

Innovators and Visionaries:

Strategies for Creating a Person-centered Health System



Partner in care



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FACCT – Foundation for Accountability

September 2003

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A HEALTH SYSTEM FOR THE 21ST CENTURY

The U.S. health system is in trouble. The cost of health care is increasing at six times the rate of overall inflation. Problems in quality and safety, long known to researchers, have become visible to the media, purchasers, and general public. The managed care mechanisms for system integration and reform have stalled. Medicare managed care is unraveling, leaving most beneficiaries with coverage similar to that provided to their own parents almost forty years ago. And the Medicare system seems unable to accommodate widely available new therapies, such as prescription drugs, or new media, such as the Internet. Disparities in access are evident and appear to be growing. And all these problems have surfaced during a period of sustained prosperity accompanied by remarkable innovations in health information, communications and biomedical and behavioral science – innovations that should have set the stage for dramatic gains in health and productivity.

Our needs have changed since the days of “major medical” insurance and Part A Medicare coverage. We live far longer, we experience more chronic illness for a longer time, we know more about healthy living, we have access to remarkable medical technologies and medications, and most Americans enjoy instant access to the entire global knowledge base from our living rooms. We have built and enjoy a society that is rich in information, highly educated, democratic, and individualistic. In matters as mundane as driving their cars and as complex as managing their 401(k) and voting for national leaders, Americans can assimilate complex information, conduct themselves responsibly, and be sensitive to the common good.

Our health care system makes little use of these capabilities and performs poorly at addressing contemporary needs. Between one-third and one-half of all medical care is inappropriate or deviates from standards of best care. High numbers of patients and caregivers are not given the basic information needed to care for themselves and are too often excluded from decision-making. Too many people do not know what good care looks like, or how to seek it out. Providers are almost never rewarded for providing the best possible care.

America needs a health care system that reflects the realities of the 21st century: a technologically enabled public, a growing aging and chronically ill population, an increasing evidence base of medical practice, and emerging information and biomedical technologies

Such a transformation will occur only when we change the payment, culture and infrastructure of health care and fully engage Americans as patients, caregivers, consumers, and citizens. We call this future system person-centered.

WHAT IS A PERSON-CENTERED HEALTH SYSTEM?

A person-centered health system has four dimensions:

Health: The system will help most people understand, be responsible for, and be able to take care of their own health to the maximum degree possible.

Health care: The system will make available the most effective professional and institutional resources to assist people when they can no longer manage their own health without that help. The system will embrace and promote the principles of 'patient-centeredness'—self-care, personalization, transparency, redesign, quality, justice, and control.

Financing: Every individual and organization – from the patient to the medical school to Medicare – will accept responsibility to use expensive resources appropriately and efficiently.

Citizenship: Society will embrace an explicit consensus of our responsibilities to each other – and the limits of that responsibility.

What would a person-centered health system look like?

Some of the distinguishing features of a more person-centered system are listed on Table 1.

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Table 1: FEATURES OF A FUTURE HEALTH SYSTEM

HEALTH

To enable more consumers to understand and manage their own health.



HEALTH CARE

To enable more consumers to understand, affect, and participate in the care they receive from health professionals.



FEATURES

- *High levels of awareness, self-efficacy*
- *General use of health risk assessment → personal plan → continuous monitoring*
- *Professionals actively support health maintenance*
- *Coverage for self-management resources, non-visit care*
- *Financial incentives for maintaining wellness*
- *Rich, accessible, private personal health information environment*
- *General knowledge of relevant guidelines, safe medication practices, wise consumerism and system navigation*

FEATURES

- *Individual physician visit not the central mode for care*
- *Physician is information coach as well as technician*
- *Care provided by multi-disciplinary and community-based teams*
- *Providers support, encourage patient autonomy, system navigation, informed choice*
- *Professionals evaluated by outcomes, conformity to evidence-based practice*
- *Patients, professionals share access to biomedical knowledge base*
- *Medical education (GME, CME, nursing) patient-centered*
- *Quality performance information widely available, easily understood for all providers*

Table 1: FEATURES OF A FUTURE HEALTH SYSTEM

FINANCING

Help consumers understand and participate in the financing of and incentives for health care services.



FEATURES

- *National consensus on health priorities*
- *Individuals know costs of health services; provider pricing available*
- *Incentives for appropriate use of resources shared between patient, purchaser, provider*
- *Incentive for behaviors that reduce collective risk; disincentive for behaviors that increase collective risk*
- *Outcomes-based payment*

CITIZENSHIP

Help Americans understand and participate in the shared goals of a healthier society.



FEATURES

- *Explicit understanding of risks covered by social insurance and risks that are individual responsibility*
- *National agreement on shared commitment to social insurance component*
- *Reform K-12 health education curriculum to address self-care, health system responsibility, navigation, information resources*
- *Implementation of National Health Information infrastructure and personal health record standards*

INNOVATORS AND VISIONARIES: SHOWING THE WAY

A sector as vast and interdependent as U.S. health care will probably not adopt these values into routine practice through governmental fiat or belief in a single bold theory. It will take years to change a system in which large, wealthy economic interests skillfully defend their pieces of turf. Instead, it will change as thousands of separate activities collectively shift the power and focus of the system from a culture of highly selected, expensive, scarce expertise to one of distributed expertise and services, supported by a financing and policy structure that maintains focus on national health goals. It will take pressure from an informed public that expects responsive, safe, high quality care and demands it of their elected officials, employers, doctors and insurers.

As a first step, the process to system transformation requires innovation and vision by health care leaders, professionals and entrepreneurs. Innovation will demonstrate the benefits of individual elements of care system redesign. Vision will provide us with an overall unified framework and begin to articulate to the public the broad goals of reform.

We are well into this first phase. There are hundreds of innovative projects happening today in chronic disease care, information technology, protocol-based medicine, palliative care, medical education, and so many other areas. Local experiments, funded and shepherded by forward-thinking leaders, have demonstrated valuable elements of care system redesign. Each one is making life better for a few people it serves directly, and implicitly educating its immediate constituency on how the health system could be different for everyone.

David Bates at Partners is giving patients a view into the information labyrinth of the academic medical center; Lee Newcomer at Vivius is allowing consumers to manage their own health care costs and decisions; Don Lindberg at the National Library of Medicine is pushing the world's biomedical knowledge directly into the patient's hands; Ed Wagner at Group Health is coordinating a rich array of chronic illness services to meet patients where they're at; Joanne Lynn and Ira Byock are redesigning end-of-life care; David Gifford and Rosalie Kane are rethinking nursing home care; Tom Scully at CMS and Foster Gesten in New York are making provider performance information available to the public; Sam Ho at Pacificare and George Isham at HealthPartners are focusing their health plans on quality performance; Chuck Kilo at Greenfield is building the perfect primary care practice while Brent James infuses quality and measurement throughout the Intermountain system; Bob Galvin at GE and Bruce Bradley at GM are redefining how employers can support informed consumerism.

But as of yet, these projects fail to achieve broad impact. Few have been able to penetrate the fabric of daily medical care in America. The best ideas

are stopped in their tracks because of the way we **pay** for health care, the **culture** of health care, and the **infrastructure** of health care. They need to be embraced by health care organizations and professionals, have a basis of stable funding, and be connected to the routine flow of patient care and community life. They need to be tied to a broad vision of system reform.

Visionaries are the writers, teachers, policymakers, philanthropists, and analysts who can see how the many diverse efforts to give people more power over their health care are part of a single national movement. They help both professionals and the public to understand the opportunities we are failing to capture and the path to system transformation. More and more voices are speaking out for reform, starting a national dialogue to help the public understand both the realities of contemporary health care and weigh in on the trade-offs that are likely to be necessary to achieve improvements.

POLICIES THAT SERVE PEOPLE

We need a strategy to remove the obstacles to system-wide reform. Each of the pillars of the current system – **payment**, **culture**, and **infrastructure** – continues to express the values and possibilities of a bygone era. Our **payment** system still reflects assumptions about medical care from the 1930s and 1960s. Our health care **culture** perpetuates a physician cult embodied in popular images of Dr. Kildare and Marcus Welby that leaves biomedical knowledge and capacity in the hands of a few inaccessible experts. And our health care **infrastructure** remains a blend of huge centralized hospital and medical office campuses and a fragmented, unconnected network of small, unmanaged, and unaccountable independent practitioners - neither of which has a comprehensive ability to deliver, exchange, or manage the exploding volume of health information to the benefit of the patient.

These pillars are so deeply sunk into American health care that they can only be uprooted through policy action – and those policy changes will only come about when the public demands them. The key, then, is to create mechanisms for the public to express its values and preferences so that policymakers can reflect them in changed payment, “cultural”, and infrastructure systems.

In making an argument for policy action, this paper goes beyond a marketplace conception of consumer involvement in health care. Some have argued that putting health care dollars back into the hands of individual consumers will drive modernizing changes through the health care system. MSAs, defined contribution benefit plans, tax credits, and the choice among competing insurance designs all give individuals more ability to make their own decisions about doctors, services and insurance coverage and certainly

present one mechanism for “sending a message” to the institutions of health care.

But many of the Americans in greatest need are least able to exercise these options. They are often sick, poor, with less skill and experience in advocating for themselves in a fragmented and technically complex system. Paradoxically, the possibility that only the younger and healthier consumers will favor the new “consumer-driven health plans” raises the risk that those most in need of accessible, high-quality care will be relegated to an insurance pool with fewer dollars in it and fewer choices available.

FACCT’s research suggests that about 50 percent of American consumers are likely to take on the role of “active consumer” and lack only the tools to do so. These consumers need to be given the tools and choices that will allow them to improve their own health care while also sending a signal to the health system about what they value.

But the other half of the public continues to expect their doctors and other providers to practice excellent medical care without being “managed” by their patients. These Americans are paying insurance premiums and taxes and equally deserve a health system that is accountable for excellence, compassion, respect, and fairness.

THE LEVERS OF SYSTEM CHANGE

Paradoxically, the U.S. health system will not be transformed through a single bold policy initiative – and it cannot be transformed without national policy changes. Recent political history suggests that such changes will not be adopted unless public pressure demands them.

Today our health care system is paralyzed, incapable of meaningful reform:

- Existing health institutions have developed successful business models in the current policy and financing environment and are unwilling to risk their financial stability in order to introduce changes;
- The most significant policy and financing instruments influencing health system behavior are controlled by federal law and administrative agencies;
- The largest health system institutions lobby fiercely against any changes to federal policy that would alter the basis of their current business model;
- The public, while enormously frustrated, does not possess a language or framework for conceiving of an alternative structure for the financing and delivery of health services;

- Citizens lack any mechanism for expressing their desire for changes in the system, for reasons both cultural (“white-coat syndrome”) and economic (third-party payment)

To create **public pressure** for change, we believe that the following must occur:

- The desired features of a reformed health system must become commonly understood and supported;
- Increasing numbers of citizens need to understand the deficiencies of our system and have opportunities to express their dissatisfaction using a common language;
- Increasing numbers of people must become more capable of self-care, successful health system navigation and decision making;
- Successful micro-models of care need to have more visibility so that leaders and citizens can visualize alternative systems;
- People will need to put pressure on policymakers to change key policy elements so that health care organizations will adopt successful innovations and serve them in a more responsible fashion;
- Public policies must be changed to reward effective, consumer-centered care.

This “strategic plan” is therefore focused less on promoting specific clinical innovations than on the **process** that stimulates and leads to their adoption. Our approach is, first, to identify 22 specific initiatives that, **collectively**, will have the effect of changing public attitudes and creating more pressure on leaders to change key policies – and, second, to encourage establishment of a coordinating “think-tank” to assist in the sharing of the best frameworks, findings, etc.¹

¹ Over the past 20 years there have been numerous efforts at regional health system reforms. Reformers have reasonably believed that it is possible to bring together all key stakeholders from a community and coordinate changes to service models at a more tractable scale. Worthy models exist; the Indiana Employers Quality Alliance, the Oregon Health Assessment Project, the Pittsburgh Regional Healthcare Initiative, and many others. But we observe that such initiatives inevitably fall short of system redesign because they lack control of the 50 percent of health care funding controlled by federal and state law and because they are themselves subject to far more powerful external forces: federal and national health plan financing, licensing and accreditation systems, and the influence of the mass media and our own cultural history. For this reason, we do not envision comprehensive initiatives to enable consumer-centered health care at the regional level, though invaluable intermediate experiments will certainly continue.

THE HIGH LEVEL ACTIONS

FACCT has compiled an inventory of current initiatives that can increase the health system’s “patient-centeredness” (Appendix 1). Based on recent discussions with health care leaders, we have also identified seven of these initiatives that are most likely to stimulate consumer-oriented health care reform if they are fully supported over the next 10 years:

Table 2: Highest Leverage Strategies
PAYMENT: pay for results
<i>P1: Universal coverage for “essential” health care services, defined by a public process</i>
<i>P2: Private and public purchasers adopt <u>outcomes</u>-based payment</i>
<i>P3: Intermediary organizations (plans, employers, unions) implement financial incentives for self-care, health maintenance, non-visit care</i>
CULTURE: elevate consumer voice
<i>C1: Create a high-visibility grassroots organization devoted to safer and higher-quality care</i>
<i>C2: Health care organizations include diverse, representative consumers and patients at every level of governance and redesign</i>
INFRASTRUCTURE: give consumers information
<i>I1: National commitment to health information infrastructure; all health care organizations receiving federal funds required to adopt standards and implement necessary systems</i>
<i>I2: Mandatory publication of performance data by all federally funded health care organizations</i>

These seven strategies are summarized in the pages that follow. Table 3 (page 17) lists all 22 of the proposed strategies.

PAYMENT: pay for results

The financing of health care must reward and accommodate effective innovation. No list of procedures or technologies or processes can be used as the basis of measurement or payment without inhibiting patient-centered care. As the financing of U.S. health care is likely to remain dependent upon large insurance pools and public sector contributions, the values of American citizens must be used as the basis for what outcomes are rewarded and what services are guaranteed.

P1: Universal coverage for “essential” health care services, defined by a public process

Key steps:

- Foundations, think-tanks develop limited set of alternative models
- Conduct public review process
- Recommendations to Congress

Models:

- Oregon Health Plan
- Jackson Hole Group 1993
- Canadian Healthcare Commission
- Evidence-based Practice Centers
- Wyden-Hatch legislation

P2: Private and public purchasers adopt outcomes-based payment

Key steps:

- Researchers identify selected conditions or demographic groups suitable for outcomes-based payment and corresponding measures (e.g., symptomatic chronic illness, acute care with functional or symptomatic objectives, high risk factors)
- Existing pay-for-performance sites begin outcomes measurement and reporting for target populations
- Portion of payment shifted to outcomes achievement

Models:

- Bridges to Excellence employer consortium
- BIPA Disease Management demonstration (CMS)

P3: Intermediary organizations (plans, employers, unions) implement financial incentives for self-care, health maintenance, non-visit care

Key steps:

- Researchers identify highest leverage process indicators and payment options
- Models documented and disseminated
- Pilot projects test alternative payment models in practice
- Evaluation results widely distributed

Models

- Capitation
- Service “bundles”
- Consumer payment for goal attainment (e.g., smoking cessation)

CULTURE: elevate consumer voice

Consumer-centered health care can only prosper if the priorities and values of the organizations that control the health system are responsive to those of society as a whole. Since we do not believe that an individual consumer market is a sound means of communicating public values to organizational leaders in this sector, other means are needed to balance the historic power of medical elites in shaping health care culture.

C1: Create a high-visibility grassroots organization devoted to safer and higher-quality care

We believe that millions of Americans have deep frustration and concern with their medical care experience, but have not been offered a channel to express that concern, nor a useful set of actions to contribute to improving the system. A credible organization could educate the general public, train and support citizen volunteers to participate in public and private processes, and advocate for policy changes that lead to system improvement.

Key steps:

- Conduct market research to identify size and composition of primary audience, first-generation messages
- Identify one or two salient issues for target audiences
- Develop initial list of action steps to offer consumer members
- Recruit interest using web-based organizing tools
- Develop business model

Models:

- Mothers Against Drunk Driving
- MoveOn.org

C2: Health care organizations include diverse, representative consumers and patients at every level of governance and redesign

Many leadership organizations are now engaged in processes to become more “consumer-centered.” The Institute of Medicine, the Joint Commission, the Georgia Coalition on Cancer Care, the American College of Graduate Medical Education, the National Quality Forum, the National Committee on Vital and Health Statistics – and many others – want to shape programs that better serve consumers and reflect consumer preferences. Yet they continue to rely upon a handful of staff members from a handful of organizations as sources of input. It is unconscionable that Congress would provide JCAHO with the principal authority to assure the quality of U.S. hospitals yet impose no requirement that patients be substantially represented in the governance of that agency.

Key steps:

- Federal action to require consumer involvement in all Federally funded or mandated health care initiatives
- Development of a network of citizen volunteers able to serve in governance and advisory roles
- Private and public purchaser requirements for consumer representation in health plan, hospital, and other appropriate organizational governance

Models

- Cincinnati Children’s Hospital Medical Center
- Wyden-Hatch legislation
- Oregon Health Decisions
- UK Primary Care Trusts and Patient’s Forum

INFRASTRUCTURE: give consumers information

The U.S. has rejected insurance carriers as the appropriate party to manage and coordinate the use of health care resources, and appears unlikely to support greater government control. In the absence of a layer of management authority, the only means of introducing rationality or efficiency in the use of resources is improved and transparent exchange of information among all stakeholders. If consumers are allowed to understand the health system and make decisions based on complete information they define as important, they may be able to do more for themselves while recognizing and rewarding excellence in the health care system.

- *I1: National commitment to patient- and consumer-focused health information infrastructure; all health care organizations receiving federal funds required to adopt standards and implement necessary systems*
Patients and consumers will not be able to exercise meaningful choices of treatments or providers, or access the information necessary to care for their health until all of their personal health information is standardized and available over an electronic network. It has proven to be impossible to generate useful performance information, reduce errors, or coordinate care in the absence of a comprehensive health information network.

Key steps:

- Congress and CMS tie federal payment to adoption of standards and interoperability
- Congress requires new IT implementation to include consumer access to and control of their personal health information

Models:

- NHII personal health dimension
 - Indianapolis Network for Patient Care
 - Santa Barbara Care Data Exchange
 - Winona (MN) Health Online
- *I2: Mandatory publication of performance data by all federally funded health care organizations*
CMS and some states have created public performance reporting systems, and the National Quality Forum has been charged with defining data requirements for such reports. Yet many of these initiatives are voluntary – including the CMS hospital performance reports, The Leapfrog Group, and the California hospital patient surveys. HEDIS and other projects have shown that poor performers simply avoid public scrutiny by refusing to share their performance information with the public. Any health care organization receiving public funds should be required to release quality and safety data for public review.

Key steps:

- Congress should permit CMS to require federally funded providers to report NQF-defined data sets
- NQF and CMS should expand the involvement of patients and consumers in the process of defining quality standards
- Congress and CMS should require disclosure of serious adverse events, as recommended in the IOM *To Err is Human* report

Models

- Minnesota “never events” reporting statute
- CMS dialysis reporting
- New York State CABG and PTCA reporting

Table 3: STRATEGIES TO ACHIEVE PERSON-CENTERED SYSTEM

PAYMENT	CULTURE	INFRASTRUCTURE
To pay for care that leads to improvements in health.	To change public expectations of the health care system.	To build national systems that support evidence-based, collaborative care.
OBJECTIVES	OBJECTIVES	OBJECTIVES
<p>P1: Universal coverage for “essential” health care services; P2: Provider compensation rewards favorable outcomes; P3: Purchaser contracts and provider payment rewards patient-centered care, informed consumerism; P4: Insurance and tax system rewards personal health maintenance, chronic illness self-care; P5: Patients share costs of discretionary health care utilization and control disposition of funds spent on their behalf; P6: Medical school funding dependent on curriculum reform; P7: Intermediary organizations provide access to and reward use of health risk assessments and monitoring systems.</p>	<p>C1: Create a high-visibility grassroots organization devoted to safer and higher-quality care; C2: Health care organizations include diverse, representative consumers and patients at every level of governance and redesign; C3: Intermediaries use common educational, awareness tools with constituents; C4: Intermediaries support self-care education C5: Physicians increase time and resources devoted to patient risk assessment and education; C6: Mass media shows potential to avoid medical care & morbidity through better health behaviors; importance of informed decision-making; C7: K-12 curriculum emphasizes responsibility for health maintenance; C8: Public reporting systems (e.g., HealthyPeople, HEDIS) increase awareness of national progress; C9: Patients aware of true costs of all health services and understand impact of others’ spending on insurance design and price; C10: President leads & adopts language-defining objectives of Medicare, other public sector health commitments; C11: National dialogue on principles of healthy society: what’s shared responsibility, what’s personal.</p>	<p>I1: National health information infrastructure and personal health record architecture implemented; federally funded providers required to implement necessary systems I2: Mandatory publication of performance data by all federally funded health care organizations; I3: Professional licensure, accreditation, authorization to prescribe support informed patient; CME, certification, boards address patient-centered care; I4: K-12 curriculum treats health as major national commitment, like defense or environment.</p>

A COORDINATING MECHANISM and A NATIONAL DIALOGUE

Many of the activities we outline *will occur* in the coming years – with or without support from external parties. Local circumstances, energetic leaders, and creative researchers will develop and refine these and many other ideas that bring health care closer to the patient and family, and make better use of information and medical technology. But these scattered initiatives can ultimately fail if the larger drivers of health system and individual behavior are not also changed. And these initiatives can achieve far greater impact if they communicate the same core messages to policymakers and the public and if they are able to share best practices and lessons learned with each other.

Two elements of national infrastructure need to be established:

1. *A national center for consumer-centered health care, and*
2. *A national dialogue on health care reform.*

1. A national center for consumer-centered health care should be established to:
 - Provide national recognition to the most successful innovations in consumer-centered health care
 - Articulate a language and framework for national health reform that leads to more patient- and consumer-centered care
 - Identify and share best practices among innovators
 - Educate leaders and policymakers about the barriers to wider adoption of these approaches and opportunities to remove those obstacles
 - Assist public and private funders to identify high-leverage projects that contribute to development of an effective reform strategy
2. A national dialogue on health care reform will allow the American public to understand both the realities of contemporary health care and weigh in on the trade-offs that are likely to be necessary. There are numerous models for effective public involvement in these substantial issues. Susan Goold at the University of Michigan has developed an interactive game, called CHAT, to educate and elicit public opinion. The development of the Oregon Health Plan included elaborate public and expert participation. Recently, the Commission on the Future of Health Care in Canada (<http://www.healthcarecommission.ca/>) undertook a remarkable and comprehensive program of public education and deliberation on several complex trade-offs faced by policymakers. Any change to important public programs such as Medicare or hospital accreditation would raise huge political storms. It is essential that the American public understands the issues and believes that its voice has been heard in the policy proposals that come forward. The Wyden-Hatch bill (S. 3063) provides a framework for such a dialogue in the U.S.

HOW WILL WE KNOW IF WE'RE GETTING THERE? METRICS FOR CONSUMER-CENTERED HEALTH REFORM

Each of the 22 strategies reviewed here should be monitored with an appropriate set of milestones and performance targets. It would be worthwhile, for example, to monitor the number of patients covered by providers whose contracts include payment based on quality performance, or the presence of consumers on hospital quality teams or the number of PCPs who provide e-mail access to their patients.

At a strategic level, however, it is helpful to consider some overall metrics to monitor progress in each of the three areas examined here.

Payment:

- Number of covered lives whose primary providers are compensated differentially based on outcomes
- Number of specialist physicians compensated differentially based on outcomes
- Number of hospitals compensated differentially based on outcomes
- Number of Americans with guaranteed basic medical insurance.

Culture:

- Increased number of Americans scoring in "independent active" or "doctor dependent active" categories on FACCT consumer activation index, or similar improvements on Hibbard activation index.

Infrastructure:

- Proportion of primary care providers using electronic medical records and offering e-mail access to patients
- No. of patients with full access to their comprehensive, longitudinal, integrated personal health record

Appendix I

BRIEF EXPLANATIONS OF REFORM OBJECTIVES

Payment

- P1: Universal coverage for “essential” health care services;
- P2: Provider compensation rewards favorable outcomes;
- P3: Purchaser contracts and provider payment rewards patient-centered care, informed consumerism;
- P4: Insurance and tax system rewards personal health maintenance, chronic illness self-care;
- P5: Patients share costs of discretionary health care utilization and control disposition of funds spent on their behalf;
- P6: Medical school funding dependent on curriculum reform;
- P7: Intermediary organizations provide access to and reward use of health risk assessments and monitoring systems.

P1: Universal coverage for “essential” health care services

Background

In the mid-1940s the American Public Health Association endorsed the notion of a health plan that would provide health care coverage to the entire U.S. population. While there is not a national consensus that every American should have health insurance, we believe that a consumer- or patient-centered health system must assure that each person has affordable access to essential health care services. Lacking a relationship with a health professional, and confidence of access to the health system, few consumers will develop the skills necessary to manage their health or navigate the health system. Given the lack of national consensus on universal coverage, a reasonable consumer-centered framework would involve defining a package of essential health services that provide a precondition for consumer-centered health care. Such a package could support both public sector and private sector experiments with benefit designs, while reassuring critics that basic needs will not go unmet as consumer-centered models are deployed. A basic benefit design could also provide an actuarial template for coverage expansion. A few states, including Oregon and Hawaii, have sought to develop unique working models of publicly financed health care that provide program participants a “basic benefit package” as a strategy to increase participation, reduce uninsurance, and control and budget costs. The basic health care package needs to limit and prioritize services and should be defined by a systematic and rational process based on cost-benefit analysis, health outcomes, and the democratic process of consensus of priorities and coverage.

Possible initiatives:

1. Increase qualitative and quantitative research on developing consensus on acceptable health benefit priorities in a community
2. Fund analysis, and demonstrations that propose integration of a basic benefits package into existing publicly funded health care programs
3. Educate health promoters, providers and policymakers about the role of trade-offs and essential benefits in a universal coverage program
4. Increase local participation in the debate and discussion around universal coverage, basic benefits, and trade-offs

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P2: Provider compensation rewards favorable outcomes

Background

For the most part, providers receive payment for professional services according to various formulae based on work inputs. The basis of these payment systems date variously from the 1930s (Blue Cross FFS), 1960s (Medicare Part A and B), or 1980s (DRGs, RBRVS). A few innovations, such as full capitation and sub-capitation, have had favorable effects on quality and utilization, but have not been widely adopted. While the federal government is the direct payer for only about 40 percent of health services, it also continues to support these payment models in other ways; for example, 70 percent of federal employees are enrolled in FFS insurance products. Interestingly, in health systems under direct federal management – the VA and military systems – providers are not paid on a FFS basis, and significant patient-centered innovations have emerged over the past decade. The persistence of an antiquated payment system means that providers and health care organizations have no motivation to develop care processes that reduce in-person visits, make use of new technology, or reduce concentration of physical resources in central campuses. These business considerations, in turn, mean that patients must accommodate themselves to the hours and physical locations established by providers, and remain dependent on the expertise and convenience of those providers for access to vital medical information and such services as prescribing and referral. Until the payment policies of federal programs and major national payers reward health outcomes and care delivered through channels other than office visits, it will not be possible to develop a patient-centered health care system.

Possible initiatives:

1. Pay for non-visit care
2. Pay for outcomes regardless of utilization
3. Pay for service satisfaction that reflects same-day access, e-mail responsiveness, telemedicine, e-mail consultation, consolidated medical records, patient access to records, coordination of care

Citations and examples:

Kilo CM, Horrigan D, Godfrey M, Wasson J. Making quality and service pay: Part 2, The external environment. *Fam Pract Manag* 2000 Nov-Dec;7(10):25-8.

Kilo CM, Endsley S. As good as it could get: remaking the medical practice. *Fam Pract Manag* 2000 May;7(5):48-52. <http://www.aafp.org/fpm/20000500/48asgo.html>

Berwick D, Kilo C. Idealized design of clinical office practice: an interview with Donald Berwick and Charles Kilo of the Institute for Healthcare Improvement. *Manag Care Q* 1999 Autumn;7(4):62-9.

Antonucci YL, Bender AD. The quality and cost of medical care. The potential for information technology to meet the challenge. *Med Group Manage J.* 1998 May-Jun;45(3):12-4, 16-9.

Meerschaert JD. Uniting quality and health care with quality-based reimbursement. *Med Group Manage J.* 1999 Sep-Oct;46(5):8-10, 12.

P3: Purchaser contracts and provider payment rewards patient-centered care, informed consumerism

Background

Health care purchasers, particularly private employers, employer coalitions, and selected health plans, have implemented “pay-for-performance” systems since the mid-1990s. Such payment systems provide financial bonuses to providers who score highly on quantitative measures of care. A second approach, now in use by The Leapfrog Group, relies on increasing market share to higher quality providers by promoting their quality performance to individual consumers. In some cases, the purchaser may create an incentive to the patient to encourage selection of higher quality plans or providers. This approach is in use by General Motors, BHCAG, Pacificare and Blue Cross in California (for tiered hospital benefits) and the Empire Blue Cross initiative with Leapfrog. Many of these approaches rely on structural measures (Leapfrog), or easily obtained process measures compiled through HEDIS, which do not address the concerns of consumer-centered care. The California IHA pay-for-performance system provides an incentive to medical groups that score highly on a consumer satisfaction survey, including ratings of access to specialty care, timely care and service, doctor-patient communication, and overall rating of care. A new diabetes incentive program (CarePoints) sponsored by several large employers will provide incentives to both doctors and patients for process and clinical outcome measures. All of these approaches could be enhanced by focusing on attainments of health and functional outcomes and other dimensions of consumer-centered care.

Possible initiatives:

1. Develop compact toolkit of performance measures reflecting dimensions of patient-centeredness for use by pay-for-performance initiatives
2. Promote importance of consumer-centered measures to target users through publications, conferences, and direct outreach
3. Evaluate effectiveness of including consumer-centered measures at increasing consumer engagement in using performance data and altering individual behavior

Citations and examples:

Salber PR, Bradley BE. Adding quality to the health care purchasing equation. Health Aff (Millwood) 2002;Suppl:W93-5.

Bradley BE. An employer's perspective on medical errors: ambitious and clear. Benefits Q 2001;17(2):26-9.

<http://www.iha.org/payfprfd.htm>

Christianson JB, Feldman R. Evolution in the Buyers Health Care Action Group purchasing initiative. Health Aff (Millwood) 2002 Jan-Feb; 21(1):76-88.

Lisa Rapaport. “CalPERS eyes tiered rates. More expensive hospitals would cost patients more.” Sacramento Bee. Aug. 17, 2002.

P4: Insurance and tax system rewards personal health maintenance, chronic illness self-care

Background

McGinnis and others have shown that 50 percent of the determinants of mortality and morbidity involve preventive, behavioral, and self-care domains, yet the U.S. allocates a small proportion of health care expenditures to enhancing these behaviors. Moreover, while professional society and Clinical & Preventive Services Task Force guidelines for both children and adults place a high emphasis on counseling, preventive, and screening services, survey data reveal that these services are provided only about 50 percent of the time. Medicare has fully covered CABG and PTCA, but patient participation in disease management programs, cardiac rehabilitation, fitness programs, and nutrition management (e.g., Dean Ornish) remain poorly covered and often challenged. Similarly, the tax code provides generous deductibility for employer-provided medical care benefits, but no comparable advantage for employee wellness or disease management programs. These payment mechanisms and policies continually reinforce a medical care and technology-based model without supporting consumer responsibility and capacity to care for one's own health.

A substantial literature demonstrates that self-care and health maintenance activities reduce medical utilization, reduce workplace productivity losses, and lead to improved health outcomes. Several studies suggest that financial and other non-health incentives increase participation in such programs, but there is not an established knowledge base of best practices regarding such incentives.

Possible initiatives:

1. Increase research base documenting relative benefit of selected health maintenance, self-care services
2. Fund development, analysis, and demonstrations of benefit designs that reallocate covered benefits for Medicare, Medicaid, commercial insurance
3. Educate policymakers of cost-benefit of preventive, self-care services vs. acute, invasive late-stage treatments
4. Conduct and disseminate research regarding most effective incentives to participation in self-care and health maintenance programs
5. Develop common messages and marketing approaches to increase participation in such incentive programs

Citations and examples:

McGinnis JM, Foege WH. Actual causes of death in the United States. JAMA 1993 Nov 10;270(18):2207-12.

Lurie N. What the federal government can do about the non-medical determinants of health. Taking a "systems" approach to structuring our government's health investments is an important first step in addressing the many contributors to health and well-being. Health Aff (Millwood) 2002 Mar-Apr;21(2):94-106.

Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. Am J Prev Med 2002 May;22(4):267-8.

Vickery DM, Lynch WD. Demand management: enabling patients to use medical care appropriately. J Occup Environ Med 1995 May;37(5):551-7.

Vickery DM, Golaszewski TJ, Wright EC, Kalmer H. The effect of self-care interventions on the use of medical service within a Medicare population. Med Care 1988 Jun;26(6):580-8.

Groessl EJ, Cronan TA. A cost analysis of self-management programs for people with chronic illness. Am J Community Psychol 2000 Aug;28(4):455-80.

Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, Gonzalez VM, Laurent DD, Holman HR. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 2001 Nov;39(11):1217-23.

Cronan TA, Groessl E, Kaplan RM. The effects of social support and education interventions on health care costs. Arthritis Care Res 1997 Apr;10(2):99-110.

Cronan TA, Hay M, Groessl E, Bigatti S, Gallagher R, Tomita M. The effects of social support and education on health care costs after three years. Arthritis Care Res 1998 Oct;11(5):326-34.

Sharkey PJ, Bey JM. Designing an incentive based health promotion program. AAOHN J 1998 Mar;46(3):133-44; quiz 145-6.

P5: Patients share costs of discretionary health care utilization and control disposition of funds spent on their behalf

Background

Over the past 10 years, many analysts have encouraged development of new benefit designs that provide consumers with wider choices of benefit options, let them control how benefit dollars are spent, and shift more cost responsibility directly to them. These designs have ranged from Medical Savings Accounts to defined contribution plans to simple increases in cost-sharing through higher deductibles, co-pays, and “thinner” coverage. Advocates of these programs believe that carefully designed plans will produce a “consumerist revolution” that will force providers to compete on efficiency and quality, lead them to focus on their strengths rather than trying to serve all needs, and incentivize them for investing in new technology. And they argue that forcing consumers to fully understand the costs of their choices will produce a rationalization of health care utilization, reducing overuse and shifting many discretionary services out of the social insurance pool where they do not belong. Skeptics foresee aggravated patterns of risk selection, a retreat from the gains in preventive care achieved by the managed care systems, creation of a class of information-poor consumers left with only bad and unaffordable choices, and an abdication of public responsibility for both quality and equity. Most advocates agree that the success of these “consumer-driven” models will depend on a richer supply of information to permit consumers to make appropriate decisions. This premise raises, in turn, fears that current levels of health literacy and financial literacy are inadequate to support a more individual market in health insurance products.

Possible initiatives:

1. Evaluate impact of various consumer-directed financing models on public understanding of health care financing and values
2. Evaluate impact of consumer-directed financing models on health service utilization and health outcomes for selected populations
3. Evaluate roles of health literacy, financial literacy, Internet use on how consumer-directed plans are utilized

Citations and examples:

Herzlinger RE. Let's put consumers in charge of health care. Harvard Business Review 2002 July; 4-11.

Robinson JC. Renewed emphasis on consumer cost sharing in health insurance benefit design. Health Aff (Millwood) 2002;Suppl:W139-159.

Solanki G, Schauffler HH. Cost-sharing and the utilization of clinical preventive services. Am J Prev Med 1999 Aug;17(2):127-33.

Christianson JB, Parente ST, Taylor R. Defined-contribution health insurance products: development and prospects. Health Aff (Millwood) 2002 Jan-Feb;21(1):49-64.

Vitt LA, Siegenthaler JK et al. Consumer health care finances and education: matters of values. EBRI Issue Brief 241 (January 2002).

Martin KE. Shifting Responsibilities: models of defined contribution. Changes in Health Care Financing and Organization (HCFO) Program. February 2002.

P6: Medical school funding dependent on curriculum reform

Background

Medical education and training programs have been slow to modify their curriculum to respond to dramatic changes in the health care environment with regard to information technology, group practice, and the shift to preventive, outpatient and primary care. And, as Gerry Anderson recently noted, "the current Medicare payment system does not require a teaching hospital to be accountable for achieving certain policy objectives when it receives IME and DME payments. Payments are made without any clear direction regarding what policy objectives should be achieved." Of particular concern, 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. ACGME has begun to address this deficit by defining "interpersonal and communication skills" and "systems-based practice" as two of the six competencies required for residency programs, but the substantive development of these elements is weak. Federal policy can stimulate significant curriculum reform by identifying the objectives of future medical training and linking DME and GME payments to implementation of a patient- and family-centered curriculum.

Possible initiatives:

1. Convene a high-level workgroup of medical educators and patient advocates to develop curriculum, community and residency program criteria to support patient-centered care
2. Establish policy criteria and performance standards for DME and GME payments and educate policy leadership

Citations and examples:

Blumenthal D, Gokhale M, Campbell EG, Weissman JS. Preparedness for clinical practice: reports of graduating residents at academic health centers. *JAMA*. 2001; 286:1027-1034.

Blumenthal D. Doctors in a Wired World: Can Professionalism Survive Connectivity? *Milbank Q* 2002; 80 (3).

Masys DR. Advances in information technology. Implications for medical education. *West J Med* 1998 May; 168(5):341-7.

Rich EC, Liebow M, Srinivasan M, Parish D, Wolliscroft JO, Fein O, Blaser R. Medicare financing of graduate medical education. *J Gen Intern Med*. 2002 Apr;17(4):283-92.

Sundwall DN. Another alternative for financing graduate medical education. *Health Aff (Millwood)*. 2001 Mar-Apr;20(2):156-8.

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Halpern R, Lee MY, Boulter PR, Phillips RR. A synthesis of nine major reports on physicians' competencies for the emerging practice environment. *Acad Med* 2001 Jun;76(6):606-15.

P7: Intermediary organizations provide access to and reward use of health risk assessments and monitoring systems

Background

Patients should be supported in their health maintenance activities by the various organizations with an interest in their health. Patients need to know what their specific health risks are and be provided simple and effective tools for maintaining their health. Organizations concerned about individuals' health should provide access and incentives for more widespread patient use of health risk assessment and monitoring systems.

Possible initiatives:

1. Conduct and disseminate research regarding most effective incentives to increase HRA utilization and individual attention to reducing key risks
2. Develop common messages and marketing approaches to increase public awareness of opportunity to address individual health risks
3. Encourage use of HRA and tracking systems by other membership and intermediary organizations

Citations and examples:

Henritze J, Brammell H, McGloin J. LIFE CHECK: A successful, low touch, low tech, in-plant, cardiovascular disease risk identification and modification program. *Am J Health Promotion*, 1992. 7(2): p. 129-136. <<http://healthproject.stanford.edu/abstract.gif>>

Anderson DR, Staufacker MJ. The impact of worksite-based health risk appraisal on health-related outcomes: a review of the literature. *Am J Health Promot* 1996 Jul-Aug;10(6):499-508.

Gemson DH, Sloan RP. Efficacy of computerized health risk appraisal as part of a periodic health examination at the worksite. *Am J Health Promot* 1995 Jul-Aug;9(6):462-6.

Kellerman ST, Felts WM, Chenier TC. The impact on factory workers of health risk appraisal and counseling in health promotion. *Am J Prev Med* 1992 Jan-Feb;8(1):37-42.

Yen L, Edington MP, McDonald T, Hirschland D, Edington DW. Changes in health risks among the participants in the United Auto Workers--General Motors LifeSteps Health Promotion Program. *Am J Health Promot* 2001 Sep-Oct;16(1):7-15.

Culture

- C1: Create a high-visibility grassroots organization devoted to safer and higher-quality care
- C2: Health care organizations include diverse, representative consumers and patients at every level of governance and redesign
- C3: Intermediaries use common educational, awareness tools with constituents
- C4: Intermediaries support self-care education
- C5: Physicians increase time and resources devoted to patient risk assessment and education
- C6: Mass media shows potential to avoid medical care & morbidity through better health behaviors; importance of informed decision making
- C7: K-12 curriculum emphasizes responsibility for health maintenance
- C8: Public reporting systems (e.g., HealthyPeople, HEDIS) increase awareness of national progress
- C9: Patients aware of true costs of all health services and understand impact of others' spending on insurance design and price
- C10: President leads & adopts language defining objectives of Medicare, other public sector health commitments
- C11: National dialogue on principles of healthy society: what's shared responsibility, what's personal.

C1: Create a high-visibility grassroots organization devoted to safer and higher-quality care.

Background

Public opinion and understanding have significantly influenced health policy over the past fifteen years. The passage and withdrawal of the catastrophic care bill, the "Harry and Louise" campaign, the clamor against short-stay deliveries all illustrate the potential of public voice in shaping health policy. We note widespread concern that national financing and quality policies need to be modified, and a recognition that various industry and professional stakeholders have a track record of effective advocacy for their own interests. Yet no mechanism exists to represent the needs or concerns of patients and consumers who are dissatisfied with and expect more from their health care system. No organization exists to provide the public with educational outreach regarding quality and safety issues, and none exists to capture public concern and provide a voice for patient experiences.

Membership organizations, such as AARP, disease advocacy groups and faith-based organizations have unique access to significant numbers of people. These groups can play key roles in empowering consumers to actively participate in their health care. A number of scattered initiatives have shown promise, including AARP's WiseRx program to educate consumers about medication use, the American Diabetes Association/NCQA Provider Recognition Program, the Arthritis Foundation's initiative on performance measures, the Presbyterian Church's national commitment to pastoral attention to quality, and the National Breast Cancer Coalition's publication series on quality of care. To date, these worthy efforts have not achieved critical mass or synergy with each other. Frequently, they feel called to address particular concerns of interest to their members, rather than systemic issues such as financing or infrastructure. At a minimum, these organizations should create and use a common language to describe quality problems, and explore opportunities for collaborative advocacy of policy or program changes. In addition, qualitative research has indicated a high interest by consumers in participating in a new organization (called, in testing, "Patient Power") to provide patients and caregivers with a forum to express concerns about the quality of health care. Creation of a new organization along these lines should be evaluated.

Possible initiatives:

1. Develop a case statement, educational program, and menu of action opportunities for a grassroots patient/consumer campaign on health care quality.
2. Test the program outline with consumers, consumer organizations, and other potential allies and critics.
3. Develop an organizational plan based on reviewer feedback.

Innovators and visionaries

Citations and examples:

<http://www.madd.org> and <http://www.madd.org/aboutus/0,1056,1814,00.html>
<http://www.nami.org>
<http://www.resultsinternational.org/us/>

Rodwin MA. Consumer protection and managed care: the need for organized consumers. Health Aff (Millwood). 1996 Fall;15(3):110-23.

C2: Intermediary organizations include consumers/patients at every level of governance and redesign

Background

Consumers – often as patients – have been almost completely passive and without influence in shaping the structure or content of health services. Many health care organizations have community boards, but these typically reflect the concerns of local business and philanthropic leadership rather than sufferers and their caregivers and are famously deferential to physician and administrative leadership. Rodwin, Berwick and others have argued that “nothing about me, without me” is an appropriate motto for the next generation of system redesign. Every organization engaged in health care delivery, planning, or policymaking should provide substantial opportunity for consumer governance and the infusion of consumer values, experiences, and opinions in the development of programs. There are some noteworthy models to consider. Group Health Cooperative of Puget Sound is owned and governed by consumer-members. Several employers operate joint management-labor committees to oversee benefits, and these have included some of the most progressive and quality-focused initiatives, including the UAW-Ford-GM-Chrysler collaborative (‘CARS’) and the Boeing-Machinists partnership. The National Association of Insurance Commissioners pays consumers to participate fully on senior guidance committees. Hospital trustees, health plan boards, accreditation agency boards should alter by-laws and procedures to dramatically expand consumer voice. Public purchasers should require contract providers to engage substantial consumer involvement in governance, program, and quality improvement processes, based on those providers’ significant expenditure of public funds.

Possible initiatives:

1. Consumer groups, public purchasers, and employers can advocate strongly and directly for increased representation on boards
2. Consumer organizations could undertake direct action, spot surveys of health care organizations, and other activities to insure proper representation on health care boards and commissions, modeled on the Italian Tribunal for Patient Rights
3. Consumer organizations could undertake surveys of patient health care experiences and publish them to raise awareness of quality issues
4. Quality improvement leaders should engage significant numbers of experienced patients on all health care QI teams

Citations and examples:

Rodwin MA. Consumer voice and representation in managed healthcare. J Health Law 2001 Spring; 34(2): 223-272.

Edington M, Karjalainen T, Hirschland D, Edington DW. The UAW-GM health promotion program. Successful outcomes. AAOHN J 2002 Jan;50(1):26-31.

<http://www.activecitizenship.net/health/pp.htm> (Italian Tribunal for Patients’ Rights)

C3: Intermediaries use common educational, awareness tools with constituents

Background

Intermediaries – ranging from employers to health plans to patient organizations - use a variety of approaches to disseminate health information to their audiences including newsletters, brochures, conferences, e-mails, employer intranets, peer educators, and onsite educational programs. When multiple organizations communicate with a common language and set of messages, the impact on the public is increased. The Leapfrog Group has followed this approach, by commissioning a communications “toolkit” and encouraging each participating organization to use elements it finds appropriate from the kit. The National Health Council has produced a media toolkit for increasing patients’ competence and self-confidence in engaging with the health system, and disseminated it to numerous voluntary health agencies. In a given community, the ideal scenario is that employers, unions, church groups, providers, and consumer advocates are all singing from the same hymnal and achieving a persistent and ubiquitous presence. One comprehensive implementation of this approach was the Stanford Five-City Project, focused on cardiovascular risk factor education.

Possible initiatives:

1. Refine development of messages and standard vocabulary to increase understanding of consumer-centered health care initiatives; create common toolkit
2. Disseminate and promote toolkit to appropriate intermediary organizations
3. Evaluate effectiveness of toolkit elements in increasing awareness, knowledge, or behavior

Citations and examples:

Milstein A, Galvin RS, Delbanco SF, Salber P, Buck CR Jr. Improving the safety of health care: the leapfrog initiative. *Eff Clin Pract* 2000 Nov-Dec;3(6):313-6.

Leapfrog Group jumps at chance to give consumers health care info. *Healthc Benchmarks* 2002 Mar;9(3):25-9.

Flora JA, Lefebvre RC, Murray DM, Stone EJ, Assaf A, Mittelmark MB, Finnegan JR Jr. A community education monitoring system: methods from the Stanford Five-City Project, the Minnesota Heart Health Program and the Pawtucket Heart Health Program. *Health Educ Res* 1993 Mar;8(1):81-95.

Fortmann SP, Flora JA, Winkleby MA, Schooler C, Taylor CB, Farquhar JW. Community intervention trials: reflections on the Stanford Five-City Project Experience. *Am J Epidemiol* 1995 Sep 15;142(6):576-86.

C4: Intermediary organizations increase and coordinate self-care education

Background

Most Americans receive important health information distributed by “intermediary” organizations, including their employer, labor union, church, health plan, and consumer organization. Prominent examples exist of successful self-care education initiatives by such groups, but these are isolated, inconsistent, and not always durable. To support a general culture shift that emphasizes the importance of each individual’s understanding and responsibility for health, these programs should be encouraged, should use consistent and proven messages, and should focus on a few common topics. See <http://healthproject.stanford.edu/publications/index.html>

Possible initiatives:

1. Convene cross-section of self-care advocates and program leaders to develop common public education themes, messages, materials
2. Promote evidence of program effectiveness to key intermediaries for more rapid adoption
3. Involve health plans and professional societies in encouraging physicians to refer patients to self-care education programs
4. Create coordinating council of self-care educators, including major voluntary health agencies, employers, academic centers

Citations and examples:

Fries J, Harrington H, Edwards R, Kent L, Richardson N. Randomized controlled trial of cost reductions from a health education program: The California Public Employees' Retirement System (PERS) Study. *Am J Health Promotion*, 1994. 8(3): p. 216-223.

Lorig K, Mazonson P, Holman H. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis Rheum*, 1993. 36(4): p. 439-446.

Vickery D, Kalmer H, Lowry D, Constantine M, Wright E, Lorea E. Effect of a self-care education program on medical visits. *JAMA*, 1983. 250: p. 2952-2956.

C5: Physicians increase time and resources devoted to patient risk assessment and education

Background

A recent series of reviews has documented the impact of physician assessment of health risks behaviors and the provision of behavior change counseling. Physician counseling appears to be more effective in some areas - such as smoking and alcohol misuse, than others - such as exercise behavior. These studies also reveal that physicians currently perform these services at far below the levels recommended by national guidelines, and rate themselves as least comfortable or prepared to provide them. The growing availability of new communications technology and the importance of health behaviors and self-care make these skills of greater importance. In addition, physician emphasis on health behaviors and self-care supports a continuing shift in public attitudes towards patient and provider roles in improving health.

Possible initiatives:

1. Support continued development of efficient office practice models that allow for appropriate staffing and time availability for counseling
2. Support further research regarding which risk behaviors and which technologies are most amenable to provider intervention
3. Convene payer community to evaluate methods for providing financial reward for effective patient counseling

Citations and examples:

Blumenthal D, Gokhale M, Campbell EG, Weissman JS. Preparedness for clinical practice: reports of graduating residents at academic health centers. *JAMA* 2001 Sep 5;286(9):1027-34.

Dickey LL, Gemson DH, Carney P. Office system interventions supporting primary care-based health behavior change counseling. *Am J Prev Med* 1999 Nov;17(4):299-308.

Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. *Am J Prev Med* 2002 May;22(4):267-84.

Eden KB, Orleans CT, Mulrow CD, Pender NJ, Teutsch SM. Does counseling by clinicians improve physical activity? A summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med* 2002 Aug 6;137(3):208-15.

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Glasgow RE, Orleans CT, Wagner EH. Does the chronic care model serve also as a template for improving prevention? *Milbank Q* 2001;79(4):579-612, iv-v.

Fries JF, Koop CE, Sokolov J, Beadle CE, Wright D. Beyond health promotion: reducing need and demand for medical care. *Health Aff (Millwood)* 1998 Mar-Apr;17(2):70-84.

C6: Mass media shows potential to avoid medical care and morbidity through better health behaviors

Background

While the individual role of mass media in improving health and health-related behaviors is not considered to be especially effective in isolation, it is an important strategy when used in combination with others. Health-specific media messages can intensify perceptions of optimism and fear, change health-related attitudes and beliefs, influence community and peer norms, and serve to change health behaviors in the desired direction. Positive health messages delivered via large-scale media campaigns have been shown to influence individuals' beliefs and lead to personal behaviors that reduce disability, premature mortality, and workers' compensation payments. The advent of new media technologies and media advocacy strategies allows us to better reach the public with programs and messages tailored to the needs and interests of individuals. Messages delivered through the Internet and other modes offer potential for improved efficacy in communicating health risk and changing behaviors. Promoting health and preventing disease is a formidable task that requires a combination of strategies, including positive, relevant, specific, and consistent health messages delivered through multiple mass media.

Possible initiatives:

1. Increase research on how to improve news and entertainment coverage of health issues to positively affect health behavior and health outcomes
2. Fund development, analysis, and demonstrations that measure the impact of health messaging through new media channels on health behavior
3. Educate health promoters, providers and policymakers as to most effective use of mass communication strategies
4. Increase research on ways to effectively target high risk populations through new media technologies

Citations and examples:

Strecher VJ, Greenwood T, Wang C, Dumont D. Interactive media and risk communication. *J Natl Cancer Inst Monogr* 1999;(25):134-9.

Wallack L. Two approaches to health promotion in the mass media. *World Health Forum* 1990;11(2):143-54.

Freimuth V, Cole G, Kirby SD. Issues in evaluating mass-media health communication campaigns. *WHO Reg Publ Eur Ser.* 2001;(92):475-92. Review. No abstract available.

Glik D, Berkanovic E, Stone K, et al. Health education goes Hollywood: working with prime-time and daytime entertainment television for immunization promotion. *J Health Commun.* 1998 Jul-Sep;3(3):263-82.

Brodie M, Foehr U, Rideout V, et al. Communicating health information through the entertainment media. *Health Aff (Millwood).* 2001 Jan-Feb;20(1):192-9.

C7: K-12 curriculum emphasizes responsibility for health maintenance

Background

The growing trend within health education is to encourage positive healthy behaviors, not just avoid negative (i.e., risky) ones. Emphasis in health education curricula should be placed on developing positive, health-related attitudes and behaviors. *Healthy People 2010* includes objectives to increase both nutrition education and injury prevention and control. Project TEACH Health (1999) believes the primary goal of K-12 health education is to teach acceptance of personal responsibility for lifelong health. Students, throughout their health education experience, are to demonstrate ways in which they can enhance and maintain their own health and wellbeing, as well as behaviors that prevent disease and speed recovery from illness. The health education curricula currently taught in schools still emphasize the cessation or prevention of risky behaviors, not the promotion of healthy ones. Although primary students are taught how to eat healthy and exercise, secondary students (adolescents) receive only limited health education addressing the negative influences of sex, drugs, alcohol, and smoking. These prevention-based programs have limited short-term effect on avoiding risky behaviors. Peer and family behavior, not education, are the primary predictors of negative health behavior in adolescents.

Possible initiatives:

1. Emphasize that students are the key owners of their bodies, and are thus their own "first doctor" when it comes to assessing their health and well-being
2. Teach older students how to search for quality health information on the Internet for both research and health education purposes
3. Add curricula and parent materials that directly addresses the importance of doctor "well visits"
4. State mandate/recommendation that schools teach the suggested "health literacy" agenda, financial matching incentives to add programs

Citations and examples:

Novello, AC, et al., (1992). Healthy children ready to learn: An essential collaboration between health and education. *Public Health Reports*, 107 (1), 3-14.

California State Board of Education (1994). Health Framework for California Public Schools Kindergarten Through Grade Twelve.

Collins, J L, et al. (1995). School Health Education. *Journal of School Health*, 65, 302-311.

Feldman, E (1990). *At the Threshold: The Developing Adolescent*. Cambridge, MA: The Harvard University Press.

C8: Public reporting systems (e.g., HealthyPeople, HEDIS) increase awareness of national progress

Background

The U.S. government and industry groups invest substantially in public health surveillance systems that provide valuable indices of progress towards national health goals. Some ambitious goals, such as the Healthy People 2000 and Healthy People 2010 projects, influence programs and funding at the state and county level, but still remain largely visible only to public health and policy experts. For consumers to become more responsible for their own health, they must both appreciate the gap that exists between current health status and health behaviors and what's possible, and the concrete steps they can take to reduce that gap. National reporting systems can be exploited to "tell a story" about how we are doing as a nation, as institutions, and as individuals. The story we tell must be orchestrated to raise awareness and motivate individuals to demand changes in national priorities, the performance of health care organizations, and the behavior of each other. The changes in smoking prevalence since 1970 suggest the value of this approach, and the evolution of the smoking cessation movement even into the doctor's office and medical record suggest a way to move from esoteric public health information to specific culture and behavior change.

Possible initiatives:

1. Select key indicators for visible media and advocacy promotion
2. Create national campaigns to motivate individuals, purchasers to drive improvement on tracked indicators
3. Establish health care quality measures linked to provider interventions relevant to indicators

Citations and examples:

Fiore MC, Pierce JP, Remington PL, Fiore BJ. Cigarette smoking: the clinician's role in cessation, prevention, and public health. *Dis Mon* 1990 Apr;36(4):181-242.

Fiore MC. U.S. public health service clinical practice guideline: treating tobacco use and dependence. *Respir Care* 2000 Oct;45(10):1200-62.

Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. *Am J Prev Med* 2002 May;22(4):267-84.

Orleans CT, Abrams DB, Gruman JC. Will healthcare take tobacco addiction seriously? Using policy to drive practice. *MedGenMed* 2001 Mar 30;3(2):15.

NCQA. State of Health Care Quality: 2003. September 2003.

C9: Patients aware of true costs of all health services and understand impact of others' spending on insurance design and price

Background

About 85 percent of Americans have health insurance that directly pays claims to providers and hospitals, and as such, most consumers are sheltered from knowing the true cost of the health care they receive. It is unlikely that people will demand a more responsive and responsible health system if they are insulated from either knowing or sharing in costs. We do know that out-of-pocket co-payments for office visits, pharmacy, and hospital visits reduces utilization of both necessary and discretionary health care services, especially among low-income populations. In a consumer-centered system, the honest disclosure of information, including cost information and awareness, is viewed as imperative if we are to individually and collectively give people the tools they need to make more thoughtful, better-informed, and quality-based health and health care choices.

Possible initiatives:

1. Increase understanding of level of cost awareness among consumers
2. Fund development, analysis, and demonstrations that measure the effects of cost awareness on type and quality of health care delivered, expected, and received
3. Evaluate the effect of cost awareness in publicly financed health care programs

Citations and examples:

Schafheutle EI, Hassell K, Noyce PR, Weiss MC. Access to medicines: cost as an influence on the views and behavior of patients. *Health Soc Care Community*. 2002 May;10(3):187-95.

Levy RA. Prescription cost sharing: economic and health impacts, and implications for health policy. *Pharmacoeconomics* 1992 Sep;2(3):219-37.

Lubalin JS, Harris-Kojetin LD. What do consumers want and need to know in making health care choices? *Med Care Res Rev*. 1999;56 Suppl 1:67-102.

Garnick DW, Swartz K. Meeting information needs: lessons learned from New Jersey's Individual Health Insurance Reform Program. *Med Care Res Rev*. 1999 Dec;56(4):456-70.

Isaacs SL. Consumer's information needs: results of a national survey. *Health Aff (Millwood)* 1996 Winter;15(4):31-41.

Lubalin JS, Harris-Kojetin LD. What do consumers want and need to know in making health care choices? *Med Care Res Rev*. 1999;56 Suppl 1:67-102.

Cunningham PJ, Denk C, Sinclair M. Do consumers know how their health plan works? *Health Aff (Millwood)*. 2001 Mar-Apr;20(2):159-66.

Thompson AM, Rao CP. The need for consumer behavior analysis in health care coverage decisions. *Health Mark Q*. 1990;7(1-2):97-114.

C10: President leads and adopts language defining objectives of Medicare, other public sector health commitments

Background

Medicare was initially proposed as an anti-poverty federal financing program, and its design did not anticipate today's concerns about safety and quality of care. While contemporary political leaders often endorse the role of Medicare in providing "high quality" care for older Americans, there is no public understanding of the program's role in assuring quality, nor is there a common definition of quality. As the basis for future reform, the President should publicly declare the purposes of the Medicare program and our society's expectations for it. This approach has been useful in other arenas, including use of national lands and education.

Possible Initiatives

1. President gives major policy speech outlining objectives for a reformed health care system
2. Advocacy organizations focus Congressional attention on ability of health care system to achieve attributes defined by President

Citations and examples:

Bloice C. Medicare's spin cycle. *Revolution* 2002 Mar-Apr; 3(2):4-5.

Boufford JI. Crisis, leadership, consensus: the past and future federal role in health. *J Urban Health* 1999 Jun; 76(2): 192-206.

Lundberg GD. John P. Peters and the committee of 430 physicians. *Yale J Biol Med* 2002 Jan-Feb;75(1):23-7.

Wagner L. Ambitious goals, political shoals. *Mod Healthcare* 1992 Nov 16;22(46): 18,20.

C11: National dialogue on principles of healthy society: what's shared responsibility, what's personal

Background

Although we live in an increasingly diverse society, the country is able to coalesce around critical social issues. For example, in the last two decades, tobacco use and drunk driving have commanded public attention, and citizens have found general agreement around how society should deal with these problems. Identifying a common vision around health care is equally imperative. In order to move forward, we must enlist the American public in an effort to identify shared values and principles around our health care system.

The health objectives outlined in *Healthy People 2010* were developed by the federal government with significant input from the Healthy People Consortium—an alliance of more than 600 national membership organizations, state health, mental health, substance abuse, and environmental agencies. Through a series of regional and national meetings and an interactive Web site, the government received more than 11,000 public comments on the draft objectives. This large scale initiative works through partnerships, a set of shared objectives and widespread dissemination.

In Canada, the Commission on the Future of Health Care has undertaken a program of public education and deliberation on the complex trade-offs in the health care system. A carefully designed public education and input process is playing out, involving television programming, community meetings, interactive Web sites and citizen "workbooks", and survey data evaluating citizen responses to difficult policy decisions. Susan Goold at the University of Michigan has developed the CHAT game, to allow Americans from across the socioeconomic spectrum to understand and weigh in on the values trade-offs implied in benefit designs. And, a decade ago, the Oregon Health Plan successfully used a large-scale public involvement process to make a potentially controversial policy change understandable and acceptable to the general public.

These efforts, as well as progress on equally pressing and complex social issues, illustrate that it is possible to find common ground with proper effort and leadership.

Possible Initiatives:

1. Begin a national dialogue on health care reform, starting at a regional level if necessary
2. Support broader and more public dissemination of Healthy People 2010 objectives
3. Support research and initiatives around dissemination of shared principles, once identified

Innovators and visionaries

Citations and examples:

Brodeur D. The search for ethical symmetry in health care reform: individual preference vs. societal need. *Issues (St Louis Mo)* 1993 May-June; 8(3):1-8.

Jays MV. Population health promotion: responsible sharing of future directions. *Can J Public Health* 1999 Nov-Dec; 90 Suppl 1:S15-7.

Sheila Burke, Eric Kingson, and Uwe Reinhardt, Editors. *Social Security and Medicare: Individual versus Collective Risk and Responsibility* (2000).

Infrastructure

- I1: National health information infrastructure and personal health record architecture implemented; federally funded providers required to implement necessary systems
- I2: Mandatory publication of performance data by all federally funded health care organizations;
- I3: Professional licensure, accreditation, authorization to prescribe support informed patient; CME, certification, boards address patient-centered care;
- I4: K-12 curriculum treats health as major national commitment, like defense or environment.

I1: National health information infrastructure and personal health record architecture implemented

Background

Analysts have bemoaned the sluggish adoption of information technology in health care for over 20 years. Many experiments have been launched, including institutional electronic medical records, community-wide CHINs, e-mail care, and telemedicine. The highly fragmented nature of our delivery and financing systems have inhibited adoption of interoperable systems, and continuing conflict over ownership of and access to the patient's medical record cannot be resolved absent a shared infrastructure and common data standards. Today, an individual's medical record may be scattered across dozens of offices throughout the country, may be handwritten or stored in idiosyncratic and inaccessible digital systems, and may contain contradictions or errors that are hidden from view. In situations ranging from needing critical information during emergency care to sharing routine self-monitoring data with primary providers, our health system is paralyzed. Virtually every worthwhile consumer-oriented delivery system reform is blocked by our inability to transfer information between patients, providers, and other key partners in health care. Every service in modern society – finance, transportation, public safety, environmental monitoring – is linked by an efficient, sophisticated, secure information infrastructure – except health care. Only the federal government, working in partnership with private sector organizations, can put in place an infrastructure that will permit reengineering of the health care delivery system. The implementation of the NHII should include significant consumer involvement, and careful attention to ensuring consumer ownership, control, and privacy of the personal health record.

Possible initiatives:

1. Establish a public-private workgroup on the national health information infrastructure with at least one-third consumer representation
2. Create a National Institute of health information and technology of comparable stature and funding as a NIH institute
3. Educate legislators, policy advocates, and industry leaders on the urgency of NHII implementation
4. Create contractual, tax, capital (e.g., Health Information Technology and Quality Improvement Act of 2001 (S.705)) or other incentives for rapid adoption of relevant NHII components across health care sector

Innovators and visionaries

Citations and examples:

National Committee on Vital and Health Statistics. Information For Health: A Strategy For Building The National Health Information Infrastructure. Washington, D.C. November 15, 2001. <http://ncvhs.hhs.gov/nhiilayo.pdf>

Markle Foundation. Connecting for Health. Personal Health Working Group Final Report. July 1, 2003. http://www.connectingforhealth.org/resources/phwg_final_report.pdf.

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.

I2: Mandatory publication of performance data by all federally funded health care organizations

Background

The design of health services and the behavior of health care providers appear to be largely shaped by reimbursement, by professional culture, and by public scrutiny. None of these factors today reflect the values and needs of patients and families. While there is almost universal advocacy for increased transparency and disclosure of performance data, there has been less discussion regarding the content of such disclosures. One means of expediting the shift to a consumer-centered health system is to allow the public to examine the degree to which their needs and values are being served by provider organizations and professionals. The Institute of Medicine, congressional leaders, and many states have recognized that transparency is essential to support health system improvement. Advocates of market-based models also believe that providing consumers with comparative information on the performance of individual hospitals, plans, or doctors will create competition on quality. A few states, such as New York and Rhode Island, have statutory requirements for the publication of such data. Some industry organizations, such as the JCAHO and NCQA, have published comparative information. The Medicare-plus-Choice program requires its managed care contractors to publish standardized satisfaction data. For these well-intentioned efforts to support consumer-centered reform, two adjustments are necessary. First, reporting systems must be mandatory and universal; second, they must involve disclosure of the information that consumers and patients most value and find most useful.

Possible initiatives:

1. Require that any provider or insurance carrier receiving federal funds report to the public on the quality, safety, and effectiveness of the services provided
2. Encourage states to pass mandatory reporting legislation
3. Establish attributes of mandatory reporting systems, including majority consumer involvement, public distribution, and penalties for non-participation or data manipulation

Citations and examples:

Lansky D. Improving quality through public disclosure of performance information. *Health Aff (Millwood)*. 2002 Jul-Aug;21(4):52-62.

Chassin MR, Hannan EL, DeBuono BA. Benefits and hazards of reporting medical outcomes publicly. *N Engl J Med*. 1996 Feb 8;334(6):394-8.

Chassin MR. Achieving and sustaining improved quality: lessons from New York State and cardiac surgery. *Health Aff (Millwood)*. 2002 Jul-Aug;21(4):40-51.

I3: Professional licensure, accreditation, authorization to prescribe support informed patient

Background

The U.S. employs a variety of structural mechanisms to assure safe care, including physician licensing, requirements for continuing education, accreditation and certification, and specialty board exams. Despite these systems, comprehensive national reviews find high rates of errors, high proportions of poor care, and low conformity to evidence based guidelines. Inevitably, these structural measures once intended to assure competence and safety have become means to protect guild privileges and revenues, and they reinforce the retention of power by a few elitists at the exclusion of patients and other health professionals. In each field, the development of a more patient- and family-centered system should involve a reassessment of the scope of these structural protections. The U.K. has created a new class of legally authorized "dependent (or supplementary) prescribers" who may prescribe less dangerous medications and those related to a particular area of expertise. Patient response to nurse prescribing has been very positive: in one study patients "agreed with providing patient-centered services and the renegotiation of traditional roles".

Much of U.S. health care is self-regulating, often reflecting the history of guild-like professional associations. The standards established by professions and trade associations rarely reflect the values, preferences, or competencies of patients and caregivers. Rarely do they require proficiency at patient-centered skills in order to retain accreditation or certification. The ABIM recently proposed inclusion of extensive measures of patient-centered care within the board recertification process, but these proposals were not implemented. ACGME has also outlined medical education competencies that begin to address these domains. All societies and associations that establish and enforce standards for professional competencies or performance should be expected to incorporate standards for patient- and consumer-centeredness.

In the U.S., the Medicare program deems any hospital that has been accredited by the JCAHO to have met minimum standards for participation and reimbursement. Yet a series of Inspector General studies has condemned the laxness of this system and encouraged HCFA to make changes. The recommended changes might induce modest changes in basic safety and accountability, but these in turn should be strengthened with accountability to consumers and their concerns.

Possible initiatives:

1. Convene consumer-professional task force to define competencies of patient-centered care and promulgate results to appropriate organizations
2. Collaborate with patient and consumer organizations to encourage professional societies to adopt and monitor such standards

3. Convene a high-level commission to re-examine state and federal scope of practice requirements with particular attention on prescribing privileges, including a possible Model Act for consideration by NAIC or NCSL
4. Require the JCAHO to involve consumers in the definition of accreditation requirements and include stringent consumer-centered care criteria and mandatory public disclosure of serious adverse events and standardized performance data as a condition of accreditation
5. Publish performance data regarding compliance of both associations and individual providers with adopting patient-centered competencies

Citations and examples:

Department of Health (UK). Review Of Prescribing, Supply & Administration Of Medicines. Final Report. March 1999.

[The External Review of Hospital Quality: The Role of Accreditation \(OEI-02-97-00051; 7/99\)](http://oig.hhs.gov/oei/reports/oei-01-97-00051.pdf)
<http://oig.hhs.gov/oei/reports/oei-01-97-00051.pdf>

Wasserman SI, Kimball HR, Duffy FD. Recertification in internal medicine: a program of continuous professional development. Task Force on Recertification. *Ann Intern Med* 2000 Aug 1;133(3):202-8.

Brooks N, Otway C, Rashid C, Kilty L, Maggs C. Nurse prescribing: what do patients think? *Nurs Stand*. 2001 Jan 10-16;15(17):33-8.

Munding MO, Kane RL, Lenz ER, Totten AM, Tsai WY, Cleary PD, Friedewald WT, Siu AL, Shelanski ML. Primary care outcomes in patients treated by nurse practitioners or physicians: a randomized trial. *JAMA* 2000 Jan 5;283(1):59-68.

Cooper RA, Henderson T, Dietrich CL. Roles of nonphysician clinicians as autonomous providers of patient care. *JAMA*. 1998 Sep 2;280(9):795-802.

I4: K-12 curriculum treats health as major national commitment, like defense or environment

Background

Health education scholars recognize that creating healthy children requires serious commitment from the school system, families and the larger community. Despite the necessity of a holistic community approach to health, students are not made aware of how society acts and reacts to the health of its individuals. Nor are they made aware of how their health is, in part, dependent on laws and government policies. Students are taught about their own health – both how to maintain good health and stay away from risky behaviors – but not about the role health plays in society, society plays in health. None of the four unifying ideas of health literacy or the nine major content areas of health education address health as a political or social issue. Health care comprises approximately 15 percent of the U.S. economy, involves over \$360 billion of government spending, and employs about 20 million Americans, but is not treated as an important social and economic system within the K-12 curriculum despite the mandatory “health” programming in most states.

Possible initiatives:

1. Add curricula in both health and U.S. government education that discusses how health, health care and insurance coverage are issues of political and economic importance in our government
2. Draft accessible and understandable pamphlets on government spending related to health care, national insurance coverage, and other health-related political issues
3. Create an educational PBS mini-series on current political issues relating to health and health care for in-class discussions

Citations and examples:

California State Board of Education (1994). Health Framework for California Public Schools Kindergarten Through Grade Twelve.

Center for Disease Control and Prevention. FastStats: Health Insurance Coverage. <http://www.cdc.gov/nchs/hus.htm>.

Heffler, S., et al. (2002). Health spending projections for 2001-2011: The latest outlook. Health Affairs, March/April, 207-218.

ADDITIONAL PERSON-CENTERED STRATEGIES

- A1: New (and existing) membership organizations advocate for improved quality required to implement necessary systems
- A2: Mass media depicts importance of informed decision making
- A3: Media covers social and policy determinants of health in ways comparable to coverage of medical technology
- A4: Physicians ensure full patient understanding of financial implications of decisions
- A5: Intermediary organizations educate consumers on importance of insurance pool, harms of cost-shifting, as cost-sharing/defined contribution grows
- A6: Intermediary organizations participate in common campaign on societal, moral hazards of continued lack of adequate coverage
- A7: Publicly financed coverage rewards positive health behaviors
- A8: Public financing rewards positive health outcomes, discourages "silo" management and incentives

A1: New (and existing) membership organizations advocate for improved quality

Background

Membership organizations, such as AARP, disease advocacy groups and faith-based organizations, have unique access to significant numbers of people. These groups can play key roles in empowering consumers to actively participate in their health care. A number of scattered initiatives have shown promise, including AARP's WiseRx program to educate consumers about medication use, the American Diabetes Association/NCQA Provider Recognition Program, the Arthritis Foundation's initiative on performance measures, the Presbyterian Church's national commitment to pastoral attention to quality, and the National Breast Cancer Coalition's publication series on quality of care. To date, these worthy efforts have not achieved critical mass or synergy with each other. Frequently, they feel called to address particular concerns of interest to their members, rather than systemic issues such as financing or infrastructure. At a minimum, these organizations should create and use a common language to describe quality problems, and explore opportunities for collaborative advocacy of policy or program changes. In addition, qualitative research has indicated a high interest by consumers in participating in a new organization (called, in testing, "Patient Power") to provide patients and caregivers with a forum to express concerns about the quality of health care. Creation of a new organization along these lines should be evaluated.

Possible Initiatives:

1. Evaluate creation of new membership organization devoted to consumer experiences in health care
2. Hold educational forums to educate membership organizations about quality of care issues
3. Support creation and testing of messages and materials organizations can distribute to members
4. Support pilot programs for organizations to test strategies for engaging their membership in the health care they receive

Citations and examples:

Delbianco T, Berwick DM, Boufford JI et al. Healthcare in a land called PeoplePower: nothing about me without me. *Health Expect* 2001 Sep;4(3):144-50.

Lang LA, Shannon TE. Value and choice: providing consumers with information on the quality of health care. Conference overview. *Jt Comm J Qual Improv* 1997 May; 23(5):231-8.

Quality of care: giving consumers a say. *States Health* 2001 Winter; 11(1):1-8.

Rotheram-Borus MJ, Rebchook GM, Kelly JA, Adams J, Neuman MS. Bridging research and practice:community-researcher partnerships for replicating effective interventions. *AIDS Educ Prev* 2000; 12(5 Suppl):49-61.

Sabin JE, Daniels N. Managed care: strengthening the consumer voice in managed care: III. The Philadelphia Consumer Satisfaction Team. *Psychiatr Serv.* 2002 Jan;53(1):23-4, 29.

A2: Mass media depicts importance of informed decision making

Background

Worldwide, as a result of marketing efforts, public health promotion and literacy efforts, and dwindling health resources, there is new effort to form partnerships between health service providers, individuals and families, health educators, and the mass media to improve health and health care. The media is a unique and effective channel for health and patient education as it incorporates elements of self-management, empowerment, and cost-effectiveness, with the increased probability of improving the quality of life for individuals and entire communities. The media, when used as a tool to effect health, can result in increased capacity for informed decision making that helps individuals to control certain factors that determine health and improve health outcomes. The research literature in this area reminds us that the conventional electronic media can have a significant, positive, and determining effect on teenage eating patterns, AIDS/HIV related behaviors, participation in prenatal testing and counseling programs, selection of prostate cancer treatment methods, and pregnancy termination options. This is not just a trend in the U.S. and Europe - consider women attending an antenatal clinic in rural Nigeria who report that the most common source of information that led to the informed selection of a specific family planning method was the electronic media (40.5 percent).

Possible initiatives:

1. Increase research on ways that news and entertainment coverage of health issues could be improved to positively impact informed decision making in health and health care
2. Fund development, analysis, and demonstrations that measure the impact of health messaging through new media channels on informed decision making in health and health care
3. Educate health promoters, providers and policymakers about the role of the media in advancing informed decision making in health and health care
4. Increase media/communication/health promotion research on ways to effectively target high health risk populations, especially racial and ethnic minorities, to practice informed decision making in health and health care as a result of exposure to popular mass media

Citations and examples:

Levin-Zamir D, Peterburg Y. Health literacy in health systems: perspectives on patient self-management in Israel. *Health Promot Internation* 2001 Mar;16(1):87-94.

Story M, Neumark-Sztainer D, French S. Individual and environmental influences on adolescent eating behaviors. *J Am Diet Assoc* 2002 Mar;102(3 Suppl):S40-51.

Marteau TM, Dormandy E. Facilitating informed choice in prenatal testing: how well are we doing? *Am J Med Genet* 2001 Fall;106(3):185-90.

A3: Media covers social and policy determinants of health in ways comparable to coverage of medical technology

Background

Mass media coverage of new health technologies has “sizzle,” responds to advertiser interests, and imparts support for our growing medical industrial enterprise. Media treatment of health innovation offers a vision of scientific grandeur and immortality, in simple-to-understand language, to members of the broader society. While educators and journalists have a role in communicating the achievements of science and medical technology, journalism should be encouraged to present such developments in a complete social, economic, and policy context. As evidenced by the very effective “Harry and Louise” campaign ads during the ‘93-‘94 healthcare reform debate, there is potential to bring relevant consumer-focused health issues to the public via the media as a strategy to inform, focus, and positively redirect health policy and health care.

Possible initiatives:

1. Teach citizens and health advocates media advocacy strategies to influence media coverage to include social and policy issues that impact health and health care
2. Fund development, analysis, and demonstrations that utilize community pressure to demand media coverage of social and policy determinants of health and health care
3. Increase research on ways to encourage the media to focus on social and policy determinants of health and health care

Citations and examples:

Handrix MJ, Campbell PW. Communicating science: from the laboratory bench to the breakfast table. *Anat Rec* 2001 Aug 15;265(4):165-7.

Mannisto M. Public press focuses on advances in medical research/technology. *Hospitals* 1980 Dec 16;54(24):65-8.

Jacobs LR. Manipulators and manipulation: public opinion in a representative democracy. *J Health Polit Policy Law* 2001 Dec;26(6):1361-74.

De Castro LD. Transporting values by technology transfer. *Bioethics* 1997 Jul-Oct;11(3-4):193-205.

Keenan DP, AbuSabha R, Robinson NG. Consumers’ understanding of the Dietary Guidelines for Americans: insights into the future. *Health Educ Behav* 2002 Feb;29(1):124-35.

Goldsteen RL, Goldsteen K, Swan JH, Clemena W. Harry and Louise and health care reform: romancing public opinion. *J Health Polit Policy Law* 2001 Dec;26(6):1325-52.

A4: Physicians ensure full patient understanding of financial implications of decisions

Background

Several studies in the U.S. and Europe have found that practicing physicians have a limited understanding of medical care costs. Doctors often report inaccurate knowledge of the costs of services, drugs, and durable medical goods. They are similarly misinformed about the cost of diagnostic tests and tend to overuse tests and treatments that do not improve health. Listing costs of drugs and services can reduce expenses and improve consistency of care and decrease the use of more expensive medications. Little is known about whether strong cost awareness by providers contributes to or detracts from the quality of care dispensed. However, it may be a difficult balancing act to maintain the benefits of cost awareness without negatively impacting some aspects of high quality care.

Possible initiatives:

1. Increase knowledge of health services costs among providers, and increase provider comfort in counseling patients regarding costs of decision options
2. Evaluate the effect of cost-conscious decision making on quality of care and outcomes
3. Assist providers in communicating relevant cost information to patients and families

Citations and examples:

Allan GM, Innes G. Family practice residents' awareness of medical care costs in British Columbia. *Fam Med* 2002 Feb;34(2):104-9.

Conti G, Dell'Utri D, Pelaia P, Rosa G, Cogliati AA, Gasparetto A. Do we know the costs of what we prescribe? A study on awareness of the cost of drugs and devices among ICU staff. *Intensive Care Med* 1998 Nov;24(11):1194-8.

Do your staff know the cost of pharmaceuticals and lab tests? *ED Manag* 1999 Sep;11(9):97-100.

A5: Intermediary organizations educate consumers on importance of insurance pool, harms of cost-shifting, as cost-sharing/defined contribution grows

Background

Employers learned, during the 1980s, that when each player in U.S. health care focused only on optimizing its own benefit costs, disastrous societal consequences ensued: cost-shifting, increased uninsurance, and so on. Yet, as they begin to implement defined contribution and similar models, they risk creating a population of consumers with similarly simplistic views.

Consumers will need to develop a degree of health and financial literacy if they are to be both effective on their own behalf and also play a responsible role in contributing to the social insurance pool. Intermediary organizations need a coordinated public education strategy that addresses basic health insurance theory and the societal need for pooling risk in a community. With the drive towards elaborate cost-sharing schemes, multiple layers of choice, numerous trade-offs, flexibility of benefits, cash balance options, plan hybridization, etc., it is even more important that today's consumers understand the issues, real costs, implications for quality, potential hidden pitfalls, and benefits of one plan over another.

Possible initiatives:

1. Increase research on best practice education strategies that teach information and skills to consumers on insurance theory and flexible health benefits
2. Fund development, analysis, and demonstrations that measure the effect of these best practice educational interventions on individual and group behavior
3. Educate employers, health promoters, providers and policymakers about the important role of consumer benefits/insurance education and effects on individual and community health

Citations and examples:

Jerussi M, Savan J. Educating employees on defined contribution health care: the time is right for an employee-empowering approach. *Benefits Q* 2000;16(4):63-8.

Miller L. The ongoing growth of defined contribution and individual account plans: issues and implications. *EBRI Issue Brief* 2002 Mar;(243):1-17.

Borland M, Smith C, Nankivil N. A community quality initiative for health care reform. *Manag Care Q* 1994 Winter;2(1):6-16.

Sofaer S. How will we know if we got it right? Aims, benefits, and risks of consumer information initiatives. *Jt comm. J Qual Improv* 1997 May;23(5):258-64.

Scahill P, Wiley P. Making a successful transition to cash balance. Using employee choice and financial education. *Benefits Q* 2000;16(4):57-62.

Nyman JA. Theory of health insurance. *J Health Adm Educ.* 1998 Winter;16(1):41-66.

A6: Intermediary organizations participate in common campaign on societal, moral hazards of continued lack of adequate coverage

Background

Effective health activism requires a clear new message and many channels and messengers, including business, education, media, community policy leaders, employers and unions, health care entities and providers, and consumers. When collective efforts by these entities speak the same message via multiple channels using effective messengers, the result is to increase the rate of change for a particular issue to the "tipping point." We have recently seen significant changes for the good as a result of midstream efforts to prevent smoking, increase awareness of and reduce incidence of HIV/AIDS, screen for and detect early breast cancer, fully immunize children and high-risk adults, educate the public about domestic violence, and make communities and cars safer. A similar strategy could slow or reverse the increasing rate of uninsurance among the chronically unemployed and low-income workers.

Possible initiatives:

1. Make a link for "regular citizens" between health insurance status, cost, and quality-of-life
2. Fund development, cost-benefit analysis, and community demonstrations that develop effective coalitions to reduce uninsurance
3. Increase understanding, through qualitative and quantitative research, on community coalition-building for reducing uninsurance

Citations and examples:

Cunningham PJ. Targeting communities with high rates of uninsured children. Health Aff (Millwood) 2001;Suppl Web Exclusives:W20-9.

Ballantyne R 3rd. The challenge ahead. With local partners, health systems take up the gauntlet against uninsurance. Mod Healthc 1998 Jan 26;28(4):42.

Appleby C. Detroit: Intersection of business, health care and community activism. Manag Care 1977 Mar;6(3):79-80.

Worden JK. Research in using mass media to prevent smoking. Nicotine Tob Res 1999;(1 Suppl 1):S117-21.

Wakefield M, Chaloupka F. Effectiveness of comprehensive tobacco control programmes in reducing teenage smoking in the USA. Tob Control 2000 Jun;9(2):177-86.

Myhre SL, Flora JA. HIV/AIDS communication campaigns: progress and prospects. J Health Commun 2000;5 Suppl:29-45.

Lerner BH. Breast cancer activism: past lessons, future directions. Nat Rev Cancer 2002 Mar;2(3):225-30.

Perz JF, Craig AS, Coffey CS, Jorgensen DM, Mitchel E, Hall S, Schaffner W, Griffin MR. Changes in antibiotic prescribing for children after a community-wide campaign. JAMA 2002 Jun 19;287(23):3103-9.

A7: Publicly financed coverage rewards positive health behaviors

Background

While there are differences of academic opinion as to the timing and amount of reward, as well as the duration and permanence of the health behavior change, there is a growing body of research literature that strongly supports the hypothesis that positive incentives (or rewards) promote desired health behaviors, decrease health care costs, and reduce the likelihood of poor health outcomes. Researchers have clearly demonstrated that for participants in publicly financed health care programs, cash and other tangible positive rewards are effective in producing desired health behaviors, e.g., participation in dental health screening programs, adolescent postpartum compliance, biochemically-confirmed smoking cessation among pregnant and post-partum women, child immunization, and adherence to prolonged tuberculosis treatment. Each Medicare and state Medicaid program administrator recognizes the need for cost-effective, health promoting care-delivery systems, but none have routinely integrated innovative reward/incentive strategies, and corresponding cost savings, into on-going public programs.

Possible initiatives:

1. Provide strategies for states to undertake large-scale demonstration projects to determine the cost-savings and health outcomes associated with publicly financed health programs that reward positive health behaviors from participants
2. Tie increased state Medicare reimbursement rates to states that reward positive health behaviors
3. Educate health promoters, providers and policymakers about the effect of rewards and positive incentives on the health behavior of low-income participants in publicly financed health care programs
4. Undertake community-based communication research to understand the best messages and channels to inform the public about the cost-saving and health-promoting role of rewards and positive incentives in publicly financed health programs

Citations and examples:

Reiss ML, Bailey JS. Visiting the dentist: a behavioral community analysis of participation in a dental health screening and referral program. *J Appl Behav Anal* 1982 Fall;15(3):353-62.

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A8: Public financing rewards positive health outcomes, discourages “silo” management and incentives

Background

The IOM Quality Chasm report noted that public financing systems – including Medicare FFS, most Medicaid, and public employee programs such as FEHB – provide no financial reward for high quality, patient-centered care. Indeed, many reimbursement policies offer a perverse incentive to excess utilization or even provide higher payment for failed ambulatory care or inpatient care that results in complications. Numerous validated outcome measures exist that could be used to recognize and reward systems and providers that use innovative, patient-centered approaches to achieve optimal health outcomes. Giving rewards for positive health outcomes has been effective in evoking positive results in the treatment of serious mental disorders, nursing home care, high-risk pregnancies, asthma control, and community-based oral health improvement initiatives. Some private sector purchasers are experimenting with “pay-for-performance” (see section 2.b.iii) but such efforts will be more effective if the very large public programs use similar incentives and send a common signal to providers and health plans.

Possible initiatives:

1. Increase research on application of validated outcome measures in the health system and community settings
2. Fund development, analysis, and demonstrations that use randomized controlled trials to measure effect of rewards/incentives to elicit best practice in the health care and community-based settings
3. Create common outcomes-based financial incentives across bureaucratic budget boundaries (e.g., Medicaid, state mental health, education systems)
4. Increase local participation in “tried and true” and innovative community-based programs to improving health outcomes and preventing morbidity using rewards and incentives

Citations and examples:

Berenson RA. Medicare+Choice: doubling or disappearing? Health Aff (Millwood) 2002;Suppl:W65-82.

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Jowers JR, Schwartz AL, Tinkelman DG et al. Disease management program improves asthma outcomes. Am J Manag Care 2000 May;6(5):585-92.

Chapin R, Silloway G. Incentive payments to nursing homes based on quality-of-care outcomes. J Appl Gerontol 1992 Jun;11(2):131-45.

Appendix II
A Model for Coordinating Multiple Interventions Supporting
Person-centered Health Care Reform

THE THREE LEVELS OF INTERVENTION

Meaningful changes in the ability of the health system to improve health will require a comprehensive strategy that encompasses a number of complementary activities. Some of these are “supply-side” interventions that emphasize patient-centered care and others are “demand-side” interventions that would increase consumers’ ability to make informed choices among their health care options or alter their own health behaviors. McKinlay’s² population model – crafted to organize a diverse set of interventions for increasing physical activity among older adults – is a useful paradigm for thinking about strategies to accelerate the evolution towards a consumer-centered health care system. It is worthwhile to apply a model of this kind for several reasons:

- Each activity that is advocated by a particular reformer or interest group has merit, but needs to be assessed both in comparison with and as it interacts with other supportive activities;
- Over-emphasis of any one strategy at the expense of a balanced approach is unlikely to prove effective;
- Evaluation of our ability to achieve overall goals requires understanding both the contribution of each activity and their collective impact;
- Fundamental messages, themes, and tools should be utilized in a common fashion across all activities to encourage more widespread understanding and adoption;
- Lessons learned from individual activities should be disseminated across all activities.

McKinlay argued that important changes required simultaneous activities at three levels of society:

1. Downstream: changes in individual behavior
2. Midstream: changes to the behavior of community organizations and other intermediaries – such as employers, health plans, or labor unions
3. Upstream: changes to the national policy environment.

A key premise of McKinlay’s argument for our purposes is the caution that over-emphasis of “downstream” interventions – meaning individual-level interventions with the intention of altering personal attitudes or behavior – is not likely to be sufficient. In the case of consumer-centered health care, there is even reason to worry that downstream interventions alone could be counter-productive to the larger social goals of improved population health. Current proposals for defined contribution benefit plans, Internet-based decision support, medical savings accounts and so on increase the likelihood that healthy, affluent Americans will opt out of the social insurance pool and exacerbate the existing disparities in access to health resources by less “empowered” people. Paradoxically, the shift to a more consumer-centered

² McKinlay JB. “The New Public Health Approach to Improving Physical Activity and Autonomy in Older Populations”, in *Preparation for Aging* (E. Heikkinen, editor) (Plenum Press, NY, 1995), pp. 87-103.

health system is currently symbolized and encouraged by those downstream activities, which may ultimately be most detrimental to improving population health. In any case, use of McKinlay's model can help us to analyze and mitigate these risks.

Applying the McKinlay Model

1. Downstream interventions

Individuals need to be provided with specific, personal tools that enable them to:

- a) select providers or insurance plans most likely to meet their needs and deliver high quality care
- b) understand what good care is and know how to demand it
- c) know what actions they can take to improve their own health

2. Midstream interventions

Intermediary organizations (including employers, unions, patient and consumer organizations, local media, medical groups, health plans) can offer services to selected populations. These interventions can increase awareness and create an environment in which consumer-centered health care is enabled. Key functions of this midstream level include:

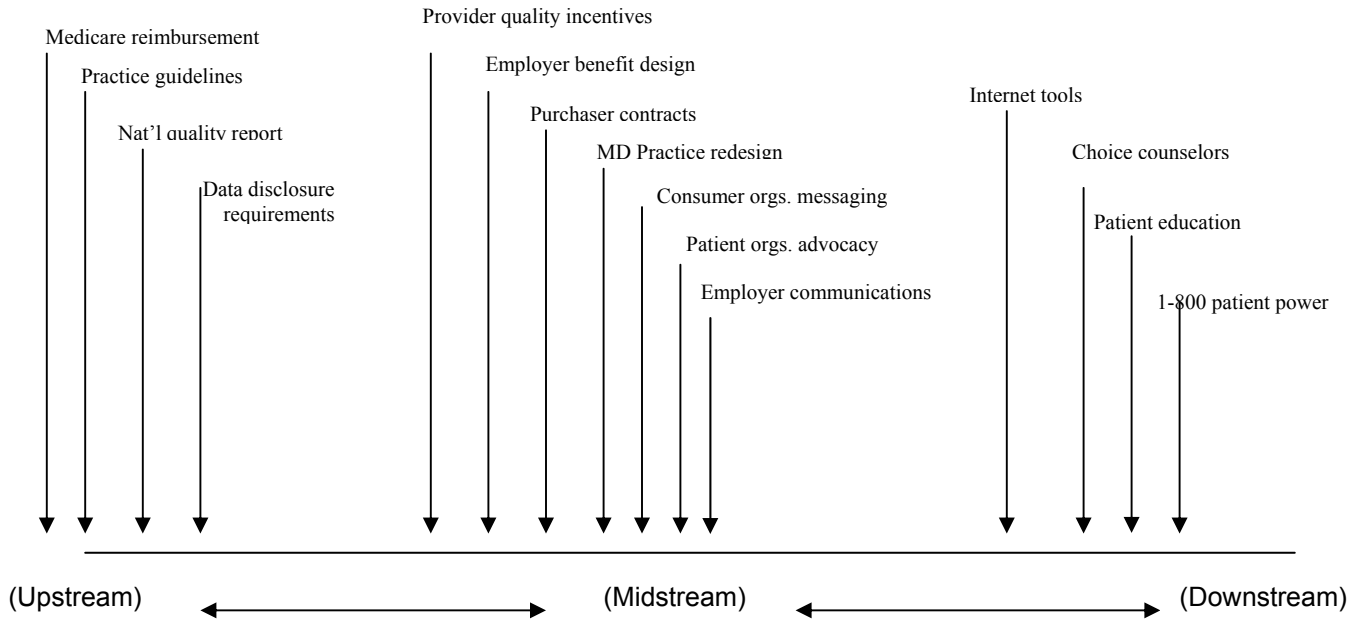
- a) To educate target groups about quality health care
- b) To alter the circumstances of consumer health decision making (e.g., degree of choice, cost consequences, benefit design)
- c) To alter the structure and delivery of health care services within individual institutions or organizations

3. Upstream interventions

Public policy and mass communications can alter societal norms and enable substantial changes in the climate in which health care services are organized and delivered. The principal domains that are subject to intervention include:

- a) National financing policies (e.g., Medicare reimbursement)
- b) Public discourse about health care (i.e., the vocabulary of public policy statements and political debate)
- c) Public information about health care (e.g., mandatory disclosure of performance information)
- d) Professional information about health care (e.g., knowledge base of medical and behavioral evidence)

The figure below illustrates how a number of distinct initiatives can be thought of in alignment towards a common objective – greater consumer empowerment.



Appendix III Key Informants, 2001-2002

Alain Enthoven - Stanford University
Allen Feezor - CalPERS
Clark Kerr - 21st Century Consumer
David Hirschland - UAW
Gerry Shea - AFL-CIO
Ian Morrison - Institute for the Future
Jim Tallon - United Hospital Fund of NY
John Rother - AARP
Karen Feinstein, Jewish Healthcare Foundation - Pittsburgh
Laurie Flynn - formerly NAMI
Lynn Etheredge - Health Insurance Reform Project
Mark McClellan, MD - Council of Economic Advisors
Mark Smith, MD - California Health Care Foundation
Michael Weinstein - New York Times
Myrl Weinberg - National Health Council
Paul Ellwood - Jackson Hole Group
Peggy O'Kane - NCQA
Peter Boland - Editor, Managed Care Quarterly
Reed Tuckson, MD - United Health Care
Steve McDermott - Hill Physicians Medical Group
Susan Edgman Levitan - formerly Picker Institute
Tom Davies - Verizon Communications
Marc Rodwin - Suffolk University
Don Berwick, MD - Institute for Healthcare Improvement
Jim Reinertsen, MD - Institute for Healthcare Improvement
Tom Ferguson, MD - Independent consultant
Dwight McNeill - Independent consultant

