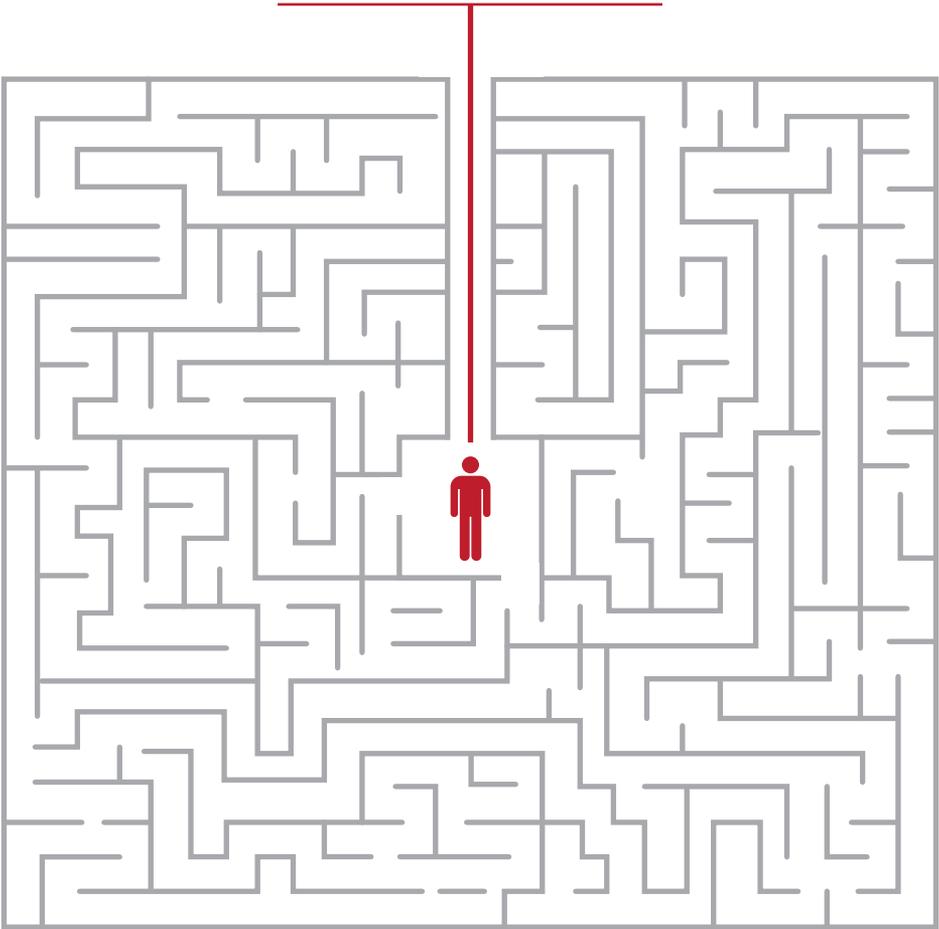


# The Health Care Delivery System

A Blueprint for Reform



# Second-Generation Consumerism

## Increasing Consumer Activation to Improve Health Outcomes and Lower Costs for Patients with Chronic Disease

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### OVERVIEW

With health care costs increasing, some policymakers have sought to make patients better health care consumers through increased cost-sharing linked with greater information on the cost of care. These may be successful cost containment strategies in the short term. But patients are just as likely to forgo necessary as unnecessary care, which ultimately leads to greater demand for more intensive and expensive care in the long term. Patients can, however, play an important role in preventing the onset of chronic conditions or preventing deterioration in health once they have

#### KEY POLICY RECOMMENDATIONS

- Building in accountability and support for patient self-management through provider reimbursement policies.
- Expanding the evidence base to identify what kinds of supports actually engage and activate consumers.
- Removing barriers that keep consumers from taking a greater role in managing their health, including removing financial barriers to making cost effective choices.

been diagnosed with a chronic condition. In this chapter we discuss tools available to identify and empower—or “activate”—patients to be better managers of their health. We also suggest health care delivery reform options to encourage the expansion of programs that empower patients to improve their health and control personal health care costs, thereby improving health outcomes and containing costs for all.

## **WHAT IS PATIENT ACTIVATION?**

In an effective delivery system, patient activation—defined in this chapter as the “ability to self-manage”—is a key outcome. The outcome is measured, and the measurement is used to improve care. At every encounter, patients are implicitly and explicitly encouraged to take ownership of their health and health care and to be proactive, and are given the support to do so. This means changing the norms for both provider and consumer behavior. It also means supporting patient self-efficacy, skill, and knowledge acquisition. Strategies that support this trio of skills are mirrored and reinforced at home, in the community, and at work. They include giving patients and consumers the appropriate amount and type of information for their abilities and their needs. The ideal endpoint is a delivery system connected to communities, with medical care organizations and health providers supporting consumer activation, and where increases in patient activation are measured as outcomes that are part of provider performance evaluations and are linked with compensation.

Preventing or delaying the onset of chronic conditions, along with effective management after diagnosis, can lower the demand for health care services. The Institute of Medicine has recommended providing support for patient self-management as a priority for improving quality.<sup>1</sup> IOM states that self-management is a critical success factor for chronic disease programs because patients and their families are the primary caregivers in chronic illness. According to the report, traditional health education that focuses on simply providing information is inadequate for people with chronic illness.<sup>2</sup> Most research on engaging consumers has been focused on patients with one or more chronic illnesses, but activating or engaging patients can also be useful as an approach for preventing the onset of chronic conditions (see chapter 6 on population health).

## **ACTIVATING PATIENTS CAN CONTROL COSTS AND IMPROVE OUTCOMES**

Finding a way to prevent chronic conditions and to lower the costs of caring for people with chronic conditions will be critical to reducing health care spending. Patients with one or more chronic conditions are a driver of the increase in health care costs. Virtually all of the growth in Medicare spending from 1987 to 2002 can be traced to the 20-percentage point increase in the share of Medicare patients receiving treatment for five or more chronic conditions. The factors responsible for these trends are likely to continue. According to the Agency for Healthcare Research and Quality, about 60 percent of adults have at least one chronic condition.<sup>3</sup> In 2005, about 50 percent of total medical expenditures were spent on treatment of chronic conditions, but about 90 percent of health spending went to treat both acute and chronic care for people with chronic conditions.<sup>4</sup>

In recent years, Congress and the Bush administration have taken steps to try to address the cost of chronic conditions. In addition to prevention funded through public health programs, Congress directed the Secretary of the Department of Health and Human Services to conduct demonstrations to determine whether case management and disease management programs could lower costs and improve patient outcomes in Medicare fee-for-service enrollees.<sup>5</sup> While reports indicate that the Medicare coordinated care demonstration has neither generated savings nor increased costs in Medicare,<sup>6</sup> many argue that a host of correctable factors led to that conclusion.

The more recent Medicare physician group practice demonstrations have shown some success and have provided important lessons in fee-for-service care management.<sup>7</sup> The report noted a need for greater emphasis on patient involvement in managing chronic diseases to assure cost-effectiveness. Challenges to successful disease management programs among group practices included limited reimbursement and lags in the availability of information to providers to determine the impact of interventions and to permit timely revisions in treatment plans. Finally, the report suggested a need for more information regarding the successful components of programs that address multiple chronic conditions, as opposed to a single condition, such as diabetes or heart disease. Consistent with these outcomes, many chronic care management experts recommend that chronic disease management programs must include a robust self-management

support focus in order to succeed. In addition, in implementing a congressionally mandated medical homes demonstration project under Medicare, the Bush administration has included in the plan design a requirement to encourage chronic disease self-management.<sup>8</sup>

Appropriate health care decision making can be challenging for patients with chronic conditions. Patients are given complex treatment regimens, asked to monitor their conditions, and told to make lifestyle changes. Barriers to making good choices include a lack of motivation, insufficient knowledge of a condition or treatment, a lack of self-confidence or skills to manage the condition, inadequate support from family members or friends, environmental or community obstacles, physical impairments, or a lack of financial resources to purchase medications or supplies.<sup>9</sup>

How well the individual is able to self-manage their health on a day-to-day basis is one of the most important factors in determining the onset of a chronic condition, as well as maintaining health and functioning. Maintaining a healthy weight, engaging in regular exercise, and obtaining preventive care require daily effort. People are more likely to make good decisions and take more actions to promote their own health if they are more engaged, informed, and feel confident that they can take care of themselves.<sup>10</sup> Those who are equipped with the skill and confidence to take on these challenges are better able to function and experience fewer health crises and functional declines.<sup>11</sup>

Recognizing the challenges faced by patients with chronic conditions, Congress revised the Medicare program to cover self-management training for patients with diabetes. Access to this service has been limited, however, particularly in rural areas. Providers perceive the certification process necessary to qualify for reimbursement as expensive and laborious. In addition, reimbursement is inadequate to justify the application process and to cover administrative and staffing costs associated with implementing the program.<sup>12</sup>

## **FIRST-GENERATION CONSUMERISM MODEL**

Both private market and public sector payers have been working to put in place infrastructure that will support a model of care designed to make patients better health care consumers. Beginning in the late 1990s, this

model has focused on reducing the demand for health care services by employing increased cost-sharing linked to greater price transparency. The dominant model has aimed to increase the information about cost and quality available to consumers and to increase consumer liability through cost-sharing, so that consumers have a personal investment in reducing costs. High deductible plans such as Consumer Driven Healthcare Plans and Health Savings Accounts reflect these approaches.

CDHPs were designed explicitly to encourage patients to play a more active role in their health care delivery. While the evidence so far indicates that those who are more activated are more likely to enroll in a CDHP, the plan design itself does not significantly increase a patient's ability to take more responsibility for their care over time. Further, the greater cost-sharing inherent in many CDHPs appears to result in reduced utilization, with consumers making reductions in care indiscriminately, cutting back on both evidence-based care and care that is less effective.<sup>13</sup>

Providing consumers with information is necessary to support informed choices, yet it is often not sufficient to stimulate action. Consumers have been slow to take interest and use information that is currently available. Research indicates that only patients who are highly motivated use comparative quality data.<sup>14</sup> This may change as the information becomes more readily available and as quality gaps and price differentials become more recognized by consumers. However, there is no evidence that giving consumers this information engages or activates them. In fact, the evidence suggests the opposite: In health care, studies have shown that consumers consider higher cost to be an indicator of high quality.<sup>15</sup>

## **SECOND-GENERATION CONSUMERISM MODEL**

### **Engaging and activating patients to better manage their health**

We actually know quite a lot about measuring and supporting patient activation. The validated Patient Activation Measure has provided insights into how and when activation occurs, what seems to facilitate or inhibit it, and clues as to how to go about explicitly supporting activation. Using the PAM and studying health behaviors, researchers have observed that those who are highly activated are overall more proactive about their health, more likely to seek out and use information to inform their decisions, and

more likely to engage in healthier behavior.<sup>16</sup> In addition, some behaviors—those that are more complex and require sustained action, for example—are rare among individuals who are at lower levels of activation.<sup>17</sup> Those lower in activation have fewer problem-solving skills, and therefore are more vulnerable to simply giving up when they encounter difficulties. Understanding the challenges and the reality or feasibility of care for individuals at each level of activation is key to providing appropriate support.

Emerging evidence suggests that people who work and live in social environments that are more supportive and encourage proactive health behaviors are actually more activated. Becker and Roblin<sup>18</sup> found that in workplaces, neighborhoods, and clinics where people were encouraged to take a proactive role in their health, people were more engaged in more health-promoting behaviors. In neighborhoods and worksites where there were opportunities to exercise and choose healthy foods, employees engaged in more of these healthy behaviors.

Activation appears to be developmental, meaning people go through phases on their way to becoming effective self-managers. For this reason, strategies that meet consumers where they are and support their progress are more likely to be successful. That is, strategies that help consumers by encouraging small steps that are realistic given their level of capability, and ones that provide opportunities to gain confidence, are more likely to be successful. Simply providing information or exhorting people to make multiple changes in how they live their lives, as is the usual approach, does not work. These exhortations typically make people feel overwhelmed, and ultimately do nothing. This dynamic tends to reinforce feelings of inadequacy and a sense of failure.

Interventions have been successful in increasing activation, particularly interventions that are designed to increase empowerment and self-efficacy. Tailoring activities based on cultural norms has been shown to be effective, including in the CDC's REACH U.S. programs.<sup>19</sup> Customizing support to the individual's level of activation is also a promising direction for increasing activation and improving outcomes. Results from a study conducted within a disease management program show that patients who were given support that was tailored to their individual level of activation had significantly greater gains in activation, greater improvements in clinical indicators, and larger reductions in costs and utilization than patients who were coached in the usual way.<sup>19</sup>

## PATIENT ACTIVATION MODELS IN CLINICAL PRACTICE

Managing a chronic illness is a time consuming and complex process that requires a new model of care. Several programs have been developed in response to this recognition to provide education and support to patients to increase their skills and confidence in managing their health problems.<sup>20</sup> Studies have shown that peer support programs targeted toward patients with one or more chronic conditions can achieve savings in our health care system.<sup>21</sup>

These strategies focus more specifically on supports to activate and engage consumers, to build capacity within individuals and communities, and to make it easier for individuals to make better health care choices. While first-generation consumer strategies focused on information provision and financial incentives, second-generation strategies will be based, where possible, on evidence about what is effective for engaging and activating consumers. Because social environments can stimulate activation and engagement, strategies that focus on building self-efficacy and capacity, fit the individual, and are reinforced by the people and institutions that surround the individual form the core of second-generation consumerism approaches.

Promising models for chronic disease self-management have been built around peer support programs. A study published by the California HealthCare Foundation identified seven successful models of peer support, including professional-led group visits with peer exchange, peer coaches, use of community health workers, support groups, and telephone, email, and Web-based programs.

Environments that appear to foster activation tend to have the following characteristics:

1. Support and encouragement from peers and authority figures (e.g. supervisors, physicians, etc.)
2. Opportunities to engage in proactive health behaviors exist, or it is easier to make cost-effective or healthy choices
3. One's values, needs, and priorities are taken into account in decisions
4. Support is tailored to the individual's level of activation and cultural norms

## **POLICY RECOMMENDATIONS**

Policymakers can implement numerous strategies to support consumers and patients in making better decisions to prevent and manage chronic conditions. The following recommendations are designed to address barriers in the health care delivery system that limit the ability of health care professionals to provide the support necessary to implement successful patient activation programs. Although not addressed here, policymakers may also consider increasing public health funding to support chronic disease prevention and health promotion programs that more actively engage patients in preventing or managing conditions (see chapter 6 on improving public health).

Many private sector health plans have implemented successful chronic care self-management programs—primarily for those individuals enrolled in managed care—but numerous barriers exist to implementing these programs in a fee-for-service system. Barriers to successful implementation of patient self-management include a lack of information about the key components of successful self-management programs, health plan benefit designs that do not support patient education or support services in managing chronic diseases, a reimbursement system that does not provide incentives for patient education and involvement in their care plan, lack of training among physicians and other health professionals, and a reluctance among physicians to adopt innovative models of care that rely on non-physician providers and patients to more actively monitor and manage chronic conditions. The following recommendations are designed to address these barriers.

### **Fund research to identify key elements of effective self-management programs**

A variety of chronic disease self-management models exist, and although studies have shown some models to improve patient outcomes and control costs, it often is not clear which elements of programs lead to these outcomes. According to a report commissioned by the Agency for Healthcare Research and Quality, a limited evidence base translates into uncertainty about programming features and wide variation in the way programs are designed, delivered, and evaluated.<sup>22</sup>

To increase the evidence base and more clearly define and evaluate effective self-management program features, the Secretary of Health and Human Services should implement a Medicare demonstration project testing those models that have proven effective in supporting self-care among chronic disease patients. This demonstration would differ from previous chronic care demonstrations by limiting participation to providers that have experience in or a commitment to supporting patient self-management. Models tested by the secretary should emphasize redesigning and supporting a team-based approach to care management; improving communication with patients and their families; educating patients on their conditions, including the development of a patient care plan; and giving patients the tools they need to take an active role in the managing their condition.

Several models have already proven effective in improving patient outcomes and reducing hospitalization. The demonstration project should seek to identify key program elements from those models that are effective in improving patient skill and confidence in managing their conditions as a means of improving health outcomes and reducing cost, rather than defining a single model of care. The secretary should also develop standards for evaluating chronic care self-management programs and provide for the adoption outcomes measures to determine which providers and patients improve patient outcomes and reduce inpatient utilization.

## **Support self-management through benefit design**

Evidence-based plan designs use financial incentives for patients to encourage the use of care that is proven to be effective, while discouraging care for which there is less evidence for efficacy. Successful strategies include reducing out-of-pocket costs for evidence-based care such as the use of preventive services and specific chronic illness medications. The point is to make the cost-effective choice (the choice reflecting high-quality care) the easier choice for consumers to make. Evidence has shown that patients with chronic conditions face a myriad challenges in managing their conditions, and financial barriers should not be an added challenge.

Under current law, Medicare chronic disease self-management for diabetes education and medical nutrition therapy consists of a limited number of visits, which are subject to Medicare coinsurance and deduct-

ibles. Based on the outcome of the Medicare self-management demonstration, the secretary should develop a broad self-management benefit under Medicare for a broad range of chronic conditions. Under Medicare fee-for-service, the chronic care self-management benefit could be structured as a list of services not otherwise reimbursed under Medicare, or it could be designed as a bundle of services. The secretary should draw on lessons learned under the Medicare demonstration program to permit varying program designs to meet outcomes. The benefit should include a waiver of Medicare Part B cost-sharing for services provided under chronic care self-management programs to assure that cost is not a barrier to patient participation.

Chronic care self-management should also be included as an optional service under Medicaid and the State Child Health Insurance Program. Defining chronic care self-management support and the immediate outcomes of that support would permit states to receive federal matching funds for services provided under these programs. As in Medicare, cost-sharing should be waived for individuals who enroll in self-management programs. States already have the authority to contract with managed care plans to provide chronic care self-management programs, but the federal government could provide incentives to states to implement chronic care self-management either through an expedited waiver process or through grants. Congress could, as an example, expand and extend Medicaid's state transformation grants to encourage the adoption of chronic care self-management in both managed care and fee-for-service Medicaid.

Finally, the secretary should make the data collected in implementing these programs available to private health insurance plans and employers. If chronic care self-management can improve patient outcomes and reduce hospitalization, private sector plans that have not adopted self-management programs may find the data useful in deciding whether to offer the services, what benefit design they wish to use, and how to structure provider payments. Once Congress and the administration have sufficient data to support chronic care self-management, policymakers may also want to consider requiring or providing incentives to plans under contract with the Federal Employees Health Benefit Program and employer plans regulated through the Department of Labor to implement chronic care self-management programs.

## Support self-management through provider incentives

Implementing self-management requires changes in traditional medical practice. According to researchers, successful models have included group visits for interested patients with comparable chronic illnesses, scheduling of extended office visits, delegating education and support functions to office staff or other trained health professionals, and systematic follow-up, which may include weekly phone calls from a nurse manager.<sup>23</sup>

Although many providers see the potential of chronic disease self-management, there are disincentives to implementing these programs in a fee-for-service model of care. Where self-management or similar programs have been implemented by hospital outpatient clinics, for example, any resulting decrease in hospitalization use has reduced revenue to the hospital. For group practices, community clinics, and solo practitioners, many of the services provided as part of a self-management program are not reimbursed under Medicare fee-for-service. Those services that are covered, such as evaluation and management, are often not reimbursed adequately to cover provider costs.

To address these issues, Congress should pass legislation directing the Secretary of HHS to develop a payment methodology under Medicare Part B for chronic care self-management services. Payments could take the form of an increase in the value of evaluation and management services, a per-member, per-month payment to clinics and physician practices, or another methodology. The medical home model of care may also lend itself to effective patient self-management support. Patient self-management support programs and outcomes (such as gains in patient activation) should be included in public and private sector value-based purchasing initiatives. Payment for such services should be tied to performance and demonstrated outcomes.

Finally, services defined in the chronic care self-management benefit that are not otherwise covered under either Medicare or Medicaid should be added to Federally Qualified Health Center services with an appropriate adjustment to the FQHC prospective payment system under Medicaid and an increase in reasonable cost payments under Medicare.

## **Ensure information technology enables self-management**

Active involvement in one's own health requires access to reliable information. Personal electronic health records can help patients to more effectively manage their care and improve their health outcomes by improving their access to information. Providers involved in chronic care self-management programs have indicated that at least one proven successful model of care relies on the ability of patients to have access to personal health records. Denying patients access to their own records sends an implicit message that they are not an important part of the care process.

Personal health records can help patients make better health care choices by providing access to information relevant to their particular conditions and treatment options. A personal health record should reflect care delivered by multiple health care providers, biometrics such as BMI or blood pressure that a person records directly, and data collected passively in the home and/or work environment by sensors and other monitors. The record can also be coupled with alerts, reminders, and other decision-support tools that help people take action to improve their health. Diaries and logs included in the record could also help individuals monitor their own progress on behavioral change, such as weight control or smoking cessation (see chapter 1 on electronic health information for a more detailed discussion on the overall implementation).

As policymakers move forward to ensure systemic interoperability in the exchange of personal health information, ambulatory programs should not be certified as meeting the interoperability standard unless the program includes secure patient access to an electronic health record. Failure to include such a provision could seriously impede the ability of providers to implement successful chronic care self-management programs.

## **Promote provider support for patient-centered care**

One of the key indicators of success in reliance on patient self-management programs is provider buy-in. Some physicians have been reluctant to relinquish patient management to the patient and a care team established to support patient self-management. The Institute of Medicine has also recognized that providers need to change medical practices to understand the importance of patient values and preferences. In addition, the American

Medical Association issued a report in June 2007 outlining recommendations for change in the system of medical education. These recommendations were in response to reports that raised concerns about medical education and the inadequacies in physicians' preparation for practice in a health system that is focused on patient-centered quality and patient safety.<sup>24</sup>

Congress can implement a number of changes to promote provider training and acceptance of patient self-management. First, Congress should request an IOM report on the key elements in medical school curriculum designed to promote patient self-management. Some preliminary work has been done on the IOM's recommendations on promoting patient-centered care. Furthermore, Congress should provide federal funding to medical schools and academic medical centers to test and implement teaching methods designed to promote patient-centered care. As successful training programs are identified, Congress should enact legislation conditioning receipt of funding for direct, or GME, and indirect medical education, or IME, on the adoption of programs designed to train health care practitioners and implement chronic care self-management programs in outpatient clinics, as part of the hospital discharge planning processes, and in other areas as deemed appropriate.

## **DISCUSSION**

The first generation of consumerism strategies focused on the provision of information coupled with financial incentives as the main approach for stimulating consumer activation. Financial incentives, particularly increased cost-sharing, do not necessarily stimulate more cost-effective choices or result in greater activation.

In contrast, second-generation strategies will be built on existing evidence of what does actually activate and engage consumers. These strategies will focus on improving consumer health and functioning and supporting self-management competencies among those with chronic illness. Key characteristics of these approaches are that they are embedded in the community as part of a coordinated web of efforts that change social norms and influence skill levels and self-efficacy for self-management. They may take advantage of peer support and lay health advisor approaches, and be linked with existing efforts. Financial incentives and informational supports will still be needed, but they will be more tailored and targeted to

increase their impact. Information about both cost and quality will become both more actionable and accessible for consumers. And plan designs and benefit packages, which seek to encourage evidence-based care and discourage less effective care, are part of this approach.

Second-generation strategies will use measurement to tailor support to patient needs, track patient progress, and assess provider performance. These strategies will require provider accountability and will connect community efforts with those in the clinical setting.

Both first- and second-generation consumerism strategies affect different segments of the population. The first-generation strategies, because they rely so heavily on information and financial incentives and penalties, tend to disadvantage those who are already disadvantaged: those with lower literacy skills; those who have less access to or fewer web skills; and those with a greater illness burden and who have less income and education. The first-generation consumerism strategies tend to enlarge some of the factors that contribute to health disparities. Because second-generation strategies are designed to support consumer competencies, connect consumers more directly to needed resources, and focus on behavioral and health outcomes, they should lessen disparities.

The second-generation consumer models will be grounded in evidence and tied to outcomes. They will be designed to increase the capacity of consumers to be actively in charge of their health and health care. Without building this capacity within the consumer population, efforts to control costs and improve quality will elude us. Building a research base for launching initiatives and tying efforts to reimbursement models are essential to strategies aimed at controlling costs.

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