

# BEHAVIOR MATTERS

*15 Years of Health Behavior Advocacy*

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BEHAVIOR MATTERS: 15 Years of Health Behavior Advocacy  
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## CHAPTER 8

# Improving Health: Is Clinical Medicine Up to the Task?

Americans pay lip service to maintaining their health, but often make sub-optimal choices.

As a nation, we invested \$80 billion in health-related research in 2001, predicated on the promise of breathtaking advances in identifying, treating and curing disease. Thanks to some stunning successes over the past few decades, few people doubt that the American biomedical research establishment can produce new knowledge that could significantly improve our health.

Too often the research fails to alter the reality.

We live in the time of the first molecular medicine approved for asthma, but we also live in the time of rapidly rising asthma rates among children. The tantalizing promise of stem cell research has us talking about a cure for diabetes at the very moment the epidemic of obesity increases the risk of lifelong chronic conditions—including diabetes—for millions of Americans. Better health is a priority and a possibility but not yet a reality.

Attention has been riveted on the health care system—on quality improvement and the reduction of medical errors, in particular—as the place where “the rubber hits the road” in delivering on the promise of taxpayer-supported research. This focus makes some sense: Health care delivery is not only the mechanism through which vast amounts of money flow, but it also will, eventually (we all hope), provide a system that will support faster and more accurate diffusion of evidence-based cures.

But there is value in looking outside of health care delivery to identify strategic points where modest changes could have a significant impact on increased use of evidence-based behavioral approaches to disease prevention and treatment, both as

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16. This essay is adapted from an address to an Institute of Medicine Clinical Research Roundtable workshop on infrastructure requirements for public health improvement in Washington, D.C., in May 2004.

part of health care delivery and as public health policy. Think of it as an echo of the ongoing debate about whether it makes sense to require safer cars or merely beef up the emergency rooms so they can better handle auto-related injuries.

I have identified three points for change here:

1. Balancing investment of public resources for health research.
2. Balancing scientific and policy priorities.
3. Balancing coverage of health findings in the media.

For each I describe how current practices inhibit effective communication between producers and consumers of evidence and explore possible changed approaches that could increase our return on investment in public research.

## Balancing Investment of Public Resources for Health Research

Our society deems it appropriate to devote huge amounts of money to combat an uncertain—though potentially catastrophic—threat of biological or chemical attack, in a concentrated effort similar to the one that sent astronauts to the moon. But the publicly funded research establishment—and the public—resist comparable efforts to develop effective interventions to prevent the impending, demographically driven explosion of illness and death associated with chronic conditions such as diabetes, heart disease, cancer, depression and HIV/AIDS.

Instead, scientists and their elected representatives ask the public to wait patiently for investigations to yield results for better treating those conditions. This process is propelled not by calculations of maximizing public benefit, but rather by the unpredictable political winds and whims.

It often takes decades for new approaches to prevent disease to reach the public, especially when the new practice or procedure has no profit potential. Consider the speed with which digital mammography has replaced X-rays—a change that confers a marginal benefit—and compare it with the pace of adoption of eye examinations for people with diabetes or fecal occult blood tests (FOBT) to detect colorectal cancer. The landmark clinical trial for eye exams was released in 1981 and the current rate of use is around 50 percent; the landmark clinical trial that established the effectiveness of the FOBT was released in 1986 and as of 2005, only 44 percent of people ages 50 and above had ever made use of this test. Contrast that record with how quickly new consumer technologies like CDs or digital cameras were adopted by the American public.

It has recently become popular to describe the delay in making use of effective preventive interventions as a “quality” problem, (i.e., the incentives to deliver these interventions and organization of work in those institutions are not sufficient to ensure that they are routinely delivered). Blaming the problem on “the system” obscures at least two important barriers. First, there is a dearth of systematically gathered information about how to modify clinical settings and professional behaviors to routinely address wide variations in the delivery of preventive services. Thus, efforts to change practice generally take place on a trial-and-error, case-by-case basis. And second, many promising approaches to prevention delivered within health care

settings lack commercial potential. The products of publicly funded prevention research then are implemented so slowly as to raise questions about whether the research investment can be justified. That basic question is seldom raised, though.

Committing significant funding for basic and clinical research—but allocating relatively limited amounts for applied health behavior research that can provide guidance about how to implement new knowledge about disease prevention and treatment—is short-sighted. There is a significant backlog of effective interventions directed toward changing behavior that are not part of routine health care. For example, programs that teach self-management skills to people with cancer, asthma, arthritis and diabetes have been shown to increase adherence and reduce disability, yet are not widely available to these people. Despite the public’s growing recognition of the nation’s obesity problem and solid evidence to support their effectiveness, school-based physical education programs and community campaigns for greater physical activity remain a low priority. And although short, structured discussions to encourage smoking cessation, detect depression or prescribe an aspirin for a patient at risk for heart disease have proved effective, such interventions remain a low priority for most health care providers.

There have been few successful commercial efforts that have focused on health behavior change. WeightWatchers and SmokEnders are notable for their long-standing success. Because such success is so rare, however, it means there are few incentives for companies to paw through peer-reviewed publications looking for promising behavioral interventions, and once found, to invest in the applied research and development required to bring such interventions to market. It remains to be seen whether disease management and health coaching companies will perform this function or whether they will continue to treat the health behavior of those they serve simply as misbehavior that can be fixed through the provision of information.

The private sector is probably not going to commit to evidence-based health behavior change development in a major way. Who else cares?

Maintaining and protecting the health of the public will demand behavior change on many fronts and so is something the government certainly should care about. Alas, no government agency has the charge of looking for promising new health behavior change findings and shepherding them to widespread application. Other than a few isolated efforts within the National Institutes of Health, notably within the National Cancer Institute, the development of implementable interventions is of low priority. The Agency for Healthcare Research and Quality and similar public and private enterprises have limited resources to address aspects of prevention that do not fit within conventional medical settings. And the Centers for Disease Control and Prevention and their partners in state government currently do not have the mandate, the technical capacity nor the funding to take most effective interventions and public health programs to scale.

But the barriers lie not just in the lack of resources to support the development effective practices and policies. Current practice restricts the growth of a “translation” work force. We need more experts to study and evaluate where and how effective health behavior change strategies can be implemented as part of health care

and public health services. Such experts must acquire skills that are undervalued in tenure-granting institutions and are thus in short supply in their mentors today. They must be able to field large demonstration studies, conduct applied research in real-world settings, perform systematic reviews of evidence, manualize interventions and develop effective dissemination strategies.

Today our universities strain to anticipate the skills and knowledge needed to perform these functions and struggle to attract students interested in applied behavioral and social science and health services research. Academia and health care institutions offer few opportunities and incentives to young people for careers that demand that they perform these behaviorally oriented translation-related activities, despite their vital importance.

How can we rework the current approach to health research to ensure that there is both supply and demand for people to do this work? If anyone knew how, I'm sure someone would have done it by now. I do, however, know that what we must try to achieve looks like this:

We need to build the nation's health-research portfolio in the same way that a person builds the elements of a financial portfolio in order to provide the greatest possible benefit over time. That means diversifying our resources to find a balance between investigator-driven basic research and mission-driven applied research, between prevention and cure. It means devising ways to identify discoveries without commercial potential that would benefit the health of the population and developing them for clinical and public health use. It means investing in, and disseminating, syntheses of research. And it means building the capacity of health systems and professionals to absorb new information and practices.

But say we have more and better evidence of what works to improve health and treat disease. How does that information make its way into policies that ensure its use?

## Balancing Scientific and Policy Priorities

Weaving together research and policy is not easy nor does it show signs of becoming easier in the future. It is clear that policy-makers are not demanding evidence to support their decisions, nor are they delaying decisions until the critical piece of research fills in a knowledge gap. So, for example, influencing the policy process to take vitally important behavior research findings into account is not a matter of scientists making cosmetic changes to their usual business, like using fewer technical terms or producing one-page bullet-point memos.

Rather, it will require changes in the questions that are asked and the ways answers are generated. There are a few common assumptions about how the different worlds of research and policy interact that bear examining:

*Assumption 1.* Affecting health policy is a matter of getting the right information in the right format to the right policy-makers at the right time.

The problem of how to make data interesting to a policy-maker is a challenge. It is probably true that by making data available and accessible researchers will

contribute incrementally to making use of what they have learned, but this does not mean that research will influence policy-making.

The people charged with making health policies that are particularly relevant to older adults in the United States are elected and appointed officials who make decisions about funding, that is, people who sit on Congressional committees and committees at the Centers for Medicare and Medicaid Services. They also are senior-level generalists within institutions: state Medicaid administrators and individuals within managed care and insurance companies.

Whether elected or appointed, these individuals rarely have a mandate to accord the highest priority to achieving lower mortality or improve quality of life. Their professional survival, whether they hold elected or appointed office, usually requires them to give priority in policy to the short-run success of their most active and powerful constituents. Getting reelected usually requires loyalty to their political party, diligence on behalf of local economic interests and prompt attention to requests for assistance from individual voters.

Career officials—that is, the regulators at the federal and state levels and insurance and managed care officials—have different priorities. Whereas people who run for office consider reelection their goal, ambitious officials in government or the insurance industry see theirs as moving up to positions of increasing responsibility. For these officials, getting promoted means running an efficient operation, preserving the bottom line and taking account of what elected officials need to do to get reelected.

The format of research results is necessary but not sufficient to influence policy-making. Using simple instead of technical language and summarizing findings in one-page memos clarify what is known but do not confer extraordinary valence for your information among policy-makers who are making decisions in complex and fast-moving environment. They merely get you into the game.

*Assumption 2.* The key to influencing policy is making the case that an intervention can produce cost savings while improving health outcomes.

It is truly a step forward that academic researchers are beginning to account for the cost of their interventions, regardless of how rudimentary these measurements may be. It shows growing recognition of the broader context in which policy decisions are made. However, it is wonderfully optimistic to believe that even a solid case for a cost-effective intervention is going to tip the balance toward one policy or another.

Professionals in politics and public management have very real reasons to be wary about claims by scientists and other advocates that they ought to change or create particular policies based on their data, even when their reports include cost-effectiveness assessments.

And this is why: Most scientists insist that their knowledge claims are inherently uncertain and describe the uncertainty of their findings in published papers, congressional testimony, speeches and in popular articles urging policy-makers to take action based on scientific findings.

It is not surprising, then, that policy-makers are reluctant when asked to implement research findings, since after carefully describing and quantifying the weaknesses of their methods, data and conclusions, researchers ask policy-makers to assume the risk that a policy may not actually produce the promised (health benefits, cost savings or cost neutral) results.

There are aspects of the research process that are anathema to the art of policy-making and aspects of policy-making that are anathema to the norms of scientific research. If we are going to better weave together scientific evidence and policy, we need to find strategies that allow us to overcome this clash of cultures.

*Assumption 3.* Policy-makers value and are persuaded by objective science.

It is useless for researchers to claim they are not an interest group. Advocacy and interest groups always cite research results and almost ask researchers to *find* evidence that will support their demands for more attention, money or authority. Policy-makers respond to this rhetoric with sympathy in public but often are not convinced to act differently.

Every successful generalist in government knows that effective policy-making usually achieves some measurable public benefit at the same time that it meets other criteria. So, for example, it may mean adjudicating among competing claims in ways that satisfy voters who elected them, giving something to almost every interest group and avoiding media attacks on government leaders and their allies among interest groups.

Researchers are viewed by policy-makers as allies of an interest group or as an independent advocacy group whose research findings are only one of a myriad of claims factored into a policy decision.

Senior public officials routinely balance competing demands when they allocate scarce resources and then evaluate how they were spent. Each demand is treasured by interest groups that compete for resources with other groups and have advocates as well as antagonists in the legislature and in executive agencies. As a result of competition among interest groups, one person's epidemic may well be regarded by another as an alarmist, trumped-up reason to siphon off buckets of taxpayer dollars.

We have been only partially successful in implementing the results of society's investment in health research in a routine and effective way. I think there are ways of accomplishing our goal while retaining a primary allegiance to science, beginning with a more collaborative relationship with policy-makers. Researchers will lose some autonomy with this approach, both as individual researchers and as a group, but the alternative is that their efforts will never reach their aim—no improvements in health will result and lifetimes of careful hard work lost.

But if policy-makers are indeed responsive to the electorate—or to public opinion—that means that the public also has a role in the process by which scientific evidence is transformed into policies that will improve health. And while factors such as science education in the schools and health literacy affect public interest in evidence-based approaches to health, the media—print, broadcast and Web-based—probably exercise the most powerful influence on public demand for new treatments and policies.

## Balancing Coverage of Health Findings in the Media

In a era of complex health information and fragmented health systems, people around the world are relying more and more on mass media to inform their personal choices about health and health care. Regardless of where they live, individuals search electronic, print and Web-based news outlets for objective information to help them make decisions on how best to prevent and treat disease. Health professionals also often find out about new developments in their field from the news media.

Public and private policy-makers rely on the media: If a six o'clock news commentator says a drug is a miracle cure, public expectations are raised and it is more difficult for insurers not to pay for it. But media coverage of advances in health science is dominated by reports on new research findings and advertisements for new products, which add to the confusion.

In a media environment biased toward novel findings, the release of new and important systematic reviews rarely receives media coverage, and previous reviews are not often mentioned in reports of single studies. For example, studies of four new smoking-cessation aids received widespread press coverage in 2004, but none of the stories mentioned the systematic reviews of tobacco-cessation interventions that might have provided a context for the significance of these new technologies. This bias contributes to a public perception that biological or genomic cures are available at the local drugstore and that science doesn't offer a particularly good guide for health decisions if researchers can't decide if a low-fat or low-carbohydrate diet is more effective for weight loss.

Journalistic apathy toward evidence summaries (meta-analyses and systematic reviews) of health interventions—especially studies that have implications for changing the status quo in treatment and policy—undermines the public's trust in science, limits its ability to make educated choices and erodes health.

Why is the best available evidence about health used only sporadically in health reporting?

Financial pressures in newsrooms have reduced the number of health and science journalists and left many of those who remain without sufficient training to evaluate different levels of evidence. The task of finding systematic reviews to reference in a story about a new development takes time. Monitoring the many producers of reviews, identifying new reviews that are newsworthy and assessing their quality in order to find a story all require resources not always available to journalists.

The availability and use of evidence reviews in policy development is a relatively new phenomenon. The many public and private producers of reviews have yet to recognize how public awareness of the evidence will help them justify decisions to cover, or not to cover, specific interventions such as arthroscopic knee surgery for osteoarthritis or autologous bone marrow transplant to treat breast cancer. The Cochrane Collaboration is the single largest producer of evidence reviews internationally, and while it has a clear vision about the value of evidence reviews to as broad an audience as possible, Cochrane nevertheless charges a fee for access to reviews. A Cochrane subscription is not yet viewed by editors as routine as subscribing to LexisNexis.

## WHAT WE KNOW AND WHEN WE KNOW IT

You are in the delivery room and the nurse hooks you up to an electronic fetal monitor to check the baby's heart rate as a means of detecting abnormalities that could lead to cerebral palsy. This is something that has been done routinely for the past 30 years. What mother would risk saying no to such a critically important test for her child's lifelong health?

Probably none. But what if the mother knew there is no evidence that the test has ever prevented a case of cerebral palsy but that it could lead to unnecessary surgery—a C-section—that can cause harm to her either now or in future pregnancies? This example from a column in the *Boston Globe* exemplifies the difficulty that doctors and, most especially, patients have in deciding the best medical course of action.

Some people learn about the potential harm of electronic fetal monitoring from obscure medical journals or newspaper columnists, but few learn about it on the front pages because daily journalism rarely delves into the muck of long-term lengthy statistical reviews of evidence. Only a select few reporters can keep up with the latest research, either because it is hard to find or requires a paid subscription.

For the most part, “news” about scientific findings means only that it is new and previously unreported. It does not mean that all prior research on the subject is rendered meaningless.

Rarely does a single study revolutionize the understanding or treatment of a disease. Rather, additional studies add nuance to a larger body of knowledge on any given topic. Capturing that larger body of knowledge in a meaningful, useful form presents a challenge to doctors, nurses, insurers, hospitals and patients, who must act on it. Systematic reviews of the published and unpublished literature and clinical practice guidelines are the tools that summarize the current state of the science and provide direction.

But “incremental” and “provisional” are not the stuff of news. Findings that add marginal insights to existing knowledge can't compete. Reporters have obvious incentives to hype stories so as to gain them greater prominence than they may really deserve. And editors have few incentives to demand the objective description of current knowledge offered by a systematic review or clinical guidelines, even if such information were easy to find and relatively simple to understand—which it is not.

As long as people are getting their health information from the media, and systematic reviews are not the key reference used to report on new findings, individuals will not have access to the best and most accurate information for the health decisions they are increasingly required to make.

Some reviews are not in themselves newsworthy or the authors conclude that there is not sufficient evidence to make a recommendation. Of course, some research syntheses are covered as news. The continuing controversies about the effectiveness of antidepressants in children, the age for and frequency of mammography, the health impact of hormone replacement treatment and the comparison of cholesterol-

lowering drugs all deserved, and received, considerable attention and have resulted in changes in individual behavior, in clinical practice and in insurance coverage decisions. Yet hundreds of reviews are conducted every year, many of which also have implications for choices about health and health care but do not attract media attention.

While evidence reviews offer health decision-makers around the world the best existing information to guide health choices, most appear on Web sites known only to the cognoscenti who understand their value and seek them. Reporting on evidence reviews by the media will help individuals find a solid scientific reference point for the health decisions they are increasingly required to make on their own. Conversely, if no effort is made to increase the use of the best available evidence in health reporting, there is no reason to believe that the general public will discover and begin to make use of this powerful information tool on its own.