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

Robert Wood Johnson Foundation

PRIMER/BRIEF

Engaging Consumers in Payment Reform Efforts That Impact Care Delivery Practices

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Efforts to engage patients and consumers in decisions about their care have evolved to incorporating consumer input and feedback on organizational decisions on how that care is received. Consumers now participate in quality and safety improvement efforts, health system policy and infrastructure discussions, and even public policy development. Attempts to engage consumers in the specific discussions of payment reform design are still emerging, in part because the specifics of payment reform policies seem far removed from—and even invisible to—the average health care consumer. In reality, these policies can affect many aspects of the health care delivery system that directly impact consumers. A growing body of evidence suggests that consumer or patient engagement can lead to better health outcomes, improvements in patient safety and quality, and more control of health care costs.[i,ii,iii,iv] To fully understand and realize the benefits of engaging consumers in payment reform, it is critical to draw on evidence-based practices. This brief outlines the reasons for engaging patients and consumers in the creation of payment reform policy and related care delivery practice discussions, offers examples of how *Aligning Forces for Quality* communities (Alliances) and other multi-stakeholder organizations can use patient engagement in their own payment reform efforts, and identifies evidence-based practices to meaningfully engage consumers in this area.

About *Aligning Forces for Quality*

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

About the Author

American Institutes for Research (AIR) provides technical assistance for the Robert Wood Johnson Foundation's *Aligning Forces for Quality* initiative. AIR is working with Aligning Forces communities to support consumer engagement efforts to promote high-quality health care at a low cost.

Why Engage Consumers in Payment Reform?

Patient and consumer engagement has been called a critical part of a continuously learning health system[v] and a necessary condition for system redesign.[vi] Simply stated, patients and consumers are critical stakeholders who both affect and are affected by policy and system design decisions. They should be important members at the table when seeking more effective and efficient systems of care through payment reform. In addition, there are two other reasons to engage consumers in payment reform.

1. ***Engagement ensures the transparency of a typically "hidden"—and distrusted—health care system.*** Transparency means more than revealing the prices of various care services to consumers. Transparency also means exposing all elements of the health care system for patients and families, many of whom see a direct relationship between the details of system operations and the impact on out-of-pocket costs. In brief, transparency builds consumer trust concerning the motives and goals of reform efforts. There is evidence that such consumer trust has yet to be earned. Research indicates that consumers often explain rising health care costs as caused by a profit motive, when this may not always be the cause. Involving consumers in

payment policies ensures that the motives behind the polices are clear to consumers while also ensuring that the reforms remain focused on their larger goal—better care at lower cost.

2. ***Engagement ensures that the care delivery practices of payment reform remain patient-centered.*** While the details of a bundled payment or other payment reform system appear far removed from the direct consumer experience, their impacts on the delivery of care are significant. Having consumers involved in creating the reforms can ensure that decision makers consider how reforms impact care delivery from a their standpoint. Engagement ensures that all aspects of the system are centered in patient needs and interests, even when aspects of that system seem removed from direct patient involvement. Reforms to achieve higher-value care—such as bundled payments, accountable care organizations, and patient-centered medical homes—have a direct effect on consumer access to and choice of clinical services and may even impact the quality of the care experience. The consumer is in the best position to help other stakeholders consider potential long- and short-term effects and reveal these policies' possible unintended consequences for patients.

Key Starting Points

Set a Place at the Table.

Invite consumers to participate, plan meetings at times/places that allow consumers to attend, build consumer participation into the agenda.

Build Capacity.

Provide context in plain language, explain technical jargon, educate on basic principles guiding reforms.

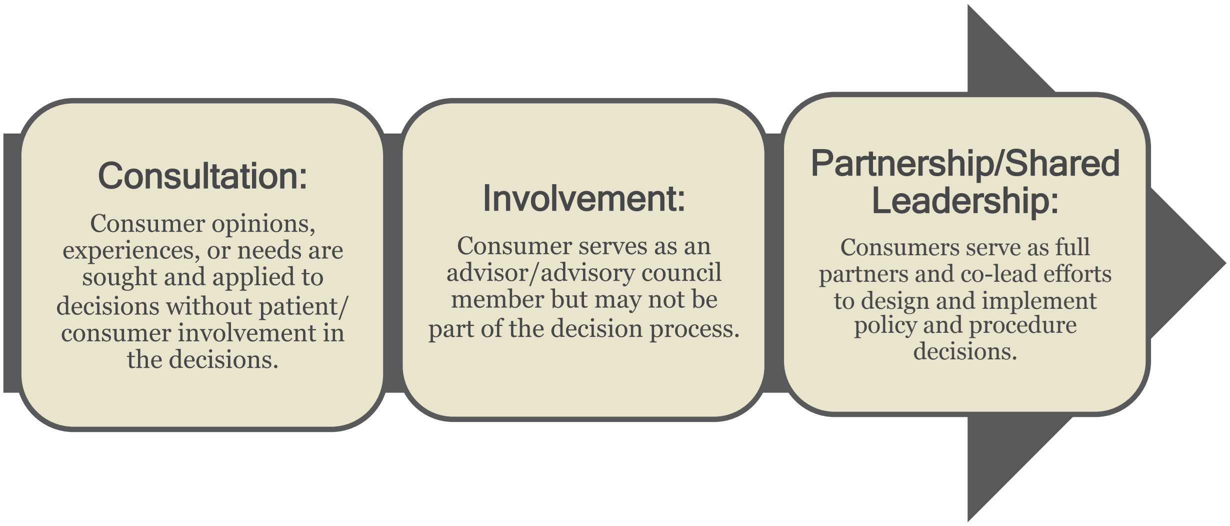
Listen.

Help focus consumer feedback through good questions, appreciate a non-technical perspective, and be careful not to dismiss feedback that lacks "expertise." Translate consumer input and feedback for technical experts. Acknowledge consumer input, and communicate its use in final decisions.

While some new payment systems may be easier for the average consumer to comprehend than others, communities can take evidence-based practices to engage consumers at various levels depending on the task at hand. There may be no single approach to involving consumers in the payment reform process, but such efforts should carefully consider the broad range of engagement options as well as the primary goals that engaging consumers can achieve.

Engaging Consumers: A Spectrum of Engagement

Often, consumer engagement is seen as an "all-or-nothing" proposition; consumers are often kept from any form of engagement on aspects of health care systems that seem inappropriate or unrelated to direct consumer concerns. Engagement in any aspect of policy or health care practice, however, should be viewed as a broad spectrum of involvement. One model of engagement by Kristin L. Carman and her colleagues, shown in **Exhibit 1,** conceptualizes the spectrum as moving from limited involvement to full-patient and consumer partnership in decision-making.[vii]



Consultation:

Consumer opinions, experiences, or needs are sought and applied to decisions without patient/consumer involvement in the decisions.

Involvement:

Consumer serves as an advisor/advisory council member but may not be part of the decision process.

Partnership/Shared Leadership:

Consumers serve as full partners and co-lead efforts to design and implement policy and procedure decisions.

Exhibit 1. A Wide Range: The spectrum of patient and consumer engagement

On one end, consumers may be involved in a consultative role, where they provide solicited opinions, needs, or experience—for example through patient experience surveys such as CAHPS. These surveys provide important feedback from consumers about their experience but do not allow consumers to share directly in developing or determining practices or policies. On the other end, consumers can be full partners in the decision-making process and work alongside medical professionals and administrators to develop and implement policies and affected care delivery practices that reflect consumer needs and interests in harmony with clinical and financial realities. Examples include health insurance co-ops in the health insurance marketplace, which are governed by boards controlled by policyholders or consumers. In between is a form of involvement in which consumers are provided opportunities for input and feedback that is used by others when making key decisions. A popular model for this is patient and family consumer advisory councils. *Aligning Forces for Quality* communities in Humboldt County, CA; Maine; and Oregon have employed such councils and have documented their work in a toolkit available at http://forces4quality.org/node/6319. Representatives from such councils, particularly those with backgrounds that are appropriate to payment issues, may be excellent candidates to involve in payment reform discussions. While full partnership or shared leadership with consumers on payment reform decisions may be less appropriate, this degree of involvement can accomplish the goals of transparency and keep reform decisions focused on patient-centered care delivery outcomes. Each community must determine the appropriate level of engagement for the task at hand.

Overcoming the Challenges

Three significant factors influence consumers' engagement in their health and health care, including payment reform, regardless of the level of engagement they chose. Organizations reaching out to consumers must understand these factors—and potential challenges—to ensure success.

Consumer capacity to engage. Consumer capacity to engage in payment reform conversations must be recognized and addressed before consumers are engaged as full partners. Capacity includes a broad range of issues, from basic literacy and the ability to comprehend complex concepts, to misinformed attitudes and beliefs about costs and payment. Limited formal education, limited ability to leave employment for meetings, or even limited transportation options can often leave the more marginalized populations out of the engagement process. While significant, these barriers can be overcome with a few simple actions:

- **Education.** Simple, clear and carefully translated materials can boost the knowledge and vocabulary consumers need to contribute to discussions of payment reform. Using plain-language descriptions, metaphors, diagrams and glossaries, most consumers can quickly increase their general comprehension and participation.
- **Exposure to multiple perspectives.** Studies in public deliberation have found that exposure to a variety of perspectives helps to expand existing consumer attitudes and opinions from an individual to a broader societal perspective. Educational materials also can be used to create this exposure, and facilitated discussions throughout the process can allow patients and consumers opportunities to hear the perspectives of payers, administrators and policymakers.

Organizational policies, practices and culture. Consumer capacity to participate in policy and practice decision-making is most hindered by organizational policies and practices that limit communication to consumers or ignore or marginalize the consumer perspective when it is voiced in meetings. The fault often lies in an organization's cultural values surrounding interaction between administrators, clinicians, or policymakers and consumers, which transforms into unconscious practices over many years. Policies and practices will likely match underlying beliefs and values of organizational leaders. Organizations may need to carefully examine their underlying (and often unspoken) shared beliefs and values regarding consumers—particularly beliefs regarding capacity and value of consumer opinion or involvement. Some initial questions may help organizational leaders begin the process of identifying cultural barriers that may be limiting consumer engagement. Such questions should be asked with consumers, as the answers from these individuals may be quite different than those from staff.

- In what ways have we involved patients and consumers in our daily operations, procedures, or policies? What collective beliefs or values does this level of involvement represent?
- Could an average consumer or patient explain our current billing and payment process? What have we done as an organization to make these policies transparent?

- Does our policymaking approach (process, meeting times, materials) make it more or less difficult for consumers to participate?
- What beliefs do we have about what consumers could contribute to our policy-making process? What are our greatest concerns?
- What existing relationships do we have with patient and consumer advocacy groups? What natural partners do we have now in the community?

Organizational leadership may need to confront current attitudes and practices by redesigning policies and procedures that enable information flow, understanding and interaction with consumers. This may include creating relationships with consumer and patient groups, exposing administrators and staff to consumer and patient perspectives, and reviewing existing approaches to decision-making to identify barriers for consumer involvement. There will likely need to be a series of initial discussions among consumers and clinicians, administrators, or policymakers about costs and payment systems so that perspectives can be shared and understood before reform efforts are begun. Cultures may take time to change, but the structures that are prohibiting full consumer engagement can be addressed quickly and efficiently.

3. **Societal norms.** A broader and more difficult barrier exists in how slowly social norms around consumer engagement in health care are changing. Our popular depictions of medical settings continue to portray consumers and patients as objects of the system, rather than active contributors. As a result, some consumers remain convinced that involvement in payment systems and policies are beyond their interest or capacity. While there is no quick remedy, health organizations can begin to change the norm by making clear and open invitations to consumers to participate, communicating about consumer participation as often as possible, inside and outside of the organization, and maintaining the commitment to engagement when initial invitations are met with resistance and mistrust.

Starting Points

Regardless of the issue being addressed, the practice of engaging consumers to participate in organizational policy and infrastructure requires several important actions. The more these actions can be established as habits across the organization, the more likely engagement efforts will find success.

Set a place at the table. Though it may seem simplistic, an often-missed first step is creating a clear invitation to participate in policy or practice design and decision-making. This step may involve creating clear descriptions of the role desired for consumers and patients, choosing meeting times and locations that enable a broad range of consumers to participate, and reassuring invited participants that their opinions and ideas are desired and do not require an advanced degree to be of value. Communication materials and plans can help, and consistency across organizational staff as they relate to consumers is critical.

Build capacity for participation. Building capacity for participation involves preparing all parties—consumers and organization staff—for fruitful interaction. Patients and consumers need not know and understand every aspect of cost and payment systems to contribute; still, it is important to provide plain-language resources prior to the meeting to explain the fundamentals of current payment systems and new approaches. For instance, a simple glossary of terms with plain-language definitions can help consumers feel more confident in the conversation. It is also important to prepare patients and consumers for the role they play in the conversation—which is to reflect on plans and designs from a consumer perspective. All parties should keep in mind that the consumer's perspective is more than the end experience (which consumers may never actually see)—it also means exploring the impact designs and revisions might have on other aspects of care, such as referrals, access, paperwork and the timing of care delivery.

Case Study: Patients as Partners

The Alliance in South Central Pennsylvania successfully brought the patient and caregiver voice into its PCMH initiative. Illustrating two suggested tactics—create new structures and provide the necessary training—director Chris Amy shares:

"We are working with 22 practices. One of the requirements for [primary care practices] being involved in the collaborative is that they recruit two patient partners from their panel…and bring them on to their practice leadership team for the collaborative. Those consumers are at equal voice with the providers, and they all work together to do the PDSAs and change work that needs to happen to become a patient-centered medical home."

"We train the patient partners—we have a staff member who supports them in any additional training, and she leads the phone conferences and the preparation dinner meetings that happen before every collaborative meeting."

Organizational staff and other committee members may need some capacity-building as well, such as guidance on communicating technical concepts using metaphors, analogies and visual displays, avoiding unnecessary jargon and acronyms, and developing agendas and discussions that fully embrace the consumer role. It is critical to discuss the difference between avoiding technical jargon and "dumbing down" concepts for consumers; while complexity of concepts may need to be broken down and assumptions spelled out, over-simplification will do little to garner truly helpful consumer input.

Listen. Most important, health organizations and systems seeking patient and consumer engagement must be prepared to receive and fully utilize the input they provide. The ideal starting point is establishing clear, agreed-upon roles for consumer partners so that expectations are realistic for all. For instance, a consumer may have very little to add to a conversation about efficiency structures in a payment process but will add great value by asking how those structures could impact patients or noting impacts that others might not anticipate. Listening to consumer input may require some active translation—both in the questions asked of consumers in payment reform deliberations and in making full use of the input provided by consumers. The first step may be to help other committee members avoid dismissing consumer comments and ideas as "uninformed" and instead listening to insights that may not be hemmed in by deep vertical knowledge in the subject or by an end-user perspective.

Utilize. As important as listening may be, it becomes a hollow activity if the input from patients and consumers is not used in some way. Utilization may take a variety of forms, ranging from influencing the way committee members think about payment reform to incorporating specific consumer suggestions into the final policy or system. Consumer input may very well throw a significant curve in the way policies and systems are traditionally deliberated, determined and implemented. The inclination to dismiss the input of consumers as uninformed and naïve must be resisted.

Acknowledge. In the consumer-as-informant approach that is often taken in health care, patients and consumers rarely have the opportunity to understand how their input is ultimately used in final decisions, policies, or systems. Full partners, on the other hand, are more likely to participate in final decisions and, therefore, more likely to own the outcomes. In addition to verbally acknowledging the contributions of consumers in meetings, it is important to communicate beyond the committee about how consumer input helped shape the final system design or policy.

Conclusion

Engaging consumers in payment reform—and many other health care organizational policy and practices—simply makes good sense. But doing so without careful attention to consumer and staff capacity for engagement can threaten the many possible gains. Consumers' input and perspective will—and should—differ greatly from those of other stakeholders. Yet, consumers' feedback on administrative and payment policies is needed to create a more patient-centered experience—in effect forcing medical administrators, experts and other stakeholders out of traditional ways of thinking. Regardless of whether the engagement opportunity is consultation or full partnership, consumers express a strong interest in participating in health care reform and they add value simply by bringing their own experiences with health and the health care system, along with their values, ethical principles and preferences. Helping them engage in meaningful ways can yield both increased consumer trust in the health care system, and the delivery of more patient-centered care, resulting in better health outcomes.

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