

# Health Affairs

At the Intersection of Health, Health Care and Policy

Cite this article as:

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Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies  
*Health Affairs*, 32, no.2 (2013):223-231

doi: 10.1377/hlthaff.2012.1133

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DOI: 10.1377/hlthaff.2012.1133  
HEALTH AFFAIRS 32,  
NO. 2 (2013): 223–231  
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Foundation, Inc.

# Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies

**ABSTRACT** Patient and family engagement offers a promising pathway toward better-quality health care, more-efficient care, and improved population health. Since definitions of *patient engagement* and conceptions of how it works vary, we propose a framework. We first present the forms engagement can take, ranging from consultation to partnership. We discuss the levels at which patient engagement can occur across the health care system, from the direct care setting to incorporating patient engagement into organizational design, governance, and policy making. We also discuss the factors that influence whether and to what extent engagement occurs. We explore the implications of our multidimensional framework for the development of interventions and policies that support patient and family engagement, and we offer a research agenda to investigate how such engagement leads to improved outcomes.

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Patient engagement has been called a critical part of a continuously learning health system,<sup>1</sup> a necessary condition for the redesign of the health care system,<sup>2</sup> the “holy grail” of health care,<sup>3</sup> and the next “blockbuster drug of the century.”<sup>4</sup>

But definitions of *patient engagement* and conceptions of how it improves care vary considerably. Angela Coulter’s well-known definition focuses on the relationship between patients and health care providers as they work together to “promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels.”<sup>5</sup>

A model of public engagement developed by James Conway at the Institute for Healthcare Improvement is organized around the settings in which patient engagement occurs: during the care experience, within the microsystem of the

clinic or ward, within the health care organization, and within the larger community.<sup>6</sup> And the Center for Advancing Health’s engagement behavior framework focuses on behavior, defining engagement as “actions people take for their health and to benefit from health care”<sup>7</sup> and providing a list of patient-initiated engagement actions.

Adding to the confusion, the term *patient engagement* is also used synonymously with *patient activation* and *patient- and family-centered care*. Although the concepts are related, they are not identical. Patient activation—an “individual’s knowledge, skill, and confidence for managing his/her own health and health care”<sup>8(p377)</sup>—is one aspect of an individual’s capacity to engage in that care. But this term does not address the individual’s external context, nor does it focus on behavior.

“Patient- and family-centered care” is a broader term that conveys a vision for what health care should be: “a partnership among

practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."<sup>9(p7)</sup>

We define *patient and family engagement* as patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care. Although we use the term *patient engagement* for simplicity's sake, we recognize that those who engage and are engaged include patients, families, caregivers, and other consumers and citizens.

Several circumstances encourage a growing emphasis on patient engagement. First, work related to patient- and family-centered care and shared decision making both reflects and accelerates the shifting roles of patients and families in health care as they become more active, informed, and influential.<sup>9,10</sup>

Second, a growing body of evidence suggests that patient engagement can lead to better health outcomes,<sup>11</sup> contribute to improvements in quality and patient safety,<sup>12</sup> and help control health care costs.<sup>13</sup> Third, virtually every discussion about the US health care system begins by noting that spending is spiraling upward while quality lags behind. In the search for solutions, gaining ground is the belief that patients are at the core of our system and, as such, are part of the solution.<sup>14</sup>

In this article we propose a model of patient engagement that presents the forms patient engagement can take, from consultation to partnership and what we call shared leadership, which includes decision-making authority. Our model also examines the levels at which patient engagement can occur throughout the health care system, in direct care, organizational design and governance, and policy making. We also examine the factors<sup>15</sup> that influence patients' willingness and ability to engage and the extent of their engagement. The factors that influence the ability of clinicians, health care organizations, and policy makers to create opportunities for engagement are also important, but consideration of them is beyond the scope of this article.

We conclude by exploring the implications of our multidimensional framework for the development of interventions and policies that support patient engagement. We also present a research agenda to investigate the pathways by which engagement leads to improved outcomes.

This framework was developed in conjunction with patient and family representatives, re-

flecting the principle of working with, rather than doing "to" or "for" patients. We note that our model is not a static one. The field of patient engagement is nascent; as it evolves, so will our model. But we hope that the framework in its current form will help inform the development of interventions and policies that support patient and family engagement.

As shown in Exhibit 1, our multidimensional framework includes three critical aspects of patient engagement. First, engagement activities range along a continuum,<sup>16</sup> from consultation to partnership and shared leadership. Second, engagement occurs at different levels: It is not confined to individual health behavior or direct care interactions; it also occurs in organizational design and governance and in policy making. Third, multiple factors affect the willingness and ability of patients to engage.

## The Continuum Of Engagement

Patient engagement can be characterized by how much information flows between patient and provider, how active a role the patient has in care decisions, and how involved the patient or patient organization becomes in health organization decisions and in policy making. At the continuum's lower end, patients are involved but have limited power or decision-making authority. Providers, organizations, and systems define their own agendas and then seek patients' input. Information flows to patients and then back to the system.

At the continuum's higher end, engagement is characterized by shared power and responsibility, with patients being active partners in defining agendas and making decisions. Information flows bidirectionally throughout the process of engagement, and decision-making responsibility is shared.

Consider this example concerning patients' electronic health records. At the consultation end of the engagement continuum, clinicians may use the records to provide information to patients—such as printouts of lab results—but patients cannot access the information directly. At the midpoint of the continuum, involvement, patients have direct access to their records, including notes from clinicians and the health care delivery system, but they cannot contribute or correct information.

In contrast, at the partnership end of the continuum, patients have direct access to their records, are able to see notes from clinicians and the system, and can add or edit information. The record reflects the entire experience of care from the perspectives of both the patient and the clinicians, and care decisions can be made

collaboratively, with all relevant information included.

In describing patient engagement in terms of a continuum, we are not suggesting that the goal is always to move toward engagement at the higher end of the continuum. Such engagement is not necessarily better for every patient in every setting. Clinicians, delivery systems, and policy makers cannot assume that patients have certain capabilities, interests, or goals, nor can they dictate the pathway to achieving patients' goals. However, the range of opportunities along the continuum is best determined based on the topic at hand and defined and created with patients' participation.

But even if greater engagement is not ideal for all people in all situations, more and more patients will want—even demand—greater involvement in care and policy decisions. With shared power and responsibility comes the potential for better, more patient-centered outcomes. For example, recent work related to patients with cardiac arrhythmia shows that patients who experienced shared decision making chose far less invasive treatments compared to those who did not.<sup>17</sup>

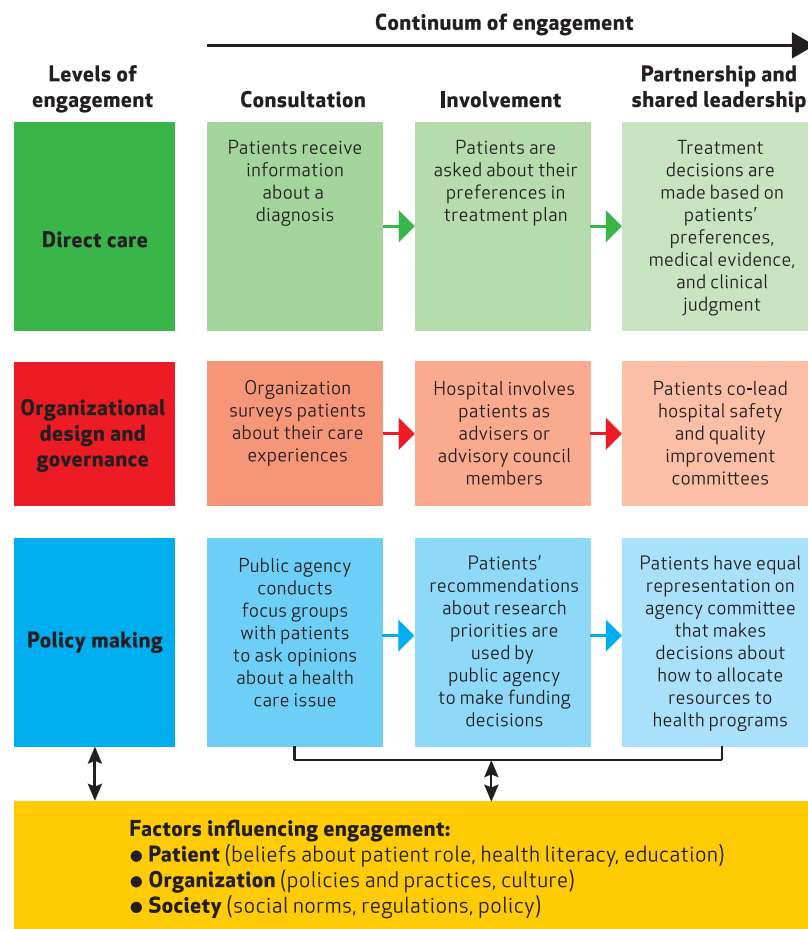
## Engagement At Multiple Levels

**DIRECT CARE** At the level of direct care, engagement integrates patients' values, experiences, and perspectives related to prevention, diagnosis, and treatment, including managing the patient's health and selecting health care coverage and providers. Although we refer to this level as *direct care*, engagement here need not involve interaction with clinicians. Patients may also engage with a range of health-related resources and groups to initiate or sustain personal health practices—for instance, seeking information about health conditions and treatments, participating in community-based self-management support groups, or using ratings of provider quality.

Patient engagement at this level ranges from a patient's simply receiving information to being an active partner in the care team, setting goals, making decisions, and proactively managing his or her health. In engagement at the partnership end of the continuum, patients communicate with clinicians about their health situation, understand the risks and benefits associated with care choices, ask questions, and access and help create their medical records. Clinicians give patients timely, complete, and understandable information; elicit patients' values, beliefs, and risk tolerance regarding care choices; give patients encouragement and support; and involve family and friends according

### EXHIBIT 1

#### A Multidimensional Framework For Patient And Family Engagement In Health And Health Care



**SOURCE** Authors' analysis. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

to the patient's wishes.

For example, a patient with localized prostate cancer might go online to look for evidence about treatment options and associated clinical and quality-of-life considerations. Next, the patient might discuss important considerations with his physician and family. Then the patient, family, and physician would work together to develop and initiate a treatment approach that considers the patient's and family's emotional anxiety about cancer, treatment preferences and goals, life circumstances, values, and risk tolerance for adverse outcomes.

**ORGANIZATIONAL DESIGN AND GOVERNANCE** At the level of organizational design and governance, engagement integrates patients' values, experiences, and perspectives into the design and governance of health care organizations such as hospitals, accountable care organizations, clinics, and nursing homes.<sup>4,18</sup> Patients

partner with organizational leaders, front-line managers, and clinicians to plan, deliver, and evaluate care. Patients also help design health care facilities; serve on hospitals' patient and family advisory councils; participate in the design and execution of quality improvement projects; and assist with staff hiring, training, and development.<sup>19</sup>

At the partnership end of the continuum, patients help set agendas, determine priorities, and share decision-making authority. Patients are engaged early and meaningfully and are not token or single representatives. For example, at the Dana-Farber Cancer Institute, patients and family members have participated as decision-making members in continuous quality improvement teams, taken part in hiring decisions, and developed and provided staff training.<sup>20</sup>

**POLICY MAKING** At the policy-making level, engagement focuses on developing, implementing, and evaluating national, state, and local health care policy and programs. Patients' engagement in policy, which is often described as "citizen" or "public" engagement, helps ensure that the health care system writ large is oriented around and responsive to patients' perspectives.

Patients collaborate with community leaders and policy makers—for instance, representatives from governments, health plans, and employers—to solve community and social problems, shape health care policy, and set priorities for the use of resources. Patients also participate in health and clinical research. At this level, engagement may include individual patients as well as representatives of consumer organizations who speak on behalf of a general constituency.

Ideally, at the partnership end of the continuum for this level, patients or their representatives set priorities and make policy and program decisions. However, it is still rare for patients to have more than a token amount of power and influence.

An example that moves toward this higher level of partnership is the Health Information Technology Policy Committee, established by the American Recovery and Reinvestment Act of 2009. This federal advisory committee designates three of its twenty seats for consumer representatives to make recommendations on policies that promote the adoption and "meaningful use" of health information technology, including its use to promote patient and family engagement.

### Factors That Influence Engagement

Numerous factors influence whether and to what extent patients are able to engage at different levels and at different points along the

continuum. In our framework (Exhibit 1) we have grouped these factors into three categories: those related to patients, organizations, and society. Each set of factors acts on its own and in conjunction with the other sets to affect patients' actions and engagement. The factors we include in the framework and discuss here are illustrative, not exhaustive.

**THE PATIENT** Individual factors that can affect patients' motivation, willingness, and ability to engage within and across different levels include patients' knowledge, attitudes, and beliefs, such as their beliefs about the patient role; their experience with the health care system; their self-efficacy; and their functional capacity, such as their health literacy, health status, and functioning.<sup>21,22</sup> Vulnerable populations—for example, people at low income levels, those who have limited English proficiency, and the elderly—may face additional challenges, such as low health literacy or cognitive decline, when trying to engage.<sup>23,24</sup>

**THE ORGANIZATION** An organization's characteristics influence patients' ability to engage in it. Hospitals, physician practices, accountable care organizations, governments, and other organizations can encourage patient engagement by demonstrating that patients' participation and leadership are central to the achievement of improvement goals<sup>25</sup> and by responding positively to patients' efforts.<sup>21</sup> Organizational policies or practices also affect how easy it is for patients to be active partners.<sup>25</sup>

Policies and practices that positively influence patient engagement in direct care include open family presence policies—that is, hospital policies that enable families to visit twenty-four hours a day;<sup>26</sup> bedside rounding—that is, conducting physician and interdisciplinary rounds at the patient's bedside;<sup>27</sup> having nurses who are coming on and going off duty give their change of shift report at the patient's bedside;<sup>28</sup> patient-centered discharge planning;<sup>29</sup> and electronic health records that patients can access and edit.<sup>30</sup> Organizational policies and practices can further promote engagement by creating expectations that patients will serve as advisers and decision makers, including on quality improvement teams, patient safety and error committees, and patient- and family-centered care councils.

**SOCIETY** The third set of factors recognizes that patients and organizations operate within a broader social and political environment and are influenced by social norms; purchasers' regulations; and national, state, and local policies. Social and community norms influence whether patients view themselves as able to contribute to improving their care, what organizations they



interact with, and overall policy making.

Purchasers' policies, reimbursement mechanisms, and benefit designs—such as having lower or no copayments for office visits to manage chronic conditions—can influence patients' behavior in seeking health care and making decisions about their care.<sup>31</sup> They can also indicate to organizations where resources should be allocated, such as to support patient engagement in discharge planning.

Policy makers can also create mechanisms by which patients can provide input and help shape public policy, such as public deliberation, town hall meetings, public hearings, or regulatory comment processes. Similarly, foundations, nonprofit organizations, and government agencies can create funding mechanisms requiring and supporting patient participation in societal decisions and priority setting.

In addition, legislative rules or regulations may specifically spur patients' participation in health care. An example here is the mandate in Massachusetts for hospitals to establish patient and family advisory councils.<sup>32</sup>

## Discussion

The framework for patient engagement that we present highlights three main implications for the development of interventions to promote that engagement. First, the continuum of engagement helps characterize the extent to which patients are involved in decision making. If evidence that outcomes are improved by greater partnership continues to accumulate, then interventions should be designed to move patients to increasingly shared power and responsibility at each level.

Second, this framework underscores the possibility that a greater impact could be achieved by implementing interventions across multiple levels of engagement. For example, interventions that increase engagement at the policy-making level may increase engagement or improve outcomes at the levels of direct care or organizational design and governance.

Third, interventions can be designed to address the factors that influence patient engagement. Interventions often focus on changing patient factors, such as knowledge or motivation, without addressing organizational and societal barriers to engagement. Although highly motivated patients may become engaged without clear opportunities and invitations, the vast majority of patients will not.

Further research may show that interventions targeting multiple factors or sets of factors simultaneously are more effective and have a bigger return on investment. For example, in the

Agency for Healthcare Research and Quality's current initiative to develop a guide to patient and family engagement to improve hospital quality and safety, hospitals can support engagement not only by educating patients about their role as a member of the care team and in discharge planning, but also by moving nurse changes of shift to the patient's bedside, training clinicians to support patient engagement, and partnering with patients at the organizational level to plan, deliver, and evaluate care.<sup>33</sup>

## Framing The Research And Policy Agenda

**QUESTIONS FOR FUTURE RESEARCH** Emerging evidence suggests that engagement can be a pathway toward achieving the goals of better quality of care, greater cost efficiency, and improved population health.<sup>18,25,34,35</sup> However, we need to build an evidence base of what works and—just as important—what does not work in achieving and sustaining productive patient engagement. Our framework suggests the following questions to be addressed in future research.

What factors, or combinations of factors, exert the greatest influence on patient engagement? What are the pathways by which they do this?

When developing interventions at one level, such as direct care, what supports are needed at the levels of organizational design and governance and of policy making to increase those interventions' effectiveness?

How do interventions at the policy-making level affect engagement efforts and outcomes at the other levels?

Do interventions in which patients share leadership demonstrate better outcomes than those in which patients are only consulted or involved? If so, which interventions are most effective at facilitating engagement at the continuum's highest end?

What are the most effective methods for organizations and policy makers to create opportunities for engagement? How can organizations recruit patients to serve on governance committees? How are committee members' roles and responsibilities defined?

How can research findings be translated into routine practice? How can we best support implementation and structure interventions that make the most of available resources?

**MEASURES** Tracking and monitoring progress on engagement requires the use of parsimonious, robust measures to assess what works, how it works, and—over time—whether engagement efforts are improving outcomes. As a starting point, existing measures should be examined for their usefulness and how they might be

applied.

For example, Judith Hibbard's Patient Activation Measure, which assesses a person's capacity for engagement, could help inform interventions to encourage engagement at the direct-care level.<sup>8</sup> Collecting patient-reported outcomes, as the Consumer Assessment of Healthcare Providers and Systems survey does, can serve a dual role: both asking patients for feedback and informing quality improvement efforts.

Scarce resources and a desire to decrease the burden of using measures may require balancing the development of new patient engagement measures against other pressing, but highly related, measure gaps such as care coordination and affordability. However, the emerging evidence linking patient engagement to improved outcomes warrants heightened attention. A process that involves multiple stakeholders—including patients—could help prioritize gaps and make recommendations throughout the measure development life cycle: conceptualizing, testing, endorsing, implementing, and evaluating a measure.

## Conclusion

We are in the midst of an important and potentially transformative shift related to patients' roles in health care. The framework for patient and family engagement that we present here makes it clear that health care professionals at all levels—clinicians, administrators, members

of professional societies, and researchers—as well as policy makers play critical roles in partnering with patients and families and supporting them in new roles. Examples across the country show where engagement is taking place and achieving results.

Yet engagement is not a quick fix. Many patients and clinicians are still operating in an older paradigm of a paternalistic clinician and system. Efforts need to be made not only to raise patients' awareness about the benefits of engagement but also to encourage and support patients' increasing responsibility and leadership.

In addition, engagement initiatives often challenge the perceived needs, norms, and assumptions of health care professionals as they make treatment recommendations amid a variety of constraints, such as short patient visits, increased complexity of diagnoses, and reimbursement policies; help manage a complex and expensive health care system; and generate scientifically valid evidence for medical interventions.

To move forward, health care organizations and policy makers will need to embrace new norms and make substantial changes in their culture, processes, and structure. Moreover, if we are to achieve the laudable goals outlined at the beginning of this article, health care organizations and policy makers cannot make changes in isolation. The pathway to true engagement involves working in partnership with patients and families. ■

The authors thank Thomas Workman for his extensive comments to finalize this framework. In addition, they gratefully

acknowledge that this framework builds on the work of many projects and the insight and perspective of many

colleagues, funders, and patients and families who have participated in and supported their work.

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## ABOUT THE AUTHORS: KRISTIN L. CARMAN, PAM DARDESS, MAUREEN MAURER, SHOSHANNA SOFAER, KAREN ADAMS, CHRISTINE BECHTEL & JENNIFER SWEENEY



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In this month's *Health Affairs*, Kristin Carman and coauthors propose a framework for understanding the elements of patient engagement, developing interventions that effectuate it, and promoting policies that spread it. They also offer a research agenda that could help illuminate more fully whether and how such engagement leads to improved health outcomes.

Carman is a managing director in the Health Program at the American Institutes for Research, director of the Center for Patient and Consumer Engagement, and a codirector of the Health Policy and Research Group, a team of more than seventy health services research professionals. They conduct research on issues of public importance in health care quality, access, financing, comparative effectiveness research, patient and family engagement, health systems improvement, public deliberation, and health-related communications.

Carman's work emphasizes explaining evidence-based information for use in decision making. She has led many consumer engagement research and technical assistance projects and currently leads four projects on this topic funded by the Agency for Healthcare Research and Quality (AHRQ) and the Robert Wood Johnson Foundation. She earned both a master's degree and a

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Pam Dardess is a senior research analyst at the American Institutes for Research. She has particular expertise in the areas of patient and consumer engagement, health care quality and cost reporting, and the development and testing of health education and information materials for patients, families, and clinicians. Dardess serves as the project director for AHRQ's effort to assess the effects of an intervention to increase the relevancy and use of public reports of quality information and the agency's effort to develop, implement, and evaluate a *Guide to Patient and Family Engagement in Hospital Safety and Quality*.

Dardess holds a number of other leadership positions, including senior researcher for the California HealthCare Foundation's Consumer Use of Cost and Quality Information project. She received a master's degree in public health from the University of North Carolina at Chapel Hill.



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Maureen Maurer is a senior researcher in the Health Program at the American Institutes for Research. She leads large projects and tasks related to engaging consumers in health care decision making and policy; creating and testing materials for patients, families, and clinicians that translate complex medical evidence; eliminating health disparities; and conducting program evaluations. Maurer is a highly experienced qualitative researcher, responsible for designing research studies, conducting in-depth interviews and focus groups, and analyzing the results of large-scale qualitative research. She earned a master's degree in public health from the University of North Carolina at Chapel Hill.



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Shoshanna Sofaer is the Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs, Baruch College, City University of New York, and a professor in the doctoral program in public health at the City

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Sofaer was named a 2013 fellow of the National Academy of Public Administration and is a 2010–13 William Ziff Patient Engagement Fellow at the Center for Advancing Health, a Washington, D.C.–based nonprofit that conducts research, communicates findings, and advocates for policies that support the ability to benefit from advances in health science. Sofaer earned both a doctorate in health planning, policy, and administration and a master's degree in community mental health from the University of California, Berkeley.



**Karen Adams** is vice president of national priorities at the National Quality Forum.

Karen Adams is vice president of national priorities at the National Quality Forum. She provides

strategic direction and oversight for the National Priorities Partnership, a collaborative effort of fifty stakeholders from the private and public sectors to achieve better health and a safe, equitable, and value-driven health care system.

Adams has held positions at the Institute of Medicine and the Commonwealth Fund, where she worked on quality and health care delivery reform issues. She earned a master's degree in management from the College of Notre Dame of Maryland and a doctorate in public policy from the University of Maryland Baltimore County.



**Christine Bechtel** is vice president of the National Partnership for Women and Families.

Christine Bechtel is vice president of the National Partnership for Women and Families, where she is responsible for strategic direction and oversight of the organization's health care programs. Her work includes managing projects funded by the nation's largest foundations, partnerships with key business

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**Jennifer Sweeney** is director of consumer engagement and community outreach at the National Partnership for Women and Families.

Jennifer Sweeney is director of consumer engagement and community outreach at the National Partnership for Women and Families. Her responsibilities include leading the organization's efforts to advance consumer involvement in health care delivery reform and to cultivate and sustain relationships with national, state, and local health care stakeholders, funders, and other partners with the goal of advancing the practice of patient-centered care. She earned a master's degree in women's studies from the George Washington University.