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Early Lessons From Four 'Aligning Forces For Quality' Communities Bolster The Case For Patient-Centered Care

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ABSTRACT The practice of patient-centered care remains in its developmental stages-hampered, in part, by limited evidence of its effectiveness. In this article we first review available evidence on patientcentered care, such as the positive effects of engaging patients in quality improvement activities. We also point out the existence of a research gap that makes it difficult to quantify the effect of "culture change" in health care, and to attribute improvements specifically to patients' involvement. We then discuss the benefits of involving consumers in the design and improvement of products and services outside the health care industry, and we present early lessons on engaging patients to improve ambulatory care in four communities—Humboldt County, California; south central Pennsylvania; Maine; and Oregon-participating in the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative. These lessons, although early, illustrate that actively engaging patients in improving ambulatory care improves provider-patient communication, identifies and avoids potential challenges to new services, and improves provider and patient satisfaction.

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ore than a decade ago the Institute of Medicine brought attention to the health care quality crisis and clarity to the definition of *quality*. The institute embraced the notion that care should be "patient-centered," defined as "care that is respectful of and responsive to individual patient preferences, needs, and values."

Today, as the United States implements provisions of the Affordable Care Act, health care providers face unprecedented pressure to improve quality and reduce costs. Pursuing the "Triple Aim" of improved health outcomes, better patient care experiences, and lower costs² presents a simultaneous challenge and opportunity to develop innovative strategies, with stakes perhaps higher than ever before.

Patients have a unique perspective on health

care and are potentially valuable partners in quality improvement strategies. Many physician practices survey patients on their care experiences.³ However, few studies measure how many practices actively engage patients to help act on survey data. Nor do we have studies that examine the impact of actively engaging patients in improving health care quality and outcomes.

The lack of data is particularly striking in the realm of ambulatory care, where the patient-centered medical home model is supposed to embody quality improvement strategies, putting the patient at the center of care. Indeed, practices based on the patient-centered medical home take a systems-based approach, looking beyond the individual doctor to the health care team, health information technology, and other resources to deliver accessible, coordinated care to maximize health outcomes and efficiency.

Although the medical home model is intended to effectively meet patient needs, experts believe that practices often miss important opportunities for patients to play an active role in transforming care delivery to ensure that it is truly patient centered. Experts also believe that these opportunities should be further exploited, explored, and studied.⁴

Effectively engaging patients in quality improvement initiatives requires a major investment of time and resources—both of which are in short supply in today's medical care environment—and a practice culture that is receptive to making processes more transparent to patients while empowering them to suggest how those processes may be improved. Practices need motivation and a clear understanding of the possible benefits of engaging patients in quality improvement before they commit resources to realizing this ideal.

This article reviews evidence on the effects of patient engagement on care delivery and how these changes enhance patient-centered care in a way that demonstrates clinical and cost impact. The findings we present from our review, along with evidence from other industries, suggest that investment in patient-centered approaches to care may be worthwhile.

We also present early lessons from four communities in the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative, which operates in sixteen communities around the country and is aimed at lifting the overall quality of health care in targeted communities, reducing racial and ethnic disparities, and providing models for national reform.⁵ The four communities we report on are Humboldt County, California; south central Pennsylvania; Maine; and Oregon.

In contrast to individual hospital or health system examples, the initiative's grantees operate on a communitywide scale. Although more rigorous study is needed, Aligning Forces for Quality may help bridge the evidence gap for actively engaging patients to improve ambulatory care quality, outcomes, and cost.

The Evidence Base

ENGAGING PATIENTS PRODUCES CHANGE A systematic review of forty quality improvement initiatives found that engaging patients in these efforts generates concrete service changes. Changes include improving access to health care, such as revised appointment policies and hours of service, and patient-centered changes to mental health and diabetes care.⁶

Randomized controlled trials show that involving patients in developing patient infor-

mation materials improves the materials' relevance, readability, and clarity. Patients' unique perspective can prompt changes that improve processes for providers, too. Studies show that adopting efforts to improve patient-centeredness increases provider and staff satisfaction and reduces turnover. 8

The experience of Georgia Health Sciences University provides a dramatic example of the potential impact. The institution first adopted a comprehensive patient-centered approach in 1993. It engages 130 patient and family advisers and is documenting measurable results.

For example, the system's Neurosciences Center of Excellence redesigned its approach in 2003 to integrate input from families into patient care. Within three years the center decreased lengths-of-stay by 50 percent and reduced medical errors by 62 percent. Meanwhile, patient satisfaction increased from the tenth to the ninety-fifth percentile, and the staff vacancy rate dropped from 7.5 percent to zero. 10

PATIENT-CENTERED CARE IMPROVES OUTCOMES Patient-centered care has produced positive outcomes in multiple care settings. At the same time, there is some evidence that patients who report better care experience are more likely than others to use more (and even unnecessary) health care services.

Studies show hospital patient-centeredness is associated with fewer unexpected complications and deaths.¹¹ In primary care, patient-centeredness also results in fewer diagnostic tests and referrals, reducing associated risks and costs.¹² Patient-centered management of end-of-life care reduces costs without shortening life.¹³

As noted, engaging patients in quality improvement efforts prompts changes that can include increasing engagement in their own care and improving their experiences with the health care system. Substantial research links these strategies to clinical and cost indicators.

For example, strategies for enhancing patient self-management and patient-provider partnerships have been shown to improve outcomes for people with arthritis, asthma, heart disease, lung disease, stroke, diabetes, hypertension, and breast cancer. ^{14–16} Improved disease management saves costs through reduced emergency department visits, hospital admissions, and lengths-of-stay. ^{17–19}

One measure of patient-centered care is obtained by surveying patients about their experiences with health care providers and systems. Patient experience, itself part of the Triple Aim of improved health care, correlates positively with a number of indicators, including clinical processes, patient adherence to care regimens,

and reduced risk of medical malpractice claims.²⁰ On the other hand, a few studies link higher patient experience scores to increased hospitalizations, higher costs, and even mortality, suggesting that patients who report better care experience may be receiving elective or unnecessary procedures.^{11,21}

These somewhat contradictory findings underscore the complexity of providing patient-centered care and the importance of conveying risks and benefits through shared decision making. New initiatives such as the Choosing Wisely campaign by the ABIM Foundation facilitate health care decision making by physicians and their patients and lead to better outcomes and lower costs.²²

HOW OTHER INDUSTRIES BENEFIT **ENGAGING CONSUMERS** Research in fields other than health care illustrates the value of engaging customers in quality improvement. For example, research has found that incorporating consumers' input into product design in industries such as personal computers, video games, and food improves the product's quality and aligns it more closely to consumers' needs and preferences. 23,24 Furthermore, engaging consumers provides early indications of how others will respond once a product has been launched. Engaging consumers in product development in the clothing, automobile, and home furnishing industries has been shown to save costs by improving consumer acceptance, reducing the risk that a product will fail in the marketplace.25

There are also risks, however. Engaging consumers in product development requires transparency, the surrendering of some control, and the possibility that consumers will propose novel but infeasible ideas. ²³ These findings are consistent with the early lessons from the Aligning Forces for Quality initiative described below.

Examples From Aligning Forces For Quality

The premise of the Aligning Forces for Quality initiative is that together, community stakeholders who provide, pay for, and receive health care can improve health care quality and value more effectively than can any group acting alone. The initiative, launched in 2006, involves sixteen geographically, demographically, and economically diverse grantee communities, encompassing 12.5 percent of the US population.

Each of these communities has built its initiative around a multistakeholder leadership alliance, which may include participation from physicians, nurses, individual consumers (patients and caregivers) and consumer groups, purchasers, hospitals, health plans, safety-net

providers, and others. Together they undertake quality improvement efforts, promote quality and cost transparency, and equip patients to make informed health care decisions.

Although all sixteen communities must include consumers at the leadership level, they employ differing approaches to quality improvement, transparency, and consumer engagement. Four "early adopter" alliances have been actively engaging patients in improving quality in ambulatory care settings. Their experiences can inform their Aligning Forces for Quality peers and contribute to the body of evidence for engaging patients in quality improvement efforts.

PATIENT PARTNERS Aligning Forces for Quality alliances in Humboldt County, California, and in south central Pennsylvania operate projects in which patient volunteers and their primary care physicians and practice staff work together on quality improvement teams. The volunteers are called "Patient Partners," to denote their role as equal members of the practice quality improvement teams. These team-based "Patient Partner projects" recruit the patient volunteers through staff recommendations or through social media or other marketing methods.

The practices use a detailed job description to identify patients who may be well suited to serving as Patient Partners. New Patient Partners undergo an orientation to establish expectations, introduce quality improvement methodology, and learn techniques for working effectively as a team. We discuss the initiatives' distinctive activities in more detail below.

▶HUMBOLDT COUNTY: Aligning Forces Humboldt is the alliance in Humboldt County, California. A rural yet geographically expansive county in northern California, Humboldt County has a population of 134,623 residents, of whom 17.7 percent live below the poverty level. ²⁶ The county has been designated as a Health Professional Shortage Area for primary, mental health, and dental care. ²⁷ Located at the California Center for Rural Policy at Humboldt State University, Aligning Forces Humboldt coordinates the Patient Partner project in conjunction with the Humboldt–Del Norte Independent Practice Association's Primary Care Renewal Collaborative.

The Practice Association began involving patients in the design and delivery of care through the Institute for Healthcare Improvement's Quality Allies program in 2006. Aligning Forces Humboldt implemented a chronic disease self-management program in 2008. These twin efforts helped the Practice Association and Aligning Forces Humboldt develop expertise in patient engagement and helped prepare practitioners for viewing patients as having roles

beyond mere recipients of care, such as helping educate fellow patients in managing chronic diseases.

The impetus for the Patient Partner project came from clinical and executive leadership at the Humboldt–Del Norte Independent Practice Association that was supportive of patient engagement, from pioneering efforts of a local consumer advocate, and from the collaborative's focus in 2011 on the patient-centered medical home model. Currently in its second year, the project involves twenty-one Patient Partners in ten practice teams, representing about 30 percent of Humboldt County's primary care offices.

The project held its first patient orientation in January 2011, after having recruited Patient Partners from among patients who had completed a local chronic disease self-management program and from other sources. The project held periodic meetings of Patient Partners throughout the year, in addition to regular meetings of the full collaborative (providers, staff, and Patient Partners together). Each collaborative meeting included an address from a provider or quality improvement expert and a Patient Partner presentation, sharing insights from the Patient Partner meetings. During one collaborative meeting about care coordination, Patient Partners presented a map of the referral process from the patient's perspective, identified inefficiencies in existing processes, and highlighted the emotional impact of care fragmentation. The Patient Partner presentations have been well received by providers and staff. During 2011 the presentations consistently scored higher on meeting evaluations for effectiveness of information shared than did the meetings' presentations by practitioners.

Integrating patients into practice quality improvement has helped move patient-centered care from theory into practice. For example, Patient Partners helped develop patient brochures and evaluated online portals through which patients can access their medical records electronically. They identified and addressed potential challenges for patients using the portals and suggested ways to rewrite office policies into patient-friendly language.

At one pediatric practice, Patient Partners designed a procedure to schedule follow-up on "well child" visits and helped develop a survey so that practitioners could better understand parents' objections to childhood immunizations.

Practitioners sometimes found quality improvement partnerships with patients to be unfamiliar and challenging. Collaborating in a structured project, such as developing a brochure, helped teams work together and ended up producing a change in culture. "What the

Patient Partner project has changed is the conversation about patient-centered redesign in the community," observed Alan Glaseroff, a primary care physician and codirector of Aligning Forces Humboldt. "Having the Patient Partners at the table means the reason for this work is front and center for every discussion" (Alan Glaseroff, Aligning Forces Humboldt, interview, September 14, 2012).

▶SOUTH CENTRAL PENNSYLVANIA: The Aligning Forces for Quality alliance in south central Pennsylvania, which includes York and Adams Counties, adapted Humboldt's Patient Partner project to enhance its existing Patient-Centered Medical Home Collaborative. The south central Pennsylvania initiative introduced its Patient Partner project to seven practices in the collaborative in 2011. The project has since been expanded to all twenty-two practices in the collaborative, which serve more than 125,000 patients in the region.

The practices and their thirty-six Patient Partners employ "Lean" methodology, ²⁸ a quality improvement approach pioneered and developed by Toyota to reduce waste and improve efficiency in automobile manufacturing. Patient Partners have focused on patient communication and self-management to help other patients take an active role in their care.

One of the successful outcomes is the creation of a "brown bag medication review," in which the patient brings all of his or her medications to a meeting with a provider to review indications and proper dosing. One practice implemented a system to alert patients if a doctor is running late for an appointment. One Patient Partner prompted another practice to add new glucometers to exam rooms. The better equipment resulted in improved interactions and patient satisfaction. Patients are happier, and staff assessments show increasing provider satisfaction with the team approach.

Serving as role models and working to improve care for all patients have prompted Patient Partners to become even more active in their own care. For example, one Patient Partner, Michael, who has diabetes, lost sixty pounds and got his blood sugar under control within five months. Ron, another Patient Partner, also lowered his blood sugar significantly. Having noticed these changes in some Patient Partners, practices have begun using a validated tool to measure baseline and subsequent changes in Patient Partners' active engagement in their own health and health care.

PATIENT ADVISERS Two other alliances have taken a different approach, focusing on establishing patient advisory groups in health care organizations and providing training and

technical assistance to support practices and patients.

▶oregon: In 2010 Oregon Health Care Quality Corporation, a nonprofit quality improvement organization, launched its Patients and Families as Leaders program. This program provided five organizations—four medical groups and one health plan—with intensive training, coaching, web-based tools, and other technical assistance to help them establish patient and family advisory councils. Although Quality Corporation's technical support ended in January 2012, the five pilot organizations maintain their patient advisory councils, and additional organizations have expressed interest in developing councils. Three of the five pilot organizations in Oregon are discussed below.

Providence Medical Group is a primary carebased multispecialty group with more than seventy clinic locations in Oregon. The organization established its patient advisory council in March 2011.³⁰ Thirteen advisers participate in established projects and initiate their own efforts to improve quality and efficiency.

For example, advisers attended a diabetes education course as "secret shoppers" and afterward recommended ways to streamline orientation and standardize materials. Advisers also presented an orientation to new clinic employees, showing films of patient interviews to illustrate ways to translate patients' comments into practice improvements.

Another project involved after-visit summary reports to help patients remember and apply the advice given by their health care providers. Some patient advisers noted that they themselves had never received an after-visit summary report but would have found it beneficial. This realization resulted in an effort to encourage use of after-visit summaries by such means as putting up posters in the clinics and making presentations to staff members. Advisers and staff measured baseline after-visit summary usage and look forward to quantifying evidence of future improvement.

St. Charles Family Care–Redmond is a primary care clinic in central Oregon with thirteen providers. It established a seven-member Patient Advisory Board in January 2011. The board initially surveyed other patients to assess how the clinic could better meet their needs. After patients reported difficulty in finding their way around the clinic building, the board recommended and obtained approval for a volunteer greeter to provide a friendly face and navigation assistance.³¹

CareOregon is a nonprofit health plan serving more than 150,000 Medicaid and Medicare recipients in the state. Its thirteen-person

Member Advisory Council meets monthly to discuss procedures and programs. For example, the council helped develop a "Better Together Guide" to help patients and providers establish shared goals and expectations for clinic visits. The advisers are viewed as authentic voices for Oregon's low-income and vulnerable populations. This reputation was instrumental in securing commitment from CareOregon's board and senior leadership to add dental coverage to members' medical coverage.³²

►MAINE: Engaging patients in primary care quality improvement is part of the Maine Aligning Forces for Quality alliance's commitment to patient-centeredness, which requires active engagement of patients and consumers. For example, even annual performance evaluations for staff members measure how well they performed in securing and retaining the engagement of patients in the activities of workgroup and project committees.

The alliance is also one of three conveners of Maine's twenty-six-practice Patient-Centered Medical Home Pilot—a program that trains health care teams and patient advisers in practice transformation. The pilot expanded by fifty practices in January 2013, and Maine's Medicaid Health Home initiative will add up to fifty-seven primary care sites by 2015.

Together, these efforts will reach every geographic region in Maine and influence care for more than 500,000 people. Pilot practices commit to implementing ten "core expectations," one of which is to engage patients actively in practice quality improvement efforts. All twenty-six pilot sites involve patient advisers, as will other practices that join the pilot later.

Maine created a Patient Family Leadership Team consisting of staff and patient advisers in 2010 to offer support and technical assistance to the pilot practices. The team's functions have since been absorbed into two key structures. First, Maine Quality Counts, the quality improvement arm of the Aligning Forces for Quality alliance, established a board-level consumer advisory council to oversee all strategic initiatives.

Second, a small technical assistance team made up of staff and patient advisers from each of the Patient-Centered Medical Home Pilot practices provides customized, on-site assistance to other medical practices, employing best practices and sharing information between pilot sites. This latter group has proven essential to implementing and maintaining successful advisory groups.

As in the other three Aligning Forces for Quality communities, practices in Maine have seen tangible results from involving patients in quality improvement activities. According to Betty St. Hilaire, patient advisory coordinator for Winthrop Family Medicine, the practice's patient advisory council has shifted providers' focus from "what's the matter?" to "what matters to you?" For example, the council found that pediatric patients experienced long waits in exam rooms before a provider arrived. Further inquiry revealed that providers looked for a clipboard outside the exam room as a signal that the patient was inside and ready to be seen but that patients did not know of this expectation. The practice has affixed stickers to the clipboards reminding patients to hang them outside the room after completing paperwork, and practice staff were coached to remind patients of this procedure. This change has improved practice efficiency as well as patient satisfaction (Betty St. Hilaire, Winthrop Family Medicine, interview, January 10, 2013).

David Loxtercamp, a primary care physician at Seaport Family Practice, reports that engaging patient advisers has helped identify the practice matters of highest priority to patients in that practice and has led to improvement in patient experience scores (David Loxtercamp, Seaport Family Practice, interview, June 1, 2012).

Establishing patient advisory groups in Maine is an evolving and often iterative process. Success depends on physician leadership and staff support, the availability of patients, practice readiness, and available resources. The groups vary in structure; this flexibility is vital because each practice needs to sustain membership and focus as situations change over time.

Authentic patient engagement was daunting for many practices at first because there were no best practices for engaging patients and families as for other aspects of care. Yet in a 2011 survey, participants in the pilot programs reported only positive results, with improved communications as a universal outcome. One practitioner remarked, "Engaging patients is the hardest core expectation but the most fun." 33

Obstacles to patient engagement cited in the survey included limited time, competing priorities, and early skepticism that engagement efforts would lead to real change. Bolstered by the creation of feasible work plans and with individualized guidance, practitioners are reaping tangible rewards: improved processes, enhanced relationships with patients, and patient-friendly materials and signage to make facilities easier to navigate and use.

Early Lessons

Although a few providers in each Aligning Forces for Quality community championed the ap-

proach of integrating patients into quality improvement activities, many at first resisted. Gaining providers' buy-in since that point has been a key to success.

For example, before implementing its Patient Partner program, participants in south central Pennsylvania surveyed provider practices about their concerns. Many practitioners were fearful of exposing their deficiencies to patients and worried that engaging patients would exacerbate their already hectic schedules.

These transparency concerns mirror those regarding consumer engagement in non-health care industries and were common among other Aligning Forces for Quality sites. Success stories from Humboldt County and Oregon helped ease these concerns in Pennsylvania.

Overall, few of the feared outcomes related to transparency have been borne out in reality (Lisa Letourneau, Maine Quality Counts, interview, June 1, 2012). Rather, practices found that being transparent with patients and consumers has helped the patients understand systems and constraints.

All four alliances emphasize the importance of providing technical assistance to practices and staff support for patients. Clear expectations among all parties foster productive relationships and increase satisfaction.

A single staff contact for patient advisers ensures accessibility, continuity, and integration into the decision-making process. This staff support requires additional time from staff whose plates are already full. But centralized technical assistance can share techniques and help staff get the most from their resources at hand.³³

Patients involved in the Aligning Forces for Quality efforts described above typically receive some compensation, usually meals and reimbursement for travel or child care expenses. Some practices also offer small stipends.

Recruiting people who represent the larger patient population can be challenging, although direct invitations from providers are often successful. Even patients who had not been optimally engaged in their care provided meaningful contributions. Participation "opened my eyes to how a practice works and the providers' perspective," said one south central Pennsylvania Patient Partner. "I realized that I play a big role in my care, [and I] took the necessary actions to improve my diabetes."

Conclusion

Despite increased emphasis on patient-centered care, few studies have examined whether actively engaging patients in improving care in physician practices improves health outcomes and cost.

Aligning Forces for Quality sites offer an opportunity to study this approach on a growing scale, highlighting concrete practice improvements, health benefits for patient advisers, and a move to a more patient-centered culture. Three of the alliances have already expanded their projects based upon positive response.

Engaging patients in quality improvement efforts does not replace the need for validated patient experience surveys. Surveys provide representative patient input, whereas directly engaging patients in quality improvement helps make that input actionable.³⁴

As noted above, a few studies suggest that high patient experience scores may correlate to the use of unnecessary medical services. However, engaging patients in improving care may help implement processes that improve patient-provider communication and thereby reduce the likelihood of delivering these unnecessary services and the health risks that can result.

Engaging patients in quality improvement requires resources, leadership support, and much transparency. Participating practices report undergoing a culture change—no small feat for busy practices. Yet this change seems to foster a more patient-centered quality improvement approach that improves patient experience without increasing costs.

Patient advisers also provide a "reality check" for proposed service changes, much as consumers in other industries help predict the response to a new product and hereby reduce risk of product failure. "Health care unfortunately oftentimes re-does things a lot. And there's an expense to that," said Cindy Klug, director of education for Providence Medical Group in Oregon. "Now you know what your patients need and want" (Cindy Klug, Providence Medical Group, interview, January 19, 2012).

Combined with patient-centered care research and lessons learned from other industries, Aligning Forces for Quality adds to the growing case for integrating patients into quality improvement efforts. Other communities involved in Aligning Forces for Quality are now exploring similar efforts. Additional examples and experts in the field provide further guidance.³⁵

Still, a quantitative research gap remains. It is hard to quantify the effect of culture change, and this change is often one among a package of interventions, which makes it difficult to attribute improvement specifically to patients' involvement. Comparing patient-centered medical home practices that engage patients in quality improvement to those without this component would help isolate the impact of each model on quality, health outcomes, and cost.

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In this month's Health Affairs, Deborah Roseman and coauthors review the available evidence on the effects of patientcenteredness—such as from engaging patients in quality improvement activities in health care—and present early lessons from four communities participating in the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative. Although early, the authors write, these lessons illustrate that actively engaging patients in improving ambulatory care improves providerpatient communication, identifies and avoids potential challenges to new services, and improves provider and patient satisfaction.

Roseman is a research scientist at the Center for Health Care Quality, School of Public Health and Health Services, at the George Washington University. Her responsibilities include providing oversight and guidance for four grantee communities of the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative to achieve high-quality health care and managing technical assistance and peer-exchange

activities to support sixteen Aligning Forces for Quality communities' efforts to engage consumers and employers and publicly report and improve patients' experience of care.

Previously, Roseman served as lead health planner for the San Diego County HIV Health Services Planning Council, where she managed the local community planning process for allocating \$10 million in annual Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funding, worked to maximize consumer involvement in service planning, and prepared annual Health Resources and Services Administration grant applications. She earned a master's degree in public health from Yale University.



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Jessica Osborne-Stafsnes is the project manager for patient engagement at Aligning Forces Humboldt, a California Center for Rural Policy project. She works with consumers, consumer advocates, and alliance partners to ensure that patients' needs and perspectives are addressed across the continuum of care.

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