respond to readiness with incremental steps, patience, and persistence.** Key to this tailored approach is to understand and offer a variety of mechanisms by which to engage patients and families in improvement efforts. Some practices believed they must have a formal patient advisory council, which can be intimidating to develop, especially for a small or rural practice. Examples from organizations across the country can help dispel that notion that there is only one way to build partnerships with patients and families. There are a variety of options for engaging patient and family advisors that are well-suited to the needs of individual practices. Because Alliance staff are community organizers for quality, they can help create or identify resources that can be shared across several organizations. This is especially important for small practices to jumpstart their efforts.

For some Alliances, an effective strategy for integrating patients and families as advisors into an existing focus on quality measurement and/or provider-focused quality improvement efforts was to slowly introduce the concepts into learning activities. For example, Maine and Cleveland “seeded their convenings” with presentations related to patient- and family-centered care and building partnerships with patients and families in care and health care redesign. These sessions described best practices for developing and sustaining partnerships with patients and families, drawing wherever possible from examples within the AF4Q Alliance.

Significant health care change efforts were already underway in these and other Alliances, such as advancing a PCMH model and integrating behavioral health into primary care. Laying the conceptual groundwork with educational sessions helped identify organizations ripe for development.

When organizations show interest but are unable to commit to regular participation, outreach helped inform and encourage them. In both Detroit and Wisconsin, for example, Alliance staff provided follow-up to clinics that were unable to participate fully in intensive technical assistance. This approach took more time but helped prepare clinics for future collaborative efforts with patients and families. No site was asked to move more quickly than was necessary to achieve informed, authentic commitment to lasting change. It is critical to understand each clinic’s readiness and current capacity, help each site identify small, doable steps that can build a strong foundation for action at a later time, and recognize when the moment is right to take action.

- **Align partnership efforts with an organization’s strategic priorities.**

- **Begin with an organizational assessment.** While the “when” of change is about readiness, the “how” is about the organization’s makeup, strengths, priorities, and goals. Due to the tremendous pressures on health care organizations today, using time and resources efficiently is a high priority. Engaging a health care organization with an initial assessment-focused discussion of provider and staff concerns helps to establish a positive, supportive direction, identify organizational strengths and priorities, and describe available technical assistance resources that would support efforts and align with existing goals. A self-assessment instrument (for an example, see *Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings: How to Get Started at*

[www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf](http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf)) can be an effective tool for beginning a candid, supportive discussion. Assessment helps health care organizations see the potential benefits of developing partnerships with patients and families, reduce anxieties around potential challenges such as time and resource requirements, and help frame meaningful partnerships as a mechanism to achieve already articulated goals.

Pairing this conversation with an onsite visit by a outside facilitator or consultant to the health care organization provides another tool for highlighting organizational strengths and opportunities for improvement, and can generate spontaneous, teachable moments. In one case, a site visit to a federally qualified health center in Cleveland, Ohio revealed the clinic's mission statement on display. The mission statement stimulated a discussion identifying opportunities to partner with patients and families to help the practice achieve its mission.

- **Engage leaders by aligning partnerships with patients and families with strategic priorities.** Working with health care organization leaders to address their challenges requires honesty, flexibility, and transparency about an organization's strengths and weaknesses. Helping leaders identify how integrating a patient- and family-centered approach can help solve existing problems and align with strategic priorities has proven to be a supportive approach. These conversations shift the mindset from viewing partnerships as an unnecessary burden to seeing them as an essential resource for change and improvement.

For example, an exploratory conversation of this kind inspired the CEO of a large integrated health system in Cleveland, Ohio to see how patients and families could help him realize strategic goals for transformation. Following similar coaching calls, one Wisconsin medical group's leaders aligned the use of advisors with efforts to improve patient experience survey scores. In a number of communities, changes in reimbursement for improved patient experience scores provide a concrete incentive for primary care practices to embark on efforts to partner with patients and families.

Alliances that were successful measured the results of changes and shared outcomes with leadership. This outcome information provides credible examples of what can be achieved in partnership with patients and families.

- **Drive culture change through expectation-setting, incentives, and transparency.**
  - **Set expectations through leadership.** Senior leaders who maintain ownership and accountability for implementing patient- and family-centered care are essential. They serve as essential role models and cultural signposts, sending a clear message that collaborative partnerships with patients and families are a high priority. Physician champions are individuals willing to promote partnerships with patients and families to their clinical colleagues. These champions are crucial to engaging other physicians and staff in embedding this new culture into the practice. Physician leaders set the tone and expectations for collaborating with advisors. They can be role models by inviting advisors into other venues of influence, such as physician and leadership meetings. Both kinds of leadership set the tone and lead by example.

➤ **Align expectations with incentives.**

One important way leadership can emphasize the priority of partnerships with patients and families is through aligning incentives for such efforts. For example, in Detroit, the Michigan Primary Care Transformation Project

(MiPCT) provided an incentive in the form of learning credits to clinics participating in a Learning Collaborative to integrate patient and family advisors into their PCMH activities. The Greater Detroit Alliance’s growing expertise on how to partner with patient and family advisors will continue to support this collaborative effort in the future.

*“At a conference, when I first heard about the Triple Aim—improving the experience of care and the health of populations and reducing the cost of care—I wanted to be part of the efforts to make this happen.”*

— Patient Advisor from Maine

➤ **Leverage available external technical assistance resources and establish a mechanism for ongoing local support.**

➤ **Access existing materials, skill-building, and capacity-building resources.**

Although meaningful partnerships with patients and families to improve care are not yet widespread, some excellent resources exist to inform and support efforts. Connect health care organizations, consumers and community leaders with resources and ongoing learning and networking, including from IPFCC ([www.ipfcc.org](http://www.ipfcc.org)), Aligning Forces for Quality ([www.forces4quality.org](http://www.forces4quality.org)), and the Patient-Centered Primary Care Collaborative ([www.pcpcc.org](http://www.pcpcc.org)). These resources provide success stories, tools, listservs, and other interactive forums that can engender participants’ confidence in their own findings and provide opportunities to learn from those who have in-depth experience.

IPFCC, for example, offers two to three webinars monthly on a variety of topics related to patient- and family-centered care and partnerships with patients and families in health care improvement. Offering webinar scholarships to interested organizations provides access to a valuable resource to meet an organization’s educational and training needs.

Similarly, written materials and other resources available through the above organizations provide best practices and ready-made tools for Alliances and health care organizations, saving them time in creating new strategies and materials.

Relevant Resources:

[\*Aligning Forces for Quality: Tools for Engaging Patients in Your Practice\*](#)

[\*Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons Words of Advice: A Guide for Patient, Resident, and Family Advisors\*](#)

[\*Partnering with Patients, Residents, and Families: A Leader’s Guide for Hospital, Ambulatory Settings, and Long-Term Care Communities\*](#)

➤ **Provide Orientation and Ongoing Support to All Stakeholders.** Many patients and families want to help make positive change but are tentative about a new role as an advisor.

Staff and clinicians have concerns about involving advisors in meetings that address issues and problem areas within the practice. Addressing these concerns and preparing all participants to work together effectively helps the experience to be a positive one. Many practices identified a dedicated resource (staff position or dedicated time for a staff member) to build relationships with advisors and facilitate their development and orientation to this new role. Ideally, this individual should be a liaison to health organization leadership and charged with ensuring partnerships stay focused on strategic priorities. They also should help providers and staff know how they can welcome and encourage patient and family advisor participation.

Healthy tension and conflict is normal as advisors participate in practice changes. The use of patient and family advisors is a disruptive innovation that helps those working in health care understand the unique perspective of those receiving care. Advisors can feel when the partnership is meaningful or authentic, and when it is not. A critical characteristic of meaningful partnership is follow-through. When advisors identify needs or problems, the clinic must respond either by making recommended changes, or with transparency by explaining why implementing the changes would not be feasible. It can be helpful to have an outside facilitator available to assist in difficult conversations to repair or strengthen collaborative relationships. To sustain effective partnerships, it is helpful to reserve time in meetings to ask about how the collaborative process is working. In this way, concerns and misunderstandings can be addressed early and proactively.

Some clinics use community resources to help prepare and support advisors. Training in communication, group dynamics, and running effective meetings can prepare new advisors to participate in ongoing committees or improvement projects.

- **Leverage the full potential of patients, families, and health care consumer advocates to build momentum for change, and to recruit and support patient advisors.**
- **Utilize Experienced Patient and Family Advisors as Coaches.** Seasoned patient advisors can be excellent coaches for health care organizations initiating partnerships with patients and families by building commitment through stories of success and helping navigate challenges through experience.

### Testimonials and Concrete Examples Build Motivation for Action

*“Seeing the examples of how it has been done in other places is incredibly powerful because people can see the possibilities.”*

— Cleveland AF4Q Leader

*“Thank you so much for inviting me to your Advisor Council Meeting. Your endeavors blaze new trails, and you have such energy and enthusiasm pushing them forward. I literally could not go to sleep last night, even though my body was tired. And to think that this revolutionary medical delivery model is happening right here!”*

— Oregon medical group Quality Director to both advisors and colleagues

*“In one rural community, the providers from a primary care practice decided to go to the community members and connect with them at the town’s local coffee shop, where many of the community members naturally congregated on weekend mornings. It was a great way for community members and primary care providers to connect with one another.”*

— Maine PCMH Program Coordinator



This coaching can take place on a practice, local, or national level. For example, the South Central Pennsylvania alliance created a Steering Committee of experienced advisors to provide guidance for monthly community-wide advisor networking meetings and mentor new advisors from other practices. These advisors helped develop the structure that would sustain the growing advisor program and reduce the burden for staff.

Advisors and staff from exemplar sites shared effective strategies and approaches with their peers during calls, webinars, and presentations. Showcasing advisors and highlighting their contributions creates the expectation within the organization and the community that engaging patients and families in meaningful partnerships will be the norm for all improvement work. The technical assistance team from IPFCC also included an experienced patient advisor who shared first-hand experiences serving as an advisor in a clinic and highlighted the results achieved through these partnerships.

- **Cultivate Patient and Family Leaders.** Seek to cultivate advisors who can eventually co-lead efforts with a physician champion. This collaboration at the leadership level sends a powerful message about equal partnerships and respects the expertise each brings to the conversation. As advisors become more experienced, they may need additional training. Attending learning sessions, webinars, and training seminars with their practice improvement teams offers information and support to identify training needs and develop skills.

*“Efforts to invite limited input from patients and families are easy and quick to do. It can be appealing to think of this work as something you do on the side when it is convenient. That is a disservice to everyone. If you think of this as a time-limited project, don’t even begin. However, if you want to have the best experience, seriously consider making a long-term commitment. Build a timeline, don’t expect immediate results, invest in recruiting individuals who want to make a positive difference. When you do that, the experience and results are phenomenal. It invigorates everyone and creates motivation during a time when morale and burnout is a common issue in the health care workforce.”*

— Wisconsin Community Leader

*“Recent changes prompted by health reform, new payment models, and CMS penalties are spurring more interest in working with patients to enhance their experience of care and to improve quality metrics. HCAHPS scores figure into hospital bonuses or penalties, driving changes across some health care systems. Accountable care organizations for population groups also are driving changes. Competition, which always has been heated here, is climbing to new levels. Primary care practices—at the center of the action—now need the help of patients to deliver good experiences and high quality in order to rise above the competition.”*

— Cleveland AF4Q Leader

- **Consult Consumer Advisory Boards (CABs).** Many Alliances convene a CAB (which sometimes goes by another name, such as Consumer Committee). The CABs have focused primarily on strategies for educating health care consumers about quality, but are often well-positioned to explore and advocate for ways for consumers to collaborate with health care providers to improve care. Provide CABs information on best practices from across the nation, to inform them of possibilities and prepare them to engage in local efforts. The CAB can help shed light on community-identified needs and expectations of local health care organizations.

Organizations can, in turn, use this information to build programs that are meaningful to both health care professionals and patients and families. The CAB representatives can also tap into community resources to assist with recruiting patient and family advisors that reflect the diversity of the community served by the practices.

## Conclusion

Authentic and effective partnerships with patients and families can change and improve dynamics and results within and among health care organizations. Building and sustaining these partnerships is a long-term commitment that requires multiple levels of engagement and support. Available resources and national expertise can provide needed skills, while local capacity is key to supporting, expanding, and sustaining efforts. The leadership of a collaborative community entity such as an AF4Q Alliance can be a catalyst that provides structure, encouragement, and support to clinics and other health care organizations as they integrate the patient and family voice in redesigning health care. AF4Q Alliance staff had built trusted relationships with medical providers and staff in the community, and with technical assistance and coaching from IPFCC, these key Alliance staff members were well positioned to support collaborative partnerships in the long-term. Leadership at the organization and community levels can play critical roles in making patient- and family-centered care and partnerships with patients and families the standard for each community.

### Keys for Sustaining Meaningful Partnerships with Patients and Families

- An available collaborative learning community to share stories and strategies, discuss challenges, and gain ideas and insight.
- An identified physician champion to guide and nurture support among colleagues.
- A staff or administrative partner to facilitate recruitment, selection, and preparation of advisors.
- A flexible approach to inviting patients and advisors to participate in quality improvement efforts.
- Actively engaged senior leaders and prepared patient and family advisors.
- Willingness to start small and build confidence and competency through a series of plan, do, study, act cycles.
- Tracking and celebrating the work of advisors and sharing this information with them, with organizational leaders and staff, and with the community.

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