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What The Evidence Shows About Patient Activation: Better Health Outcomes And Care Experiences; Fewer Data On Costs

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ABSTRACT Patient engagement is an increasingly important component of strategies to reform health care. In this article we review the available evidence of the contribution that patient activation—the skills and confidence that equip patients to become actively engaged in their health care—makes to health outcomes, costs, and patient experience. There is a growing body of evidence showing that patients who are more activated have better health outcomes and care experiences, but there is limited evidence to date about the impact on costs. Emerging evidence indicates that interventions that tailor support to the individual's level of activation, and that build skills and confidence, are effective in increasing patient activation. Furthermore, patients who start at the lowest activation levels tend to increase the most. We conclude that policies and interventions aimed at strengthening patients' role in managing their health care can contribute to improved outcomes and that patient activation can—and should—be measured as an intermediate outcome of care that is linked to improved outcomes.

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The Affordable Care Act recognizes that engaging patients in their own care is a cornerstone of successful health system reform and is critical to the success of accountable care organizations and patient-centered medical homes. A growing body of evidence links patients' activation levels to their health and cost outcomes. In this article we review evidence of the contribution that patient activation makes to health outcomes, costs, and patients' experiences of care.

The terms *patient engagement* and *patient activation* are often used interchangeably. The terms are also frequently used to convey different meanings or are poorly defined.

Patient activation emphasizes patients' willingness and ability to take independent actions to manage their health and care. We use the definition developed by an author of this article, Judith Hibbard, and colleagues. This definition

equates patient activation with understanding one's role in the care process and having the knowledge, skill, and confidence to manage one's health and health care.¹ Activation differs from compliance, in which the emphasis is on getting patients to follow medical advice.

We use *patient engagement* to denote a broader concept that includes activation; the interventions designed to increase activation; and patients' resulting behavior, such as obtaining preventive care or engaging in regular physical exercise. The focus on activation and engagement rather than compliance recognizes that patients manage their health on their own the vast majority of the time, making decisions daily that affect their health and costs.

The evidence linking patient activation with health outcomes, patient experience, and costs has grown substantially over the past decade. Besides reviewing the strength of that evidence, we identify important research gaps and address

two key policy questions: What are effective strategies for activating patients? And can patients who are disengaged and not activated become activated?

In this review we include studies that quantify patient activation using the Patient Activation Measure and that link activation levels to health outcomes, costs, and patients' experiences of care. The Patient Activation Measure is a so-called latent construct—a variable that can't be measured directly but instead is assessed through a series of answers to questions—that gauges a person's self-concept as a manager of his or her health and health care. The measure is scored on a 0–100 scale, and people are categorized into four levels of activation, with level 1 the least activated and level 4 the most activated.

The score incorporates responses to thirteen statements about beliefs, confidence in managing health-related tasks, and self-assessed knowledge. Examples include the following: “I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself”; “I know what treatments are available for my health problems”; and “I am confident that I can tell a doctor my concerns, even when he or she does not ask.” Responses are degrees of agreement or disagreement.

The measure has been proved to be reliable and valid across different languages, cultures, demographic groups, and health statuses.^{1–7}

Evidence Of Better Health Outcomes

Multiple domestic and international studies have empirically demonstrated that people who score higher on the Patient Activation Measure are significantly more likely than people who score lower to engage in preventive behavior such as having regular check-ups, screenings, and immunizations. More highly activated people are also significantly more likely to engage in healthy behavior such as eating a healthy diet and getting regular exercise. Moreover, those who score higher are more likely to avoid health-damaging behavior such as smoking and illegal drug use.^{1,2,8–15}

Less activated patients are also three times as likely to have unmet medical needs and twice as likely to delay medical care, compared with more activated patients.¹³ Highly activated patients are two or more times as likely as those with low activation levels to prepare questions for a visit to the doctor; to know about treatment guidelines for their condition; and to seek out health information, including comparisons of the quality of health care providers.^{10,16}

Chronically ill patients with higher activation

levels are more likely than those with lower levels to adhere to treatment; perform regular self-monitoring at home; and obtain regular chronic care, such as foot exams for diabetes.^{2,8,9,11,12,17–25}

These findings stem from studies of patients with a range of conditions and economic backgrounds.

For example, Kimberly Rask and colleagues followed patients with diabetes from an inner-city public hospital clinic over a six-month period and found that patients with higher activation scores were more likely to perform foot checks, obtain eye examinations, and exercise regularly, compared to patients who scored lower on this measure.¹⁹ In a study of patients with serious mental illnesses, Michelle Salyers and colleagues found that higher Patient Activation Measure scores were positively related to patients' management of their own illness and were negatively related to substance abuse.¹⁵

Two studies tracked how changes in Patient Activation Measure scores over time were related to subsequent behavior changes. First, Hibbard and coauthors followed patients with one or more chronic diseases over a six-month period.⁹ Increases in Patient Activation Measure scores were linked to improvements in eleven of eighteen actions, including regular exercising and keeping a blood glucose diary. Lisa Harvey and colleagues reported similar results among employees: When Patient Activation Measure scores increased, multiple behaviors improved, regardless of the employees' activation level at baseline.²⁶

In addition to the documented linkages between activation and healthy behavior, activation has been shown to be associated with better health outcomes. Several studies have reported that patients with higher activation scores are more likely than patients with lower scores to have biometrics such as body mass index, hemoglobin A1c, blood pressure, and cholesterol in the normal range.^{8,17,25,27,28}

These findings, from both cross-sectional and prospective studies, were significant even after sociodemographic factors, disease severity, and insurance status were controlled for. Moreover, many of these findings have been reported within disadvantaged, ethnically diverse, and medically indigent populations.^{19,29–33}

Patient activation has also been linked to outcomes among patients with many different types of health conditions.^{11,14,15,31,34–40} In addition, many of the findings have been replicated in studies conducted in different countries, including Denmark, Germany, the United Kingdom, Japan, Norway, Canada, the Netherlands, and Australia.^{3–7,20,36}

Evidence Of Better Health Care Experiences

Several studies have documented that more highly activated patients consistently report more positive care experiences.^{1,11,41-44} Jeffrey Alexander and colleagues found that patients' reports of higher-quality interpersonal exchanges with physicians, greater fairness, and more out-of-office contact with physicians were associated with higher patient activation scores.⁴¹ Daniel Maeng and coauthors found that patients with higher scores and one or more chronic disease reported fewer problems with care coordination than did patients with lower scores.⁴²

Most of the studies looking at patient activation and patient experience are cross-sectional, which makes it impossible to know the direction of causality. However, new evidence suggests that highly activated patients report better care experiences from a given provider than do less activated patients who see the same provider.⁴⁴ Highly activated patients may have the skills and confidence to elicit what they need from their providers.

These findings suggest that patient experience scores, such as those on the Consumer Assessment of Healthcare Providers and Systems survey, may be a reflection of a transaction that is shaped by both the clinician and the patient and is not just a measure of provider performance.⁴⁴

Evidence Of Lower Health Care Costs

Several studies have reported that after disease severity and demographic characteristics were controlled for, highly activated patients had lower rates of costly use such as hospitalizations and emergency department visits, compared to less activated patients.^{8,25,36,45} In a study of more than 25,000 patients in a large delivery system in Minnesota, we found that for every additional ten points on a Patient Activation Measure score, the predicted probability of having an emergency department visit was one percentage point lower.⁸ The study controlled for health and demographic factors.

In this month's *Health Affairs*, we and Valerie Overton publish the first study that specifically examined patient activation and cost of care.⁴⁶ We found that Patient Activation Measure scores were predictive of the same year's and the next year's billed costs of care, with less activated patients having significantly higher costs than more activated patients.

Evidence Of The Ability To Increase Activation Levels

Evaluations of interventions to increase patient activation have been carried out in a variety of settings: the workplace,²⁹ hospitals,⁴⁷ disease management programs,⁴⁸ the community,^{22,49-51} and primary care.^{29,52} These studies include publicly and privately insured populations and patients with various health conditions. Interventions ranged in duration from just one visit to periods of six months.

All of these studies have documented improvements in activation scores as a result of the intervention being tested. On average, improvements ranged from 2.5 to 6.5 points on the 100-point activation scale. Concurrent with the increases in activation, several of the studies have shown improvements in health outcomes, including health-related quality of life; clinical indicators, such as low-density lipoprotein and blood pressure; adherence to treatment; improved health-related behavior; increased participation in care; and reduced symptoms, hospital readmissions, overnight hospital stays, and use of the emergency department.^{22,28,29,47-52}

The studies vary in their sample sizes and degree of rigor. However, collectively they help identify the types of interventions that yield increases in activation.

Interventions shown to increase activation have one or more of the following focuses.

SKILL DEVELOPMENT, PROBLEM SOLVING, AND PEER SUPPORT A good example of this type of intervention is Kate Lorig's diabetes self-management program, which uses trained lay leaders in community settings to facilitate workshops aimed at helping chronically ill patients handle problems better, engage in appropriate exercise, and communicate with providers. The program is community based and is typically not linked to any delivery system. Participants have demonstrated increases in activation that have been sustained for up to twelve months after participation.⁵⁰

Benjamin Druss and colleagues adapted the self-management program to patients with serious mental illnesses and tested it in a controlled trial.²² At the six-month follow-up, participants in the intervention group had significantly greater improvements in patient activation than those in usual care, along with greater improvements in adherence, physical activity, and quality of life.

Two studies carried out in safety-net clinics that focused on skills development, such as question formulation, have been shown to increase patients' skills, participation in care, and activation levels.^{29,52}

A quasi-experimental study conducted in

senior centers evaluated an intervention that focused on peer support and the development of self-management skills such as condition monitoring and increasing physical activity.⁵¹ The intervention focused on the importance of taking an active role in managing one's conditions and offered specific strategies for doing so. Participants' Patient Activation Measure scores and physical activity increased, and their quality-of-life scores and health status had improved at a six-month follow-up.

Michael Parchman and colleagues showed that the baseline Patient Activation Measure scores of patients with diabetes had improved at a one-year follow-up, when the patients engaged in participatory decision making with providers.⁵³ Further Patient Activation Measure score improvements were associated with increases in medication adherence and levels of HbA1c and low-density lipoprotein cholesterol.

CHANGING THE SOCIAL ENVIRONMENT These interventions seek to change the social environment to facilitate people's changes in beliefs, social norms, skills, and opportunities to engage in healthy behavior. In an experiment involving two large companies, employees were randomly assigned to a control group or to a group receiving one of two different workplace interventions focusing on wellness or being an informed health care consumer. Although the two intervention arms emphasized different issues, both included health classes, environmental changes such as posters and information campaigns, and personal coaching for high-risk employees. The findings showed that people receiving either of the interventions significantly increased their activation, by an average of five points.²⁸

TAILORING SUPPORT TO THE PERSON'S ACTIVATION LEVEL The goal of tailored coaching is to encourage people to take actions at which they are likely to succeed. Participants who are less activated are encouraged to take small, manageable steps; those who are more activated are encouraged to make more substantial behavioral changes.

In a small study, Martha Shively and colleagues randomly assigned patients with heart failure to a group receiving usual care only or a group given tailored coaching along with their medical care.⁴⁵ The coaching was designed to help patients develop self-management skills, with the level of intensity tailored to the patient's level of activation. The researchers found greater increases in activation scores and greater corresponding decreases in hospitalization for the intervention group, compared to the group receiving usual care alone. Notably, the decreases in hospitalization among the intervention group were observed whether participants' baseline

activation scores were high or low.

In a quasi-experimental study conducted in a disease management program, coaches tailored support to the patients' Patient Activation Measure scores.⁴⁸ Coaches encouraged patients to make changes that they were likely to succeed at, starting the less activated patients with smaller steps. The findings showed significant improvements over the course of six months in activation scores; adherence to treatment; clinical indicators, such as blood pressure and low-density lipoprotein levels; and reductions in emergency department use and hospitalizations, compared to patients in the control group who received usual coaching, with no tailoring according to patients' activation level.

One interesting finding from the intervention studies was that patients who started at the lowest activation levels tended to increase their Patient Activation Measure scores the most. This result may partly be a ceiling effect—that is, the patients who began with high scores had less room to improve—but it is encouraging that an effective intervention can activate patients who were previously passive.^{48,51,52}

Overall, interventions that tailor support to the person's level of activation, build skills and confidence, use peer support, and change the social environment have a positive impact on activation as well as other outcomes.

Although there is a growing body of intervention studies investigating different population groups and conditions, many limitations and gaps remain. There is a need to expand the evidence base about the efficacy of different strategies in different settings. And although it appears that several different types of interventions are effective, there is no indication which are most effective or which will work best with specific patient populations. More controlled trials are needed to develop this evidence base.

Studies are starting to emerge that look at the impact of web-based interventions or portals on patient activation. The results are encouraging, but more research is needed in this area.^{54–57} Also, although less activated people appear to benefit from interventions, they are less likely than others to participate in them in the first place.⁵⁷ Research is needed to identify strategies that increase the participation of less activated patients.

The Patient Activation Measure In Innovative Delivery Systems

Innovative delivery systems are measuring activation to improve and individualize patient care and to strengthen the patient's role in improving outcomes. They are improving care principally

by tailoring coaching, education, and care protocols to patients at different levels of activation. Delivery systems are also making more efficient use of their resources by providing more support to patients who have a heavy disease burden and limited self-management skills (less activated patients), and less support to patients with greater skills.

For example, Fairview Health Services in Minnesota—a large not-for-profit health care system with forty-one primary care clinics, specialty care clinics, and hospitals—routinely collects Patient Activation Measure data as part of primary care. Fairview is also participating in the Centers for Medicare and Medicaid Services' Pioneer Accountable Care Organization model.

The patient activation data are collected by Fairview's front-office staff in the waiting room or by medical assistants in the exam room. The resulting activation score is then entered into the patient's electronic health record. Fairview is also laying the groundwork for collecting Patient Activation Measure data online via the patient portal, known as MyChart, in the EPIC electronic health record system.

Within Fairview, the Patient Activation Measure is increasingly viewed as a vital sign that is key to individualizing patients' care plans. Fairview's clinicians are being trained to use motivational interviewing to help match patients' care plans to activation levels. Additionally, Fairview is using the Patient Activation Measure score to reduce hospital readmissions. The health system also uses the score when patients are discharged to tailor the type and amount of support provided to patients at that stage. By targeting extra support to people with the weakest self-management skills, and providing less support to those with adequate self-management skills, the Fairview staff is seeking to reduce readmissions with fewer resources.

Another example is the Courage Center in Minnesota, the recent winner of an innovation grant from the Centers for Medicare and Medicaid Services. The Courage Center provides a patient-centered medical home for patients—many of them eligible for both Medicare and Medicaid—with complex chronic illnesses or disabilities. The patients have high rates of expensive utilization, averaging 10.8 hospital days per year. With careful management and responsive clinicians, the center has been able to increase Patient Activation Measure scores seven points on average, over roughly twelve months. It has also reduced hospital days by 71 percent, to 3.1 days per year—a significant change. By helping patients prevent crises, the center gives patients a greater sense of control over their

situation.

One strategy the center uses is to have the Patient Activation Measure score drive care protocols. For example, when a patient with a low activation score calls the center, the staff addresses the patient's needs by marshaling the necessary resources, including medications or medical advice, before the call concludes. This strategy is based on the assumption that less activated patients are less likely than others to call back and follow up on additional unresolved problems that could lead to hospitalizations (Nancy Flinn, Courage Center, personal communication, October 3, 2012).

And in the Pacific Northwest, the PeaceHealth system's patient-centered medical homes use Patient Activation Measure scores in combination with information on disease burden to match care to patients' needs.⁵⁸ This approach takes into account patients' clinical profiles as well as their ability to manage their health. Patients with greater disease burden and lower Patient Activation Measure scores are matched with more highly skilled clinical team members.

For example, a patient with the lowest level of activation and the highest disease burden would be matched with a physician and a registered nurse. A patient with the highest level of activation and the lowest disease burden would be matched with a peer support group.

Fairview Health Services, the Courage Center, and PeaceHealth are examples of innovative organizations that are using their existing quality improvement infrastructure—electronic health records and information systems, team-based care, and population-based care—in a more targeted way to support patients and personalize care. These organizations believe that their investment in patient engagement will pay off in better health outcomes, better experiences for patients, and lower costs. The extent to which these approaches can be adapted to other care settings will depend, in part, on health care organizations' existing infrastructure and their ability to capitalize on that infrastructure.

Discussion

The research shows that more activated patients have better health outcomes and better care experiences than patients who are less activated.^{25–27} Studies also show that activation can be modified and increased over time—and that certain interventions are effective in increasing activation.^{45,48–53} This has been shown with medically indigent patients, different racial and ethnic groups, and patients with multiple chronic conditions.

These findings highlight the contribution that

patient activation makes to health outcomes and patients' experiences with care. More research is needed to understand the contribution that it may make in terms of health care costs. Results suggest that increasing patient engagement may be an important element in strategies designed to reach the so-called Triple Aim⁵⁹ of health care reform: better individual and population health and lower costs.

The results also point to the need for a systematic approach in encouraging patients to play a more active role. It is important to integrate patient engagement strategies into all efforts to improve the effectiveness and efficiency of care.

Innovative delivery systems, such as those described above, are including patients as part of the solution, recognizing that high-quality care should help patients gain the skills, confidence, and knowledge they need to manage their health.

The emerging evidence suggests a potentially new quality goal: increasing patient activation as an intermediate outcome of care that is measurable and linked with improved outcomes. Quality improvement efforts that systematically work to expand the patient's (and the family's) ability to participate in care are a pathway toward improving outcomes. Such an approach is both necessary and achievable. ■

Judith Hibbard is an equity stakeholder in and consultant to Insignia Health.

NOTES

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In this month's *Health Affairs*, Judith Hibbard and Jessica Greene assess the evidence on the effects of "patient activation"—the skills and confidence that equip patients to become actively engaged in their health care. The authors cite a growing body of evidence showing that patients who are more activated have better health outcomes and care experiences, but they also find that there is limited evidence to date about the impact on costs. Arguing for more research to buttress this evidence, they recommend that patient activation be broadly assessed as an intermediate outcome linked to improved health outcomes over time.

Hibbard is a professor emerita in the Department of Planning, Public Policy, and Management and a senior researcher at the Health

Policy Research Group, Institute for Sustainable Environments, all at the University of Oregon. Over the past twenty-eight years, Hibbard has focused her research on consumer choices and behavior, with a particular emphasis on testing approaches that give consumers and patients more knowledge and control over their health and health care. Hibbard's studies examine such topics as how consumers understand and use health care information, how health literacy affects choices, and assessments of patient engagement.

Hibbard holds a master's degree in public health from the University of California, Los Angeles, and a doctorate in social and administrative health sciences from the University of California, Berkeley.



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Greene is a professor and director of research at the George Washington University School of Nursing. She focuses on evaluating health policies and strategies for improving quality of care. Greene also serves as principal investigator in a study—funded by the Commonwealth Fund—of how a health system uses an innovative physician compensation model to drive improvements in care delivery, and as co-principal investigator of another study—funded by the Gordon and Betty Moore Foundation—of changes in patient activation over time.

In addition, Greene serves as an advisory board member for *Medical Care Research and Review*. She holds master's degrees in public health and international affairs from Columbia University and earned a doctorate in public administration from New York University.