



Strengthening Consumer Engagement: A Critical Ingredient in Successful Health Reform

The Problem

Consumers are shut out, confused and frustrated by our complex and fragmented health care system. The system leaves many without insurance, including some who may qualify to enroll. It also contributes to inefficient, poor quality care that drives up the costs for everyone. The major expansion of health insurance currently being developed could exacerbate these problems unless consumers are more fully engaged in the system, in their own care and in improving care for others.

The Remedy

First, provide consumers with the information and the trouble-shooting services they need to get the right care at the right time. Second, systematically engage consumers in helping providers, insurers and policymakers learn from and reduce problems. Setting up the structures to achieve this remedy will require a modest investment. The potential benefits include fuller enrollment, better quality care for all and a more responsive, consumer-friendly health system.

Past Evidence of Consumer Impact

Although limited by a lack of stable and independent funding, consumer engagement has already helped improve access, enrollment and quality of care for many patients. For example:

- Informed and empowered patients across the country are better at managing their chronic conditions.
- A consumer-run help-line in Massachusetts has helped flag emerging issues with health care reform for attention from policymakers.
- Community and faith-based organizations have helped to design innovative outreach strategies that expand enrollment in public programs.
- Parents of children with special health needs have been instrumental in crafting hospital and insurance policies that improve coordination and quality.
- Patient advocate offices in a number of states are helping consumers resolve problems with their insurers, or get the care they need.

These examples suggest that a comprehensive structure of consumer engagement could go much further, enabling a newly-expanded health care system to continually serve patients better.

A Model Framework

To ensure that consumer engagement is sustained and anchored in the community, we recommend a local or state-based structure, funded by dedicated money from the federal government. That structure could include the following components, housed or serviced by nonprofit consumer-based organizations, which know and have earned the trust of their communities.

Help-lines: A phone number and email address through which consumers could get information about and assistance entering and navigating the health system. This would include help finding and enrolling in public and private insurance plans, accessing needed care and resolving problems.

Consumer Councils: Representatives of various patient and consumer organizations who would advise providers, insurers and policymakers about problems and potential solutions through periodic public reports. Council staff would compile and analyze data from help-lines and other sources to identify patterns that require action.

Scheduled Surveys: Polling of, and outreach to, community members who face significant barriers to health care, but may not use the help-lines. This might include elders, children with special needs, racial and ethnic minorities and those with low incomes or low literacy. The goal would be to identify what works and doesn't work for society's most vulnerable patients.

National Synthesis of Patient Experiences: All these components would funnel reports to the national level, to help Congress and the Obama administration make needed adjustments in health policy that are grounded in consumer experiences.