

**Patient Engagement and
Patient Decision-making in US Health Care**

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Section I: Introduction

An abundant literature confirms that patients who are more involved in active communications with their doctors, who participate in shared decision-making, and who understand their own responsibilities for managing their health achieve better outcomes and are more satisfied than others.¹ We also recognize that not all patients seek this kind of engagement, and that clinical engagement is more commonly achieved for female, younger patients, with female physicians, and in circumstances where life-and-death decisions are not in play. These findings are now about twenty years old – but survey and performance data continue to show that patients in the United States are not always encouraged or allowed to be as engaged in their health care as they would like.²

The clear benefits of “patient engagement” will not be more widely achieved through a purely clinical paradigm, focused only on the relationship between patient and doctor. Bodenheimer and Wagner noted that adoption of their “chronic care model” requires “that conditions must be favorable in all 3 of the overlapping galaxies that affect health care institutions – the general community, the health care system, and the institution itself.”³ In the U.S., those conditions are not favorable; the “system” and “institution” themselves have no business or professional motivation to increase the adoption of patient engagement practices. Instead, our assessment of patient engagement must go well beyond the person’s role as patient, i.e., as ill person receiving care from a professional. We must examine all the ways in which a person can shape and participate in the care he or she receives.

We conceptualize patient engagement across a hierarchy of roles, centered on personal health and working outward to overall community behaviors:

- People making personal health and lifestyle decisions that affect their need for professional health services (e.g., smoking, adhering to medication recommendations).
- Patients engaged in a model of clinical partnership, what Kennedy recently called “sharing power and responsibility, ... a subtle negotiation between professional and patient as to what each wants and what each can deliver.”⁴
- Patients and consumers making decisions about their use of health care resources, such as selecting a specialist, hospital, or treatment.
- Consumers participating in a particular payment and financing model, such as selecting an insurance plan or benefit design.
- Citizens participating in governance and community initiatives, such as hospital trustees, government advisory committees, and voluntary public health initiatives.
- Citizens participating as voters and advocates in public debates about health policy, including publicly financed coverage and access, patient safety, licensing and certification, quality of care, medication access, regulatory policy, research funding and priorities, and privacy.

The research literature – and certainly the advocates for and investigations into “patient-centered care” – has emphasized the second of these six roles: the degree to which the health system

supports patient participation in specific care decisions. Recent U.S. policy has emphasized the third and fourth roles – how patients select doctors, hospitals, and health insurance plans – in the belief that consumers’ choice of providers and plans can influence clinical and marketplace behavior. This narrow view of patient engagement perpetuates the power differential in favor of existing health care institutions. It neglects the cultural and financial realities – that our health system is an expression of what we believe about ourselves and what we pay for – both of which are actively manipulated by public policy, public and professional education, advertising and media, and business practices.

A patient engagement strategy needs to create a favorable environment in which people can exercise their capabilities for self-care, informed decision-making, and representation of their own values. We would not try to reshape public education only by helping parents and grade school students improve their interactions with classroom teachers over daily homework assignments. Instead, we seek parental involvement in PTA and school boards and in policy debates over funding, curriculum and accountability standards, because we understand that all of those environmental factors will affect the teaching and learning experience. To create a patient-centered health system, the public needs to engage in health care in more numerous and fundamental ways than simply as “patients”.

A. Barriers to Patient Engagement

We can group the barriers to participation in care and decision-making into two broad categories: system-side barriers and patient-side barriers.

1. System-side Barriers

a. Culture

The delivery of health services continues to be dominated by professional guilds which are reluctant to share medical information, self-care technology, and resources with patients and families and have been slow to reorganize the delivery system to address patient requirements and preferences. Graduate and continuing medical education, federal payment policy, licensing practices, accreditation standards and media portrayals of health care all perpetuate the physician- and hospital-dominated model.

b. Infrastructure

The United States lacks a national health information infrastructure that could provide patients with information and a means to exercise control over decisions. The professions and health industry maintain a monopoly on both personal and systemic information, and are unwilling to invest in or collaborate in development of a standardized, open, and interoperable infrastructure.

c. Financing

The persistence of service-based payment provides little incentive for professionals, health care organizations, or entrepreneurs to develop patient-oriented services, such as shared decision-making, chronic care management, disease management, non-visit care, e-health, palliative care, family caregiving, and supportive services.⁵

2. Patient-side Barriers

a. Health Care Activation

Patients vary in the degree to which they wish to be involved in health care decision-making. Maibach and Gowen have identified four consumer segments, labeled Independent Active, Doctor-dependent Active, Doctor-dependent Passive, and Independent Passive. In the employed, under-65 population, the distribution of these four groups is 35%, 33%, 25% and 7% respectively. Hibbard has defined an activation index that captures several dimensions of self-care and collaborative care for chronic illness, and identified six progressive “stages” of activation ranging from “beliefs” to “staying the course under stress.” Both of these studies highlight the diversity and complexity of patient readiness to play a more engaged role in care.⁶

b. Health Literacy

About 40% of Americans – and as many as 80% of elderly patients – are unable to comprehend medication directions or a standard informed consent document.⁷ In addition, about 30% of the U.S. population lack internet access with higher proportions of low income, elderly, and non-white populations without convenient access.

c. Cultural Diversity

Non-English speaking patients, and English-speaking Hispanics, report substantially more negative judgments about whether their doctors listen to them, answer their questions, or explain medications and procedures adequately.⁸

d. Saliency

Each individual patient needs specific information suited to a particular stage of illness, set of decision requirements, and personal values. Broadcast information – such as patient education brochures, web sites, and report cards - is rarely personalized enough to be of great interest.⁹

e. Unpredictability

Patients often make decisions at one time, appropriate to one set of circumstances, which come into play at a later time in different and inappropriate circumstances. A doctor selected for bedside manner and health maintenance skills may be poor at diagnosing a complex illness; a health plan selected for a particular benefit design may be found to have inadequate benefits for a newly diagnosed problem. There is no way to “train” a family to anticipate future needs as these decisions are made.

f. Financing

Patients facing insignificant out-of-pocket costs may be careless consumers of expensive technology, including diagnostic tests, physician visits, and medications. Patients without adequate insurance coverage may “take what they can get” and feel uncomfortable challenging those providing “charity” services.

This array of patient-side barriers suggests three implications. First, that some types of people are more ready to take on the active patient role than others; second, that clinicians must assess and respond to the preferences and abilities of each patient and family; and, third, that community strategies must be targeted and tailored to specific audiences.

Despite the earnest efforts to develop consumer information services, far too little research has been done to identify patient information requirements. A series of opinion surveys by Kaiser Family Foundation, Agency for Healthcare Research and Quality (AHRQ), and the California Healthcare Foundation outlined the kinds of information people would like to see when selecting a doctor, health plan, or hospital. The Foundation for Accountability (FACCT) and Picker have conducted condition-specific studies to identify patient information needs in such areas as diabetes care, end-of-life care, early childhood health, and HIV/AIDS care. FACCT has also developed comprehensive decision models, illustrating the changing information requirements patients report as they progress through a course of illness and treatment. Levinson, Kaplan, and others have studied the information patients wish to have in hand when they see their physician. Hibbard, McGee, Cleary, Sofaer and others have evaluated diverse formats for presenting performance information to consumers.¹⁰

Generally, this body of research suggests that patients and families:

- want a great deal of information, both in the context of receiving care and as they select providers and plans,
- prefer information that is layered but transparent (i.e., includes both summary scores and the ability to examine specific details of interest and understand how the summary is constructed),
- prefer information that is highly personalized to their specific needs,
- want content relating to the experiences of “people like them”,
- prefer information that is offered or sponsored by a trusted source, and
- have diverse preferences regarding presentation format, including print, web, and talking to a person associated with a trusted source.

Section II: Current State of Patient Engagement and Patient Decision-making

Because the system-side barriers to patient engagement are so powerful, few transformative patient involvement projects have been attempted or evaluated. Several modest experiments have been tried:

A. Shared Decision-making

Building on the work of Mulley and Wennberg, a number of controlled trials of interactive shared decision-making tools and similar decision aids have been conducted for such clinical decisions as coronary bypass surgery, radical prostatectomy, and use of hormone replacement therapy. These generally find increased satisfaction, more active patient participation in decision-making, and a modest preference for more conservative treatment by those exposed to the interactive educational tools.

B. Consumer “Report Cards”

Beginning with the Medicare hospital mortality reports and the New York State Coronary Artery Bypass Graft surgery reports in the late 1980s, there has been significant interest in public disclosure of quality performance information. These efforts have been shown to have modest effects on physician referral decisions, consumer selection of health plans and care systems, and

employer contracting. Hibbard and others have argued that consumer report cards primarily affect institutional behavior by creating public and peer pressure to address deficiencies.¹¹

C. Patient Communication Skills Training

Several projects have trained patients to be more active in questioning their doctors and volunteering important information. These have demonstrated significant increases in the patients' ability to get needed information from their doctors and improved outcomes as a result.¹²

D. Patient Health System Education

AARP, the Leapfrog Group, California Health Decisions and others have attempted large-scale public education interventions to increase patients' ability to seek out and ensure safe care. Some efforts have focused on educating people to identify hospitals and providers adopting recommended patient-safety practices; others focus on educating patients to understand and investigate potential medication safety problems. None of these efforts has been systematically evaluated.

E. Self-management Support

Wagner's chronic care model places primary emphasis on the health system's commitment to educating patients and families to manage chronic illness. In a review of 39 studies, Bodenheimer et al found significant improvements in health outcomes for patients enrolled in self-management programs as well as measurable cost savings, usually attributed to reduced hospitalization rates.¹³

F. Pre-visit Patient Preparation

Wasson and colleagues have tested both a print/mail-based and web-based intervention with elderly patients to exchange history, symptom and preference information prior to a visit. The print/mail approach has been shown to lead to patients receiving more help from their doctors with physical function, fall prevention, and assistance for memory problems.¹⁴

G. Personal Health Records

A number of large, integrated health systems, including the Veterans Health Administration, Kaiser Permanente, CareGroup, and the University of Colorado Medical Center have implemented patient access to their electronic medical records, as well as some early attempts to enable patients to supplement, comment upon, and control release of their personal health information.¹⁵

H. Consumer-directed Health Plans

U.S. employers are introducing health insurance products which require greater consumer financial contribution and provide the opportunity to exert greater financial control. Analysts predict that the increased patient role as buyer, coupled with improved information resources to guide decision-making, will stimulate innovation, patient engagement, and improved system responsiveness. These products are only one to three years old and no rigorous evaluations have been performed.¹⁶

Twenty years of innovative projects demonstrate positive or neutral effects of greater patient involvement on both satisfaction and health outcome. Yet such innovations have stayed at the margin of routine health care, and many patients continue to report that they are not as involved in their care as they wish to be. In the FACCT/Robert Wood Johnson Foundation surveys of chronic care in America, only about 50% of patients reported that their doctor involved them “most” or “all of the time” in health care decisions; between 48% and 66% of patients, depending upon diagnosis, described their provider as “Helpful” or “Very helpful” on a range of specific education and self-care support functions. This lack of participation is reflected in low rates of medication adherence and lifestyle change, and high rates of what Wennberg calls “supply-sensitive services,” unchecked by informed patient choice. Despite an extensive research base, daily practice does not seem to involve fully engaging patients in their care.¹⁷

Section III: How can Policy and Practice Improve Patient Engagement and Decision-making?

There are many proven models for increasing patient engagement and decision-making within the clinical setting. These models can not only improve the ability of individual patients to achieve favorable outcomes, but they also set the stage for the reengineering of health care itself. As patients and families become more capable of caring for themselves and accessing information and medical technology directly, the economic and structural models of health care may evolve. We can certainly imagine an environment in which the delivery of professional and technical health services is decentralized, largely mediated by communications technology, and less subject to control by a management and professional elite.

In each of the three areas mentioned above - culture, infrastructure, and finance – there are both policy instruments and health system programs that can accelerate this transition towards a person-centered system.

A. Cultural Change

Federal and state agencies have the potential to influence several of the mechanisms that define or reinforce the dominant medical culture:

1. National Leadership

The U.S. public continues to evaluate health policy primarily in terms of the adequacy of insurance coverage, despite growing public awareness of quality and patient safety problems. The President and leading legislators, in supporting initiatives such as Medicare prescription drug benefits and children’s health insurance, should provide a vocabulary and set expectations for the health benefits to be gained from public investment in health care. A concept of health citizenship that encompasses rights, responsibilities and accountability would create greater legitimacy for the changed patient role.

2. Medical Education Curriculum

The changing role of the patient and family in the care process and the increased opportunities for patients to utilize health information are not systematically addressed in training the next generation of physicians. Federal policy can stimulate significant curriculum reform by

identifying the objectives of future medical training and linking Direct Medical Education (DME) and Graduate Medical Education (GME) payments to implementation of a patient- and family-centered curriculum.

3. Public Education Curriculum

Most states now require a health education curriculum as part of K-12 public education. Curricula in common use, and the relevant state standards, do not prepare young people to be effective health care citizens. They do not address patient responsibilities, appropriate expectations of the health system, how to navigate the complex American system, how it is funded and managed, or key policy issues. Public education curricula and state standards should be revised to address these themes.

4. Certification

Professional societies, such as the American Board of Medical Specialties, have been considering changes to criteria for board certification which would require demonstrated proficiency at shared decision-making, and include patient evaluations of their physicians. Such intermediary organizations can accelerate patient engagement by the expectations and standards they set for credentialing and certification.

5. Family-centered Quality Improvement

The quality improvement model, as initially articulated by Deming, James, Berwick and others, provided for extensive “customer” involvement, yet patients and families are rarely consulted or asked to participate on teams when health systems undertake quality initiatives. Health care organizations should design their quality programs with substantial patient involvement, and should implement data feedback systems that involve patients and families concurrently with providers.

6. Patient-provider Agreements

Paul Ellwood, Clark Havighurst and others have argued that the mutual expectations of patients and providers should be reflected in a written agreement or contract between them. Such an agreement would specifically address shared decision-making, maintenance of electronic health records, use of practice guidelines, and provision for alternative dispute resolution. Appropriate agreements could be distributed and used by activist patients or progressive health care organizations.

7. Public Education Initiatives

The Leapfrog Group and the Bridges to Excellence collaborative are distributing educational materials, largely through worksites, to encourage employees to ask critical questions of their hospitals and doctors, particularly with regard to evidence-based practice and patient safety protocols. In order to send a convergent message to the public, each employer or union is working from a common pool of materials and customizing them as appropriate to their particular circumstances.

8. Advocacy Training and Support

A number of patient and consumer advocacy organizations - such as Family Voices, the National Breast Cancer Coalition, the National Partnership for Women and Families, and the International

Association of Machinists - are aggressively pursuing patient engagement strategies. They recognize their need for external support, including funding, training, and technical services. Current interests include development of a “boot camp” to train advocates in understanding and responding to policy initiatives that affect quality and safety, and creation of a “data resource center” which allows them to access statistical data relevant to their population through an easy web interface.

9. Media Messages

American public beliefs about medical care and patient roles have been influenced by extensive media portrayals, dating from 1930’s movies to current television series. Recent pharmaceutical ad campaigns have encouraged patients to “ask your doctor” and been shown to stimulate significant increases in patient-provider discussions about treatments – with controversial results. Proponents of increased patient engagement can use their advertising buys and sponsorship decisions to promote images of active patients.

B. Infrastructure

The absence of a centralized financing and management system has slowed adoption of information and policy infrastructure in the United States. Recognizing the pluralistic nature of the U.S. health system, policy action should focus on creating and enforcing information standards that level the playing field and enable consumers and patients to play more active roles.

1. Personal Health Information

Patients remain dependent and are less engaged if they lack prompt and equitable access to both public and personal health information. The fragmentation of providers and their information systems, the low adoption rate of electronic medical records (EMR), the lack of standards and interoperability in electronic systems, the lack of a common patient identifier to permit consolidation of records, and patients’ inability to control access to their personal health information create profound barriers to patient engagement. U.S. Secretary of Health and Human Services Tommy Thompson recently announced an initial set of voluntary standards for electronic medical records, and the Center for Medicare and Medicaid Services (CMS) has commissioned a workgroup to identify functional specifications that would qualify an EMR for reimbursement. The National Committee on Vital and Health Statistics has published a blueprint for a National Health Information Infrastructure, with an emphasis on the role of a personal health record – recently amplified by the results of the Markle Connecting for Health initiative. These public-private standards should be given wide visibility, and federal funding to health care organizations should be made contingent upon adoption of these standards on the grounds of patient safety and national security.

2. Performance Information

Informed decision-making is not possible without relevant and understandable information about performance. Serious efforts to provide patients with information on quality of care delivered by hospitals and health plans have had limited impact. The National Quality Forum (NQF) has a *de facto* mandate from CMS to identify consensus measures, but the NQF process lacks patient involvement and is not designed to support patient engagement. Moreover, the initial standards identified by CMS and NQF (as well as the Leapfrog Group) are voluntary, and past experience

suggests that institutional participation will be limited and self-serving. Federal policy should mandate disclosure of performance information and allocate reasonable funds for collection of patient-centered information about quality of care. No provider should be allowed to receive federal funding for health care services without public disclosure of standardized performance information.

3. Patient Safety

Current U.S. policy is moving, simultaneously, in contradictory directions. The Food and Drug Administration (FDA) is expanding its efforts to monitor medication errors, primarily through provider reporting, and some states – such as Minnesota – are requiring adverse event reporting. At the same time, the Congress has passed legislation creating Patient Safety Organizations that would be prohibited from disclosing adverse event reports filed by doctors and hospitals. Patient engagement could be facilitated in two ways: first by developing a patient medication error reporting system under FDA auspices, to alert patients to the risk of error and provide them with a means for communicating such errors and, second, by requiring disclosure of serious adverse events, as recommended by the Institute of Medicine *To Err is Human* report (1999).

C. Financing

Provider payment – and patient financial responsibility – should be structured to stimulate increased patient participation in care. Payment can be targeted to reward processes that involve patients or to reward outcomes that are likely to reflect greater patient involvement.

1. Process-based Payment

Both Casalino and Wagner have identified organizational practices that are associated with improved outcomes and efficiency, noted the importance of formal self-management programs, and argued that payment should favor adoption of these practices. As Berenson has proposed, public and private payers should develop a set of systems criteria and reward providers for implementation, perhaps through a tiered partial capitation formula.¹⁸

2. Outcomes-based Payment

The Bridges to Excellence consortium (including major employers such as General Electric, Ford, UPS, and Verizon) has identified specific clinical outcomes for diabetes, as well as key process measures. Physicians and patients who – together – achieve desired levels of glycosolated hemoglobin, lipid control, and blood pressure receive financial and in-kind rewards. For selected conditions with widely accepted outcomes criteria – such as diabetes, hyperlipidemia, and asthma – outcomes-based payments should be introduced.

3. Patient Financial Responsibility

Market theorists believe that greater financial responsibility will increase patient engagement in the decision to seek care and the level of care chosen. Evaluation studies of defined contribution health plans are underway, and several health plans are proposing tiered hospital networks. Recent experience with prescription drug formularies suggests that patients will make more conservative decisions, presumably reflecting greater information seeking and active participation in decision-making, when faced with significant out of pocket costs. Policymakers should monitor these three innovations (consumer directed plans, tiered hospital networks, and tiered pharmacy benefits) closely to assess their impact on utilization, adherence, and health

outcomes; an experimental study modeled on the Health Insurance Experiment would provide helpful policy information. In addition, experiments which provide financial benefits directly to patients – either through incentives for adoption of healthy behaviors (smoking cessation, exercise programs) or reduced co-pays for adherence to medical protocols – should be systematically evaluated.

It should not be assumed that physicians and hospitals are the best channels for stimulating increased patient engagement. The business models of U.S. health care organizations depend upon the retention of near-monopoly control by professionals and institutions over health information, health technology, and the practice of medicine. Successful patient involvement inevitably involves a shift in information, access to technology, and power; it is not in the interests of major stakeholders to encourage such a transfer. On the other hand, other stakeholder groups may feel a natural affinity with greater patient engagement: pharmacists, nurses, information technology companies, pharmaceutical companies, disease management programs, and so on. Policy and program initiatives meant to increase patient involvement should include opportunities for these sectors to participate as well. The pharmaceutical care model, for example, provides a rich opportunity for patient education and participation in chronic disease management, and exploits an existing, highly used community resource in the local pharmacy.

Advocates of patient engagement should also take a wide view of opportunities to advance these ideas. In the United States, the pending Medicare prescription drug benefit legislation could provide a vehicle for increased patient information and participation in decision-making. Final legislation could require disclosure of medication safety and outcomes information, improve patient counseling requirements, create an accessible on-line, integrated medication record, and mandate the availability of easily understood, transparent pricing and product information.¹⁹

Section IV: Issues for Discussion

What is the role of symbolic national leadership in increasing patient engagement? By defining national health goals, by setting accountability standards for provider performance, by insisting on citizen involvement in policymaking and standard-setting bodies?

How can payment systems be structured to reward “patient-centeredness”?

How can more active patients be supported and legitimized, or mobilized as a political force, to assist in introducing more patient-centered policies over the objections of existing stakeholders (e.g., physician societies, pharma, hospital lobbies)?

Is the growth of patient involvement simply an organic phenomenon that will occur in sync with larger social trends, or does it need to be orchestrated and supported as a strategic initiative?

Under what financing model could increased patient financial responsibility lead to greater engagement in health without producing more severe inequities in access and health status?

References

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- ¹ Kaplan SH, Gandek B, Greenfield S, Rogers WH, Ware JE Jr. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. *Med Care* 1995 Dec; 33(12): 1176-87; O'Connor AM, Rostom A, Fiset V et al. Decision aids for patients facing health treatment or screening decisions. *BMJ* 1999 Sep 18; 319(7212): 731-4; Braddock CH 3rd, Edwards KA, Hasenberg NM et al. Informed decision making in outpatient practice: time to get back to basics. *JAMA* 1999 Dec 22-29;282(24): 2313-20.
- ² Keating NL, Guadagnoli E, Landrum MB et al. Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *J Clin Oncol* 2002 Mar 15;20(6):1473-9; Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision-making? *Arch Intern Med* 1996 Jul 8;156(13): 1414-20.
- ³ Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA*. 2002 Oct 16;288(15): 1913.
- ⁴ Kennedy I. Patients are experts in their own field. *BMJ* 2003 Jun 14;326: 1276.
- ⁵ Hibbard JH, Greenlick MR, Kunkel LE, Capizzi J. Mode of payment, practice characteristics, and physician support for patient self care. *Am J Prev Med*. 2001 Feb;20(2):118-23; Hobbs J, Wald J, Jagannath YS, Kittler A, Pizziferri L, Volk LA, Middleton B, Bates DW. Opportunities to enhance patient and physician e-mail contact. *Int J Med Inf*. 2003 Apr;70(1):1-9.
- ⁶ Maibach and Gowen, ... Hibbard JH, Stockard J, Mahoney ER, Tusler M. Conceptualizing and Measuring Activation in Patients and Consumers. Presented at First Congress on Improving Chronic Care, Seattle Sept 9, 2002.
- ⁷ Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, Nurss JR. Inadequate functional health literacy among patients at two public hospitals. *JAMA*. 1995 Dec 6;274(21):1677-82.
- ⁸ Morales LS, Cunningham WE, Brown JA, Liu H, Hays RD. Are Latinos less satisfied with communication by health care providers? *J Gen Intern Med*. 1999 Jul;14(7):409-17.
- ⁹ McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med*. 2001 Sep;23(3):227-34; Post DM, Cegala DJ, Marinelli TM. Teaching patients to communicate with physicians: the impact of race. *J Natl Med Assoc*. 2001 Jan;93(1):6-12.
- ¹⁰ Hibbard JH, Peters E. Supporting informed consumer health care decisions: Data Presentation Approaches that Facilitate the Use of Information in Choice. *Annu Rev Public Health*. 2003;24:413-33.
- ¹¹ Marshall MN, Shekelle PG, Davies HT, Smith PC. Public reporting on quality in the United States and the United Kingdom. *Health Aff (Millwood)*. 2003 May-Jun;22(3):134-48; Hibbard JH, Stockard J, Tusler M. Does publicizing hospital performance stimulate quality improvement efforts? *Health Aff (Millwood)*. 2003 Mar-Apr;22(2):84-94.
- ¹² Greenfield S, Kaplan SH, Ware JE Jr et al. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988 Sep-Oct; 3(5):448-57; Post DM, Cegala DJ, Miser WF. The other half of the whole: teaching patients to communicate with physicians. *Fam Med* 2002 May; 34(5): 344-52; Stewart M, Brown JB, Donner A et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000 Sep; 49(9): 796-804.

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- ¹³ Bodenheimer 2002. Glasgow RE, Funnell MM, Bonomi AE, Davis C, Beckham V, Wagner EH. Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams. *Ann Behav Med.* 2002 Spring;24(2):80-7.
- ¹⁴ Wasson JH, Stukel TA, Weiss JE, Hays RD, Jette AM, Nelson EC. A randomized trial of the use of patient self-assessment data to improve community practices. *Eff Clin Pract.* 1999 Jan-Feb;2(1):1-10; Wasson JH, James C. Implementation of Web-based interaction technology to improve the quality of a city's health care. *J Ambul Care Manage.* 2001 Jul;24(3):1-9.
- ¹⁵ Sittig DF. Personal health records on the internet: a snapshot of the pioneers at the end of the 20th Century. *Int J Med Inf.* 2002 Apr;65(1):1-6; Ross SE, Lin CT. The effects of promoting patient access to medical records: a review. *J Am Med Inform Assoc.* 2003 Mar-Apr;10(2):129-38.
- ¹⁶ Herzlinger RE. Let's put consumers in charge of health care. *Harv Bus Rev.* 2002 Jul;80(7):44-50, 52-5, 123. Newcomer LN. Shifting power: is the consumer next? *Physician Exec.* 2000 Nov-Dec;26(6):18-9, 22-3.
- ¹⁷ Wennberg JE, Fisher ES, Skinner JS. Geography and the debate over Medicare reform. *Health Aff (Millwood).* 2002;Supp Web Exclusives:W96-114.
- ¹⁸ Casalino L, Gillies RR, Shortell SM, Schmittdiel JA, Bodenheimer T, Robinson JC, Rundall T, Oswald N, Schaufli H, Wang MC. External incentives, information technology, and organized processes to improve health care quality for patients with chronic diseases. *JAMA.* 2003 Jan 22-29;289(4):434-41; Berenson RA, Horvath J. Confronting The Barriers To Chronic Care Management In Medicare. *Health Aff* 2003 22(2).
- ¹⁹ Motheral B, Fairman KA. Effect of a three-tier prescription copay on pharmaceutical and other medical utilization. *Med Care.* 2001 Dec;39(12):1293-304.