The Health Legacy Partnership
Co-founded by the
Joseph H. Kanter Family Foundation and the
Agency for Healthcare Research & Quality (AHRQ)

Outcomes Research
Knowing what works best in healthcare

William Novelli
Mark McClellan, MD, Ph.D.
David Brailer, MD, Ph.D.
Carolyn Clancy, MD

Bipartisan Support for National Health Outcomes Database

United States, Department of
Health & Human Services
Office of the National Coordinator for Health Information Technology

Agency for Healthcare Research and Quality

Joseph H. Kanter, Chairman
National Health Outcomes Database

Report of accomplishments from the Joseph H. Kanter Family Foundation and the Health Legacy Partnership on information technology outcomes research

“This is so simple, so logical and so powerful in its implementation that it boggles the mind our society has not done this before now.”

– Former Senate Majority Leader George Mitchell

“Anyone who says one man can’t make a difference hasn’t met Joe Kanter.”

– Former Senate Majority Leader Bob Dole

Sen. Bill Frist says the [outcomes] database would be the “fruition” of federal efforts to improve the quality of health care in the United States.

– Los Angeles Times, August 2000
Thanks in large measure to the leadership of Joe Kanter and the Health Legacy Partnership, the momentum for putting a national health outcomes database in place in this nation is palpable. Our work at Research!America helps demonstrate that the American public is well aware of, and deeply concerned about, the problems such a database would go a long way toward solving. Large percentages of Americans say they or someone in their immediate family has experienced a medical error, and 60% believe the U.S. no longer has the best health care system in the world. The public has “caught up” to expert opinion in terms of awareness of the problems we face.

Research!America polls show that majorities of the public are willing to share information on their health—and this is necessary in order to make a database work. People do have questions and concerns about the use of confidential information, including maintaining confidentiality itself, and these concerns must be addressed. Addressing concerns should not, however, distract leaders from moving forward to meet the public’s expectations of putting research to work to assure better health. Our polls also show that research—including what the experts call “health services research”—is a clear public priority and that the public is willing to pay for it via increased taxes. Research!America poll data published in the Journal of the American Medical Association (Sept. 21, 2005) shows that two-thirds (67%) of Americans say they are willing to pay $1 more per week in taxes for more medical research.

No one doubts that the time is at hand for action. In addition to both expert and public support for change, other components are now in place to enable aggressive advocacy for establishing a national health database—sooner rather than later. The nation is graying, and costs of health care threaten to loom out of control, compromising America’s global economic competitiveness and jeopardizing gains in quality of life made possible by decades of medical and health research advances. The Administration has set a 10-year goal for putting electronic health records in place. Meanwhile, the Health Legacy Partnership has mobilized leaders from across political party lines and across a broadly representative group of experts in the field, as well as those who represent the public’s interests, to stress the urgency of the situation. The Partnership also has put forward a concrete plan, modeled on the Federal Reserve Board, for overseeing the management of a health system linked to a national database. It’s time to take the next steps forward to test this model conceptually and then in practice. It’s also time to fund the Agency for Health Research and Quality (AHRQ) at the billion dollar level.

We’re so close to the tipping point. Advocacy can take us there. In the words of former Congressman John Edward Porter: “You can change the image of things to come. But you can’t do it sitting on your hands.”

---

Many health care providers believe that 8 out of 10 recommendations on diseases or procedures by doctors are anecdotal—meaning “No Evidence.” Therefore, HELP authorized Harris Interactive Inc. to survey physicians on outcomes of 10 major diseases. The survey concluded that the overwhelming desire of the doctors was that they must have more outcomes on “What Works Best.” If you want to show your support for more scientific health data for your doctor and your family send your email address, fax number, or mailing address to:

The Kanter Family Foundation/Health Legacy Partnership

888 16th Street
Washington, DC 20006
202-349-9853
www.healthlegacy.org

4770 Biscayne Blvd., Suite 1150
Miami, FL 33137
Phone: 305-576-4310
Fax: 305-576-1359
We Remember Dr. John Eisenberg

The Kanter Family Foundation and the Health Legacy Partnership pay tribute to the remarkable career of Dr. John Eisenberg, a pioneer in the field of health services research.

Eisenberg, who died in 2002 from a brain tumor, was dedicated to reducing medical errors and improving patient safety as head of the Agency for Healthcare Research and Quality. The agency’s building in Rockville, Md., has been named for Eisenberg.

Dr. Eisenberg was the first government partner with the Kanter Family Foundation in working for widely accessible outcomes research to help patients.

“He had a vision of the future and was one of the first to endorse a national health outcomes database,” Joe Kanter said.
Access to Your Medication’s Track Record

Washington – A wealthy 78-year-old businessman from Century City is looking to apply his golden touch to the nation’s health care system.

Joseph H. Kanter, who made his first fortune in real estate and then launched a successful banking career, wants to work with the federal government to establish a national health outcomes database.

The idea, he says, is to help patients and their doctors make decisions by establishing a computerized record of how various drugs and treatments have worked in similar cases in the past.

“You wouldn’t buy a stock unless you had 10 years’ earnings, 10 years’ dividends, 10 years’ sales and 10 years of what the stock price was,” Kanter says. “[So why] accept from a doctor a treatment that may or may not save your life or even kill you without the relevant information?”

Kanter has trod an unlikely path to his current role as populist health care crusader. He and his wife decamped from their home in Miami to California when Kanter decided he wanted to be in the movie business.

As a newcomer in Hollywood, Kanter says, he did reasonably well. He produced several films, including the Academy Award-nominated “Ironweed” starring Jack Nicholson and Meryl Streep.

Kanter has always taken a hands-on role in the treatment of his own medical problems, and three years ago decided to commit his time and money to making health care data widely available to other patients.

He is working with a branch of the U.S. Department of Health and Human Services to develop the database. On Capitol Hill, he has the backing of Sen. Bill Frist, R-Tenn., the only practicing surgeon in the Senate.

Frist says the database would be the “fruitition” of the federal efforts to improve the quality of health care in the United States.

Dr. John M. Eisenberg, director of the health department’s Agency for Healthcare Research and Quality, recently announced his agency’s support for the project. He and Kanter have invited representatives of the largest health and disease-related organizations to attend an Oct. 30 planning conference in Washington.

Kanter says the project is unprecedented because it would cater to patients, not just clinicians.

“It will not be written in medicalese,” he says, “[but rather] in language that can be understood by an average patient,” whom Kanter identifies as someone with a seventh-grade education.

The Chicago-based American Medical Association offers its own “national guidelines” data on the AMA’s Internet site, says Yank Coble, the group’s secretary-treasurer.

Kanter says the AMA data is targeted at professionals, not health care consumers.

Though Kanter believes his database would help physicians prescribe the most effective courses of treatment, he concedes that some doctors oppose the plan on the grounds that it would eliminate the “placebo phenomenon.”

“If you combine the natural tendency of the body to heal with the placebo effect of people thinking their doctor is God, you get patients recovering without treatment about 20% of the time,” Kanter says. “So the medical profession is saying, ‘We don’t want to cause the public to lose faith in us.’”

The issue of protecting patients’ privacy presents another complication. Kanter says many people would be very nervous about having their treatment records stored on a widely accessible database.

The key to allaying privacy concerns, he suggests, would be to ensure anonymity.

Twice in the past year, Kanter and the Healthcare Research agency have convened panels of medical and technical experts to assess the feasibility of constructing a workable database.

Researchers at these meetings, he says, have concluded that the technology exists to build a compendium of treatment results indexed by age, sex and other patient variables.

“If someone has a secondary condition, like diabetes for instance, that [fact] may affect the treatment, so the case would go in its own special category,” Kanter says.

Other major challenges include figuring out how to translate medical jargon into patient-friendly terms, and establishing standard recording procedures.

Eisenberg suggests funding could be another stumbling block. Although his office has established that there is public interest in health outcomes information, he is not sure the agency has enough cash to help Kanter finance the database.

For now, Kanter says, he will concentrate on raising awareness of the project.

“Not many people outside the field know about it,” Kanter says. “Everybody knows about clinical research, which produces treatments and vaccines, but very few know about outcomes research.”

Betsy Zeidman of the Fair Care Foundation, a national patient advocacy group, believes the outcomes database will prove a boon to health care consumers.

“The Kanter partnership with the deferral government is vital,” she says. “Obviously, evidence-based medicine is the key to saving both lives and money, and the digital age finally allows everyone to know what works.”
Since the 1990s, Joe Kanter has worked to advance the cause of a national outcomes database for patients and doctors. At the fifth annual Health Legacy Partnership conference on Jan. 14, 2005, Joe Kanter looked back – and ahead:

Seven years ago, the National Press Club organized a “Newsmaker Breakfast” for me. I asked then-Majority Leader George Mitchell and future Majority Leader Bill Frist to join me in an effort to make a difference in health care.

I used shorthand to describe our mission as a National Health Outcomes Database. But let me be perfectly clear. I am no big fan of a big government-controlled database in the sky. My technical people tell me it is more accurate to describe our initiative as a voluntary sharing network that will enable us in “real time” to both advance and evaluate innovation in medical care.

I am grateful for my business success in our free enterprise system, the greatest the world has ever seen. I wanted to give something back by utilizing free enterprise practices to reform the health care system.

Our first partner in these efforts was the Agency for Healthcare Research and Quality. The late Dr. John Eisenberg, the administrator of AHRQ, was the first government official to endorse the creation of the National Healthcare Outcomes Database.

Dr. Carolyn Clancy, who succeeded Dr. Eisenberg, is the most enduring partner for AHRQ’s unwavering leadership in outcomes research - the essential building block of information that both professionals and consumers need to make intelligent medical decisions.

The Joseph H. Kanter Family Foundation funded two “think tanks” consisting of approximately 60 outstanding health professionals. The first was to determine feasibility and the second to determine the first steps that would be needed in its development.

It is important to note that AHRQ has recently committed $139 million to the innovative use of health information technology to improve the quality and safety of health care. AHRQ’s investment in this initiative represents the leading edge of President Bush’s vision for the nation’s health care system. What AHRQ has begun will bring our dream much closer to reality: medical information on the best treatments available delivered in “real time” to medical professionals and consumers.

There are two separate phases in every new endeavor - first, the policy and second, the execution. Today we celebrate the creation of a bipartisan policy for the collection of data on “what works best” and the appointment of Dr. David Brailer as national coordinator for health information technology.

He will play a critical role in making the database a reality for all Americans. We are grateful for his strong support and for the continuing strong support from the administration and a bipartisan coalition of lawmakers in Congress. The statements by The White House, Secretary Tommy Thompson at HHS and Dr. Brailer are further proof of this broad support.

Now that our policy mission for outcomes is completed, we need to begin the second phase of execution by delegating our efforts to create a database and by supporting Dr. Brailer, the new national coordinator, as our leader.

Today you will have an opportunity to hear from Dr. Brailer and some of our partners who have been involved in the implementation of our mission.

In fact, the Health Legacy Partnership’s new mission is to make certain that we receive maximum benefits from the new technologies and collection of information. Several years ago, we visualized a voluntary private-governmental organization like Health Legacy Partnership to manage data collection.

Today, in order to institutionalize our Health Legacy Partnership, we call for a new bipartisan voluntary policy organization to integrate our fragmented health care system. As we try to visualize the future, we should utilize the historical success of the Federal Reserve System for banks created in the early 1900s as a pattern to develop the Federal Reserve System for Health – in shorthand - FReSH. The FReSH board of governors, or FedHealth, would consist of patients, health care providers, national corporations, and government leaders providing broad policy oversight and long-range planning for the health care system. The execution and the priorities will be determined by the professionals and Congress, who will also determine the specifics for advancing a framework for accountability and what responsibilities will be delegated to whom.

Celebrating Accomplishments, With Much Work Left To Do

While this journey isn’t short, nor for the faint of heart, because of your interest and support... this journey is much closer to becoming a reality.

– Joe Kanter
There are many other important reforms of the health care system that must be established if data collection is to reach its full potential. We must lower the costs of high-quality care, we must fix the malpractice insurance problem, consider pay for performance and establish more competitive pricing.

We must close the gap between the insured and the uninsured, and we must establish equal care for minorities and other groups traditionally shut out of the health care process.

The free enterprise system in the United States was built by ownership or property rights and the laws that protect them. Historically, Americans are wary of government. The Federal Reserve System for banks was not a government effort to nationalize banks. Quite the contrary. It was the free enterprise’s democratic method to make the banking system work.

Money is the blood of our economic system. The complexities are best understood and managed by economists. The health care system, like the banking system, needs the expertise of health care providers and participation of patients in order to determine the priorities and the details of how the FedHealth should function and what they should be doing.

Making the health care system work would be the purpose of the Federal Reserve System for Health.

I started this journey into making health care more effective 10 years ago. As most things, it started with a personal health issue and blossomed into me wanting to “give something back” to the American people and the system that has been so good to me and my family.

I want to kick off this meeting by saying that while this journey isn’t short, nor for the faint of heart, because of your interest and support, AHRQ initiatives, support from President Bush and Secretary Thompson, and broad support in the Congress for health information technology, this journey is much closer to becoming a reality.

We are truly on the right road. But we need to continue to work together to get there. I want to thank you all for coming here today, your support in the past and for your continued effort and support in the future.

Now let’s move forward together, honoring the legacy of Dr. Martin Luther King, whom we remember this weekend, by doing something big and really making a difference.

When Joe Kanter launched his drive for a national health outcomes database, he recounted what he learned after he had been diagnosed with prostate cancer:

> I was dismayed to find that it was impossible to figure out with any degree of statistical accuracy what had worked best to treat men of my age, with my health background and with my lifestyle.

> No matter how much I paid or who I asked, I simply couldn’t determine what were the relative advantages and disadvantages of the various available treatments for prostate cancer. I could not get comparative, longitudinal data on how treatments might impact the quality of my life in the short, medium and long term.

> This just shouldn’t be. How could I – how could any of us – be expected to choose a treatment that will make a difference in how we live – maybe even whether we live – without having reliable data upon which to base our choice?

> That’s why I’m working to build a national health outcomes database. People tell me it’s too big a task. But my experience with prostate cancer led me to resolve to create a new tool for patients and physicians so they don’t have to confront critical health decisions lacking sufficient data.

We deeply appreciate the work of all the contributors and their staffs in making this brochure possible.

– Joe Kanter

If you want to join our membership at no cost to you, call or email Joe Kanter at **www.healthlegacy.org**
Medicare Moves Toward Evidence-Based Medicine

Speech by Dr. Mark McClellan, administrator of Medicare and Medicaid Services, to HELP Conference on Jan. 14, 2005:

My interactions with the Kanter Family Foundation over the years and with the Health Legacy Partnership have been instrumental in shaping some of the key ideas that this administration is trying to pursue in its health policy. So this is a meeting that I didn’t want to miss.

This is a reflection of a shared effort to pursue a common mission of developing a health care system where doctors and patients have the support they need close at hand to make the most effective decisions possible.

A key part of giving patients and health professionals the support they need is strong practical evidence on what really works. That evidence is too often lacking because we haven’t done enough to develop it. And because we don’t have the information technology systems and the other support in place so that the patients and doctors can get it when they need it.

At Medicare, we’ve got a big role to play in supporting better evidence and better care through our coverage and payment decisions. And we’re also committed to helping patients and doctors use the best evidence possible so they can make the right decisions, so we can get the most out of the $500 billion Medicare spends annually.

As you all know, too often this isn’t happening today. Too often patients are faced with the wrong decisions, with errors in executing what were good intentions for the right decisions. And very often decisions are based on limited knowledge about what does or doesn’t work. And even when we got the knowledge, the success rates of our medical technologies are often 10, 20% reductions in the rates of important outcomes.

We’re not doing a really good job at targeting treatments to the patients who can get the most from them. My concern is that if we don’t do better, we’re not going to fulfill the promise of 21st century health care, including more personalized care and preventive care.

Today it’s costly and time-consuming to get new treatments to patients to prove that they worked through the whole pre-market development process. And once a treatment reaches a market, we also need to do more to use new opportunities to help patients and providers realize more value from the treatments available to them. Once a treatment reaches a market, we also need to do more to use new opportunities to help patients and providers realize more value from those treatments, so we can provide more effective, complete health care at a lower cost.

Our failure today to translate the knowledge we have into patient care means needless suffering. It means avoidable deaths every day. Too many of the patients in this country, too many of our 80 million beneficiaries, receive the wrong treatments or fail to get the right ones. And not just new treatments but well established ones as well.

We have suspicions and expectations about what works. But we don’t even know for sure. So, despite the bright promise for medical science, we’ve got a formidable challenge.

If we don’t get to be as good at improving the actual delivery of care as we are often are in talking about it, we’re not going to be able to fulfill the potential for 21st century medicine because we’re not going to be able to afford it.

And it’s that that I want to try to address in my time at CMS. You know the alternatives are not good. The so-called solutions when costs in programs like Medicare, Medicaid keep rising and we can’t find ways to offer a better value, the solutions are things like cutting the payment rates arbitrarily and limiting benefits.

And that’s why it’s so important for CMS to work as we’re trying to do right now, to support a health care system that’s truly personalized. Aimed at preventing illnesses and
complications. And aimed at achieving the best outcomes for individual patients at the lowest cost.

The idea of patient-centered care is in the current of medical science today. I’ve been impressed at how many of the treatments that are coming on line in the next few years have the potential to be targeted to individual patients, based on their own personal aspects of diseases, their own molecular profile, their own preferences. Patient-centered care is one of the most promising trends in modern medicine, and our health care system needs to reinforce it – not ignore it.

To make sure that we’re making effective decisions, even progress on broad evidence-based medicine and treatment guidelines isn’t really going to be enough to get to truly personalized care. Our health care system needs to do more to promote more individualized care because that’s the only way to take advantage of what modern technology will have to offer to improve health and keep costs down. We need individual patients working with doctors and other health professionals to get the treatments that are best for them at the lowest cost. Those treatments should be based on their individual health profiles, solid knowledge about what works best for them and their own preferences.

But this is only going to happen if we start with developing better evidence about what actually works at a very particular level and if we do more to start developing that evidence.

And we want to give a big push to developing it. In particular, CMS wants to support the development of higher quality data derived from the routine delivery of health services through large, simple trials, through registries and through the analysis of clinical data gathered through the greater use of electronic health records.

To refine the evidence available to patients and doctors, when they’re considering treatment, we need to do a better job of gathering this type of evidence.

Now, under the law, Medicare only covers interventions that are considered reasonable and necessary for diagnosis and treatment. This is to make sure that Medicare is spending its money on services that are likely to improve health outcomes for beneficiaries. And as we’ve begun making coverage decisions faster, we’ve begun extending coverage to more new technologies more quickly.

But what shouldn’t be an integral part of medicine, at least for an innovative and personalized health care system, is the failure to take steps to resolve uncertainty about the risks and benefits of potentially important treatments, year after year after year. It shouldn’t take many years to learn that a treatment is truly effective for certain kinds of patients, or that other kinds of patients have important risks that outweigh the benefits for treatments that overall for a broad population may be effected. We can do better than overall mild to moderate effectiveness. We can do better at targeting the benefits of medical therapies.

And to address this, we’ve established a link between our coverage of innovative diagnostic and therapeutic technologies and our commitment to evidence-based medicine. We’re covering new technologies in potentially important uses, where the benefits are not necessarily proven if they’re provided in the context of clinical studies that we can expect to generate new medical evidence.

I want to conclude by emphasizing that we’re really going to need to work together to make these changes happen. We’re in a public/private health care system, a pluralistic one. This system has many tremendous advantages in terms of flexibility and responsiveness and innovation. And that’s going to really help us as we keep working to find better ways to deliver care. But it also means that no one of us, no one entity can solve the problems that are confronting our health care system when it comes to innovation and affordability.

We’re the biggest health care payer in the world at CMS and so we know that we need to help be part of the solution. But to move our system towards better evidence-based medicine, towards better adoption of health IT, towards better care for patients, we need to be a participant among partners. We want to mobilize some coordinated leadership of all the key stakeholders in our healthcare system to help achieve the vision that this very important conference and the Kanter Foundation have laid out.
Information Technology Crucial To Better Care

Speech by William Novelli, CEO of AARP, to the Kanter Foundation/Health Legacy Partnership conference on Jan. 14, 2005:

I want to commend Joe Kanter, the Kanter Family Foundation and the Agency for Healthcare Research and Quality for sponsoring this conference.

The conference theme made me think of the popular 1960s slogan, “Power to the People.” Given the importance of health care in our society today, I think you’ve captured the 2005 version of that with “Power to Patients.”

Because if we are going to improve health care in America, there is no doubt that we must give people information to make informed decisions. And, patients must use their power to help themselves and thereby to improve the nation’s health system. The old adage is certainly true — information is power.

At AARP we have created a Ten Year Social Impact Agenda. This is where we will devote our resources over the coming decade. The goal of this agenda is that people 50+ will have independence, choice, and control in ways that are beneficial and affordable for them and for society as a whole.

As we see it, our national challenge is to improve the quality of people’s lives while finding ways to keep America’s pension, health care and other systems affordable and sustainable, so they will endure and remain for generations to come.

To accomplish this, our Social Impact Agenda is focused on five areas: the first is economic security, including Social Security, a longer work life for those who desire it; acquiring and managing personal assets, and providing assistance to those in need.

Using information technology more efficiently, focusing on wellness as much as on disease, establishing a culture shift so that quality becomes a system feature of health care, expecting accountability, and rewarding high-quality care are not revolutionary ideas. They already exist in other sectors of the economy — but not yet in health care.

– William Novelli, CEO of AARP

The second area of focus is health and supportive services — and I will be getting to that shortly.

Third is livable communities. For the most part, this is about housing, transportation and mobility. But the connections between these issues and others that define quality of life are considerable.

The fourth area is about global aging and exchanging best practices with other countries, many of which are further along the aging curve than we are. We have a lot we can learn from other countries and much we can share with them as well.

The final focus of our Social Impact Agenda is access to information — and providing it in credible, user-friendly ways that make it possible for our members and their families and others to navigate through the welter of information we have already and the even greater quantities we will have in the future.

It’s hardly a surprise to anyone here that, of all the factors that contribute to - or detract from - one’s quality of life in later years, health is the most basic. So, improving the quality of health care and reining in health care costs are the most important steps we can take to improve the quality of life for people throughout the lifespan and to responsibly address our major demographic shift to an older population.

As experts, you know that improving U.S. health care is complicated by many factors, including the size and complexity of the system, its dynamic nature, and the highly fragmented nature of health care delivery, occurring millions of times each day in patient-provider encounters.

In addition, there are many views of the relative value of different health care expenditures. Not everyone has the same perspective and not everyone is motivated by the same incentives. I know that none of you minimizes the challenge inherent in improving our health care system.

We are members of the National Coalition on Health Care. Dr. Henry Simmons, President of the Coalition and someone many of you know, often calls the health care situation “A perfect storm,” consisting of three interrelated elements: poor
quality, decreasing coverage, and rising costs. This leads to the conclusion that we need fundamental reform, and we need it soon.

The Institute of Medicine provided this assessment. “The nation’s health-care delivery system has fallen far short in its ability to translate knowledge into practice and to apply new technology safely and appropriately. The health care delivery system also is poorly organized to meet the challenges at hand.”

Some say that there really is no “system” of health care in America today. Our non-system, if you will, is a patchwork of the genuinely amazing, the adequate, and the truly awful. For example, we have the world’s preeminent medical research organization in the National Institutes of Health. And we have some of the finest hospitals in the world. But we also have 45 million uninsured people. About six million of them are between 50 and 64, among whom are members of AARP.

We have at our disposal some remarkable technology, some of which is expensively overused, while other technologies - especially information technology - is underused. Here are some sobering findings from the eHealth Initiative:

- More than 90 percent of the 30 billion annual medical transactions are conducted by phone, fax, or stamped mail.

- Only 13 to 15 percent of hospitals have implemented some type of Computerized Medication Order Entry system. Physicians in these organizations enter fewer than 25 percent of their orders using the system.

- Only five to ten percent of individual practitioners use electronic medical records, and, fewer than five percent of physicians write electronic prescriptions.

This all sounds pretty primitive - more like the turn of the 20th century than the practice of medicine in the early years of the 21st. Why should this be so? We have astounding medical equipment for imaging and surgery. We have technology and we have the people, so why aren’t we delivering the goods?

Why are there so many medical errors, leading to some 100,000 unnecessary hospital deaths each year, according to some estimates? Why are so many uninsured?

I imagine we can come up with a long list of reasons, but one candidate to top the list is a lack of a genuine health information infrastructure. I presume that most of you, like AARP, believe that we need to build one.

Part of that infrastructure is better use of information technology to improve the flow of information about patients, to improve diagnoses and imaging, to get quicker access to lab reports, to reduce memory overload, to improve communications with patients, and to let people access their own information.

As you know, many practices and hospitals have wonderful internal communications networks - so they can talk to one another, but they can’t reach the outside world. A patient who has a primary health-care provider here, an orthopedist there, a urologist three miles downtown, and other providers scattered around the city may never hope to get all his doctors in one room at one time.

But with IT - the components of which exist today - all these practitioners could be on the patient’s same virtual page at the same time and could better coordinate her care.

IT is only one step, though an important one, toward an improved health care system. The second is a sharper - even a relentless - focus on quality and safety.

All Americans stand to gain from improved quality. We must address the imperative to bridge the “quality chasm.” We have identified some guideposts from the perspective of AARP and its members and families, to assess progress toward achieving quality improvement. These are:

A. Implementation of health information technology to enable physicians, medical and long-term care facilities to conduct clinical and administrative activities in a paperless environment;

B. Collection and reporting of standardized measures of physician, hospital and nursing home performance that will facilitate transparency, public accountability and quality improvement activities;

C. Realignment of provider and practitioner reimbursement to reward high quality; particularly with respect to nursing homes, and

D. Implementation of remedies such as better state oversight, funding for more staff with more training, and reinventing the culture of nursing homes to focus primarily on the quality of life of their residents.

Let me take a moment and discuss each of these individually. As you know, information technology is a key to rapid quality improvement. Innovations like computerized
physician order entry can help reduce errors by improving accuracy and legibility of prescriptions and medical records.

That’s one reason why we are pleased that the new Medicare law contains a provision for electronic prescribing.

IT can provide decision support tools to clinicians, such as: prompts to conduct recommended procedures; timely feedback of lab and other test results; enhance coordination; monitor and modify medications and patients’ progress; facilitate access to evidence-based guidelines; improve access to medical advancements for both clinicians and patients; and enhance physician/patient communication.

As noted by Dr. David Brailer, the problems of high costs, medical errors, variable quality, and administrative inefficiencies are closely linked to the inadequate use of IT as an integral component of medical care.

As we have come to learn, the U.S lags behind other nations in the adoption of electronic medical records, and it will take a strong effort by the public and private sectors to overcome market barriers and the absence of common standards and policies. As we move forward, it will be important to ensure that consumers have access to and control of their personal health information. On this point, consumer access, we believe that AARP can play an important role.

On my second guidepost, Collecting and Reporting Standardized Performance Measures - as a consumer-choice model takes hold in the marketplace, there is a need for information about cost, benefits, and health care quality to support consumer decision-making.

In addition, many purchasers, regulators, and advocates also believe that publishing and disseminating information about the performance of doctors, hospitals, health plans and long-term care providers will advance quality improvement. To support both decision-making and quality improvement, it is necessary to have valid and reliable performance measures.

Continued research by AHRQ and others will help us to better understand the types of measures that will be most meaningful to consumers. We also need to improve the presentation of information to make it more salient and comprehensible.

Too much data will not necessarily translate into better consumer decision-making and, in fact, can lead to bad decisions. Again, I think AARP can be helpful in understanding consumers’ needs and offering consumer-friendly tools.

Next is Rewarding Performance. In our current system, practitioners and providers are essentially paid the same whether or not they provide quality care. Thus, there is little financial incentive to improve quality. As
measurement becomes more comprehensive and the number of evidence-based measures increases, then purchasers and health plans can make progress with performance-based reimbursement. Once consumers have sufficient information to be able to factor quality into their decisions, we could consider financial incentives for consumers to choose higher performing providers.

The next guidepost is Addressing Quality Issues unique to nursing homes. We all know that quality problems in nursing homes are widespread. In a recent 18-month period, 20 percent of nursing homes were cited with violations of quality standards that caused actual harm or immediate jeopardy to residents.

Over 90 percent of nursing homes fail to provide the staffing levels needed to provide basic resident care and avoid putting residents at risk of preventable illnesses and injuries. Staff turnover is very high, with several studies reporting turnover rates above 50 percent for RNs and above 100 percent for certified nursing assistants. Most nursing homes are not considered pleasant places in which to work or live.

Remedies that promote more effective regulatory monitoring and oversight, funding to improve staffing, and better decision support tools to help families select the facilities that best meet their needs are all essential to remedying the poor quality of life and care experienced by so many residents and their families.

In the long run, a more efficient, patient-centric health and long-term care system - one that offers the right health care and support services at the right time in the right setting - will improve quality and bring system-wide health care savings. However, we cannot achieve these savings without an infrastructure to support improvements.

Earlier I said that part of our AARP Social Impact Agenda is navigation—the access to information and the tools and help to use that information. This is particularly important in health care.

Health consumers need to know more about the physicians and hospitals available to them, about medications, both prescription and over-the-counter, about prevention, about healthful behaviors, and so much more. There is plenty of information available, of course. I referred to it earlier as a welter. But it’s also helter-skelter.

Right now, someone seeking health or medical information must have some luck and good hunches, useful contacts and computer skills to get what they need. But for those who don’t have all that - including many of our members - we intend to help people navigate the web to locate and use valid and reliable information. We are considered a trusted source and we think we can do this.

Last summer, we launched a 1.0 version (consisting of links to Healthwise, the National Library of Medicine’s Medline Plus, and Medicare Interactive) to test the feasibility of our offering navigational assistance to people seeking health information on the Internet. We call our site the AARP Health Guide.

The response to the test was encouraging, and we are now considering ways to expand this tool to make the information personal and interactive. Of course, many of the improvements we’d like to make depend on a robust health information infrastructure.

Using IT more efficiently, focusing on wellness as much as on disease, establishing a culture shift so that quality becomes a system feature of health care, expecting accountability, and rewarding high-quality care are not revolutionary ideas. They already exist in other sectors of the economy — but not yet in health care. In other words we have the parts of the infrastructure. But, as it often says on the box, “some assembly is required.”

We intend to be as supportive of this assembly as we possibly can. We all know that the infrastructure is not an end in itself, but a means to a very good end - better health for all of us now and for our children and grandchildren. And for AARP, it will be a big step toward our social impact goal of independence, choice and control in ways that are beneficial for older Americans and for society as a whole.
Speech by Dr. David Brailer, national coordinator of information technology, HHS, to HELP conference on Jan. 14, 2005:

I appreciate very much your having me come and join you to talk about the ongoing work of the Health Legacy Partnership. We announced in July 2004 the Decade of Health Information Technology, A Framework for Strategic Action.

We did that for two reasons: the president gave us 10 years to get this done; and it coincided with one of the anniversaries of the landing on the moon. Just as the moon landing took 10 years to accomplish, framing the president’s health IT goal in a similar timeframe puts this effort into context.

The convergence of numerous activities and active debate not only in the administration and the private sector but also on Capitol Hill and elsewhere has resulted in considerable movement on the health IT front. Acting on this momentum, the government will serve as a catalyst for change.

We know from numerous studies that there is a systematic and reproducible health status benefit that comes from the use of good, timely, clinical information at the point of care and that information technology, like electronic health records (EHR), are the only way we can get that information to the requisite people in the appropriate amount of time. Whether a physician uses this information during an office visit, during complex treatments delivered in a hospital setting, or by patients or consumers, we recognize that information is therapy. We have reached a point where there is little debate about the benefit that comes from this. It is time to figure out how to do this for all patients and providers.

Why then, if the benefits are so obvious to some, has it not happened on a wider scale? Some will tell you it’s because physicians don’t want to change the way they practice medicine. I am a physician and I can tell you that I’ve never seen physicians walk away from new therapies when they see a benefit to their patients. But, moving towards using health IT can be complicated and expensive. In economic terms there is a “first-mover” disadvantage.

Today there is no reason to put in place interoperability if other providers are only thinking about their own practice. While buying an EHR may result in some workflow benefits, there are several challenges that must be overcome. These are not about technology. This about changing the businesses’ purpose, strategy, role, interaction, relationship to customers, work with employees, and communication methods.

We have seen what happens whenever the adoption of EHRs is seen as a technology purchase - it fails. It does so appropriately because it is a sign that management did not understand what they were doing. And, when it is seen for what it is, a vector of change in how the business operates and relates to its customers, and does what it’s supposed to do - produce good care - it can succeed.

However, it remains inordinately complicated. It is no surprise for instance that the Commonwealth Fund, the Center for Studying Health System Change, and others, have shown an adoption gap between the big and the small providers.

Therefore we have these two big challenges - the interoperability gap and the adoption gap that have really stymied how the market moves forward.

And this is why there is a legitimate role for government to deal with these. These are market failures, which could worsen. If the adoption and interoperability gaps are not addressed, it is not hard to imagine what could happen. Big organizations put in electronic health records, which are not interoperable, therefore data is not portable outside of their boundaries. We know that there is very good evidence that EHRs, even those that are not interoperable, can lower operating costs in large organizations by offsetting transcription costs, improving their revenue, improve their communication processes with customers, and strengthen physician retention and affiliation preferences. These are all things which are good for business operations and which help maintain and grow market share.

This speaks to why every industry in America put in point-of-service automation, whether it’s retail, computer systems in grocery stores, clothing stores, or its wholesale supply management systems or, in the case inventory based businesses, for instance, for logistics systems in transportation. I recently spoke with Fred Smith, the FedEx

Joe, you’ve given us all a benchmark for persistence and vision. We’re living the life of Joe Kanter’s vision.

– Dr. David Brailer
CEO who explained that FedEx is a company that is truly one big computer system that happens to have a bunch of trucks and planes.

Health systems that have put these systems into place could not go through the complexity, the challenges, the relationship issues, the risks, without having a patient care improvement purpose in mind. But, they also get a strategic benefit out of it. So, in that world where we don’t address the adoption gap, or the interoperability gap, we will end up with very large systems that already have significant market power, having a lot more market power. A level playing field is therefore needed.

Today a lack of standards exists. We want to see a certification process set out a minimum set of standards, not only for communication of data but for security and for functional features including certain types of decision support. The certification process could be viewed as a good housekeeping stamp of approval. This will help physicians know what to look for when they are buying an EHR product.

If these products become standardized, the question becomes how do we connect them together so that the exchange of data can happen between two EHRs with nothing in between? A world that is broker free has not yet been defined. And, even if that could happen, how do we deal with all the multilateral exchange where data exists in laboratory systems and pharmacy systems, hospital systems, various other practice systems? This is not yet feasible but it can be done. It’s been done in other industries and its been done in healthcare for claims.

We now need to do it for clinical data. We expect to conduct prototype projects to test out various ideas. The Nationwide Health Information Network will need a national set of connectivity tools and the certification of electronic health records so that they can connect to it. In addition we are also working through the Federal Health Architecture to get the federal government to standardize the way it does health care business. We see significant benefits for federal activities from the Nationwide Health Information Network.

Addressing the adoption gap and addressing the interoperability gap are synonymous with addressing the public policy issues that health information technology have put at our feet. I know we will get to where we need to be, but much works remains. So, what are we doing to get there? We have a number of activities underway. We plan to award contracts this fall in response to four requests for proposals which will address issues concerning EHR and interoperability standards, a certification process, an infrastructure for the Nationwide Health Information Network, and security and privacy for patient data.

Lastly, the American Health Information Community (the Community), a group of leaders representing various stakeholder interests from outside the federal government as well as leaders from within who represent departments and agencies heavily involved with health care purchasing and delivery, will come together this fall to provide recommendations to the Secretary of HHS, the chair of the Community, on how best to advance solutions to meet the president’s goal for widespread adoption of interoperable EHRs within 10 years.

There will be significant activity underway this year to continue to address the adoption and interoperability gaps as well as several other key areas.

---

I am pleased that the foundation has chosen Arnold & Porter to provide legal services that assist the foundation in carrying out its charitable and educational purposes and providing very important public benefits.

– Richard Hubbard

Dr. David Kibbe of the American Academy of Family Physicians chats with participants.
Harnessing Health IT To Make Better Decisions

Speech by Dr. Carolyn Clancy, director of the Agency for Healthcare Research and Quality, to HELP Conference on Jan. 14, 2005:

The Agency for Healthcare Research and Quality has been glad to work with Joe Kanter and the Health Legacy Partnership over the last five years. The foundation’s activities and these conferences have stimulated discussion in areas vital to future of the American health care system.

Joe’s interest in this arena was stimulated by early work on shared decision-making. This pioneering work by Jack Wennberg and his colleagues was inspired by the radical idea that when there are two or more options, the penultimate decision-maker must be the patient.

An important consequence is that the patient’s preferences and decisions are often quite different from those that doctors might make on their behalf. This may cause some discomfort for the clinician, but we know it’s the right thing to do for the patient. We hope that decisions about treatment are being made each day by informed patients who are working in partnership with their clinicians using good information. We all know that in many cases, this is still the exception.

The good news is that we now have the knowledge and the tools that can make this scenario the rule in the American health care system. Early adopters have invested in electronic health records, decision support and other tools that make the right thing to do the easy thing to do. And communities have launched initiatives to assure that patients’ information is available and accessible when it is needed.

I am very proud that AHRQ is on the leading edge of this health care revolution. In 2004, AHRQ made an initial investment in President Bush’s vision for a HIT-driven health care system. This is a very broad-reaching initiative that is an important means to an end.

AHRQ has recently funded $139 million for more than 100 multi-year demonstration grants and contracts to promote the use of health information technology. This will enable caregivers to improve patient safety by reducing medication errors and duplicative or unnecessary testing, and helping ensure that important information follows patients as they move among health care settings.

In addition, AHRQ also awarded $25 million in 5-year contracts to five states: Colorado, Indiana, Rhode Island, Tennessee and Utah.

The funding will help them develop statewide networks designed to share individuals’ health information and make it readily available to health care providers when needed.

Lastly, $18.5 million was allocated to establish the AHRQ National Resource Center for Health Information Technology. The National Resource Center will foster collaboration and serve as a source of information on best practices and promising HIT tools.

Our investments in HIT set the stage for revolutionizing how we provide care.

In 2005, Americans are fortunate to live at a time when investments in biomedical science have resulted in a plethora of new diagnostic and therapeutic options. Every day there is a broader array of choices for treating hypertension, heart failure, and other chronic illnesses as well as new techniques for managing cardiac and other diseases.

Unprecedented innovations in diagnostic evaluation and prediction bring us closer to a vision of personalized health care than ever before.

These new opportunities are only the beginning and they present a challenge to clinicians, payers and health care organizations. With greater choices come questions. Which innovations represent added value, or only modest enhancements to current choices? Which fail to reach their potential?

Consumers and patients also face increasing challenges in making health care decisions. As health care expenditures continue to rise, individual consumers are facing differential cost sharing for alternative options and sites of care.

They now have a crucial stake in identifying which options offer the best value for their needs and preferences.

As it stands now, the current clinical research enterprise does not produce the information needed to make informed decisions. We need to do more to develop better evidence about the benefits and risks and the cost of alternative choices. This is imperative.

– Dr. Carolyn Clancy, director, AHRQ
As it stands now, the current clinical research enterprise does not produce the information needed to make informed decisions.

We need to do more to develop better evidence about the benefits and risks and the cost of alternative choices. This is imperative. We also need to know more about the safety of existing products and services.

To fill these gaps, we need to follow two paths: do more with what we already know from the medical literature, and to identify what we don’t know and support research and innovation in a timely manner to fill the void.

However, with over 18,000 clinical trials published in 2004 alone, it is a Herculean task to discover what we know and where gaps still remain.

I am very proud that AHRQ has been a leader in synthesizing clinical evidence on a wide range of health care issues that have addressed a critical need for information.

AHRQ will support systematic reviews on key questions for a list of 10 priority conditions determined by Secretary Thompson: ischemic heart disease, cancer, chronic obstructive pulmonary disease/asthma, stroke (including control of hypertension), arthritis and non-traumatic joint disorders, diabetes mellitus, dementia (including Alzheimer’s disease), pneumonia, peptic ulcer/dyspepsia, and depression and other mood disorders.

These reviews will be kept current, and they will be disseminated to a wide variety of audiences in formats that can be used whenever and wherever they are needed.

We are deploying the power of HIT to develop and deliver the best possible information to clinicians and patients in real time -- and to give consumers the tools they need to be full partners in their health and health care.

This will revolutionize the practice of medicine and the delivery of health care services. We have an unprecedented opportunity to improve the health of all Americans.

---

Dr. Carolyn Clancy, head of the Agency for Healthcare Research and Quality, warns about medical errors.

---

Dr. Sean Tunis, chief medical officer, Centers for Medicare and Medicaid Services
Working Toward Consensus On An Outcomes Database

Speech by former Senate Majority Leader Bob Dole to the 2003 HELP conference:

I got a call one time from George Mitchell who asked if I knew Joe Kanter. I didn’t, and George said, “You ought to talk to this guy. He knows a lot. He’s had prostate surgery, about your age, and maybe there are some things that we can do together that might help figure out what treatment options work.”

I’ve had a lot of operations. I had all kinds of problems in World War II, including a couple of fractured vertebra and a paralysis in the neck down, and then losing my right kidney, and then having a couple of hernia operations and an operation on the left kidney, and then having prostate surgery and then an aneurysm about two years ago.

So I’ve had a lot of opportunities to meet a lot of doctors and they’re outstanding people. There’s no reason I should even be here today.

I want to thank Joe Kanter. I learned a lot from him. This guy had prostate surgery and wasn’t certain what to do. And I remember when I had prostate surgery in 1991 I wasn’t certain what to do. I was like everybody else. They said the “C” word and I was scared. I thought this must be the end.

And so I started looking around very quickly and thought about whether I should have radiation, should I have surgery, should I have watchful waiting? And I opted to do the radical prostatectomy.

But it would have been nice at that time to have an outcomes database and review it with a doctor who could say, ‘Well, we’ve done this, this, this, and this, and this seems to be the most successful.’

– Bob Dole, when he was diagnosed with prostate cancer

It would have been nice at that time to have an outcomes database and review it with a doctor who could say, ‘Well, we’ve done this, this, this, and this, and this seems to be the most successful.’

well, just get it out of there and forget about it, not worry about it. And that’s what I chose to do. I’m in good health and quite active and doing a lot of things.

This is very, very important. The fact that Sen. Mitchell and Joe Kanter and others here have been able to work together in a nonpartisan, bipartisan basis makes all the difference. I can’t recall any legislation that was passed when I was in the Senate for 27 years that really had an impact unless it had bipartisan support.

You’ve got to get a consensus. Once you have a consensus and you’re able to bring people together who have different ideas and different views at the beginning, you’re probably going to end up with pretty good legislation.

I’ll just give you one example: the Social Security legislation in 1983. I had the great honor of working with a departed friend, Pat Moynihan, a Democrat, on Alan Greenspan’s commission. We worked and we worked and we knew we had to do something.

Before long we had Speaker Tip O’Neill and President Reagan agreeing to a bill that nobody liked. Nobody thought it was any good, which probably meant it was a pretty good piece of legislation. That’s because everybody had an opportunity to contribute something to the legislation.

So we fixed Social Security. We thought it was going to be for 75 years, but if it’s 40 years that’ll be a big, big achievement for seniors who rely on Social Security and Medicare.

We live in an entirely different world from when I first became a patient way back in 1945. And you just look at all the technological advances since that time. And it’s strange to me that somebody hadn’t thought of this outcomes database long before.

We hope to be able to work with people in almost every state and make an outcomes database a part of legislation. Joe, I thank you for your contributions, your wife, your family, the fact that you’re willing to give your time, your money. Because you believe in what you’re doing is, I think, what America’s all about.
Let’s Use, Not Waste, Resource of Medical Data

Speech by former Senate Majority Leader George Mitchell to HELP Conference on Oct. 22, 2003:

This is an important conference about an objective that we all share. And it’s one of those rare public policy issues on which there really are not two sides to the question.

The potential benefit is indisputable and therefore, given the enormous need, it’s imperative that all of us do all we can to realize the objective, which really has only one purpose - to help save lives, and help Americans live healthier, better, longer lives.

It’s hard to think of a more noble objective. I’m especially pleased to join with my colleague, Sen. Dole. I served for six years as the majority leader in the Senate. During that time Sen. Dole served as the minority leader. We disagreed on many, many issues, but I’m proud of the fact that never once did we have a personal disagreement. We recognize that it is possible in our democratic society to disagree in a civil and responsible way.

And as a result of that, we developed a close friendship, which has extended beyond the Senate. So when Joe Kanter and I started working together, I told Joe that I thought that one person who really could help in the effort was Sen. Dole. And of course he’s done so and has become the official spokesman.

In 1997, Bill Frist and I joined with Joe Kanter at the National Press Club to talk about Joe’s vision of creating a national health outcomes database. The goal was lofty. It was, and is, an enormous challenge. But in the intervening six years we’ve seen great strides made by many groups in and out of government to achieve that objective. The Agency for Healthcare Research and Quality is working on several programs involving the collection of data to help patients and caregivers.

Although it has received little public attention, I regard the creation of the agency and the establishment of its mission as one of my most significant Senate accomplishments. When I first introduced legislation to create the agency, then known as Health Policy and Research in what was then known as the Healthcare Finance Administration, I had an incomplete understanding of the problem and little realization of the enormous potential.

And that’s why I was so pleased that the Kanter Family Foundation and the current agency have teamed up to create the Health Legacy Partnership and to bring it to the stage it’s at today. I regard it as a continuation and hopefully a completion of the effort that I began so many years ago.

The Kanter Family Foundation, the American Academy of Family Physicians, the eHealth Initiative, and the Markle Foundation are working with several government agencies to provide better, safer, more efficient health care for all of us.

As everyone in this room is aware, and I think most Americans are aware, very little of the information gathered around the country at hospitals, clinics, and doctor’s offices is shared with others. This medical data is, in a very real sense, a national resource that’s being wasted - literally kept on the shelf when it could be available to help others in their search for good health.

With the advent of technology, why can we not create a centerpiece of information that can be used to heal, to cure, to save lives? Other industries have done it - transportation, finance, hospitality, and many others. But our health care system, so critical to the individual health of every human being, is lagging behind.

As I said earlier, it’s one of those rare public policy issues in which there simply is not a valid and sustainable argument in opposition to the proposal.

This national outcomes database is so simple, so logical, and will be so powerful in its implementation that it boggles the mind our society has not done this before now.
Speech by Senate Majority Leader Bill Frist to HELP Conference on Oct. 22, 2003:

As a physician and a scientist as well as a senator, I have a unique perspective on the mission of the Health Legacy Partnership. In 1997 I joined my friend Joe Kanter and former Democratic Senate Majority Leader George Mitchell at the National Press Club in bipartisan support of improved research on national health outcomes.

Since then a government-private partnership between the Agency for Healthcare Research and Quality and the Kanter Family Foundation has co-founded the Health Legacy Partnership, which has over 200 supporting partners of national health associations, not-for-profit organizations, health care leaders, government agencies, and for-profit national corporations.

Much has been accomplished. The Centers for Disease Control has made tremendous progress in their effective management and collection of data for a bioterrorism and infectious disease database. Together CDC and AHRQ recently announced the funding of 22 projects called a Partnership for Quality. We are recognizing that information technology has the potential to help all Americans.

There is still much more to be done. We are moving further in the direction of improving patient outcome, supporting chronic disease management, and integrating new technology into health care through the Senate-passed Medicare bill, patient safety legislation, and other areas of focus.

By supporting the expansion of quality patient outcomes research, we can make great strides in improving health care for all Americans. We must continue to move forward in the collection and the evaluation, dissemination, and analysis of information related to everyday health care, which can then be made available to clinicians and patients on all sorts of illnesses and what works best.

A recent Rand health study conducted on behalf of AHRQ and the Kanter Family Foundation concluded that based on discussions with patients and clinicians, it is clear that comparative outcome information is lacking for many treatments and that patients make difficult decisions every day with little or poor information to inform those choices.

I do want to acknowledge a few people. First, Joe Kanter. Joe, I appreciate your continued support. I’m glad to be a continuing part of your efforts to improve health care for all Americans. Keep up the good fight, Joe. All of us here are with you. To my friends and colleagues Sen. Dole, Sen. Mitchell, and the participants of this conference, we all appreciate the work you’ve done on critical health issues.

I appreciate your desire to look for continuing opportunities to improve health care outcomes research and provide appropriate incentives for industry to embrace new technology that can improve patient care.

To all of you at today’s conference, the Senate will continue to address these critical issues through the Medicare bill, enhanced patient safety efforts such as insuring the confidentiality of information used to analyze and improve patient care, and through an ongoing focus on the important role of health outcomes research to improve the quality of care for all Americans.
Medical Outcomes Database Can Cut Costs, Help Patients

Opinion piece written by former Senate majority leaders Bob Dole and George Mitchell. Reprinted from Aug. 17, 2003, Washington Times:

In the weeks prior to the August recess, Congress worked diligently to address a variety of health care issues, including reforming Medicare and expanding access to our nation’s health care system. While these issues are certainly vital, we must not overlook the importance of another aspect of health care reform, which is actually improving the quality of health care services being delivered. One way to do this is to improve the information available to our doctors, hospitals and patients – allowing them to make better, more informed decisions.

When patients in our country are faced with a serious diagnosis, often they solicit medical opinions from a variety of qualified physicians and surgeons. In response, patients often find they receive a surprising variety of different, and sometimes opposing, treatment recommendations. Typically, what patients really want to know is, for a person of their age and health, which of the treatment alternatives provide the greatest probability of achieving the desired outcome? Unfortunately, most patients quickly learn this type of information is not readily available to them or to their doctors.

A friend of ours, Joe Kanter, discovered this reality when he was diagnosed with prostate cancer and felt unable to determine the best course of treating the disease even though he had the resources to access the best information available. He has since devoted much of his life to the vision of a National Health Outcomes Database, a database that would help present information to providers and patients on the best treatment alternatives available for a particular patient. The Kanter Family Foundation has formed a unique public-private partnership with the Department of Health and Human Services called the Health Legacy Partnership, which is setting health policy and working toward assisting in the development of the database.

Patients today, like Mr. Kanter, are demanding to play a key role in their own health care decisions. We see this in many forms – from a growing focus on elective surgical procedures, to consumer-driven health plans, to use of the Internet as a tool to learn about a diagnosis and its treatment options. These patients want trusted information to help facilitate important decisions.

Unfortunately, our nation’s health care system does not currently have an effective means of collecting and tracking information that can provide patients with statistical evidence of the most effective treatment options. By creating a national database, we can enable a centralized repository of “outcomes data” that makes use of information technology to model and predict the best course of treatment for a given patient diagnosis and profile.
Nothing can replace the tremendous skill of our nation’s physicians. But increasing the amount of information available to both health care professionals and patients alike equips them with better information for making informed decisions. Indeed, this “evidence-based medicine” approach is gaining acceptance and popularity all across our nation’s medical establishment, and new technology in our hospitals is providing the tools our professionals need to make effective use of evidence-based guidelines.

Some of our own government agencies have started to take the initiative on this issue. For example, the Centers for Medicare and Medicaid Services has begun to recognize the importance of empowering consumers with data about their health care. This agency currently provides information to consumers about how well certain providers, such as nursing homes and home health companies, care for some of their patients.

Capturing information related to outcomes can also help to significantly reduce health care costs. In determining the best course of treatment through empirical evidence, we can reduce some of the wide variation in treatment patterns found between different hospitals and physicians. Employing a more standardized approach in health care, based on good data, can help us achieve significant cost savings and productivity gains through economies of scale.

While a national outcomes database is closer to reality, it will take many years to complete. And although there are many challenges to creating this sort of database – everything from actually defining an outcome, to systems for the collection of data, to privacy safeguards – the potential quality of care benefits outweigh the obstacles and demand our best efforts and attention.

Americans benefit from the highest quality of health care in the world. But progress in medical science is based on the accumulation of knowledge over time. That makes a national health outcomes database not only essential but just plain common sense.

Bob Dole and George Mitchell both work with the Kanter Foundation.
A Quiet Revolution Needed
To Share Medical Information

In an urgent call for more useful data to assist patients and doctors, Dr. Robert Brook helped set the tone for the first Kanter/HELP conference in 2000:

Dr. Brook is director of RAND Health and professor of medicine at the University of California, Los Angeles.

It is impossible for me as a physician to deliver good care. Let me explain why.

Over the last 30 years we have invested heavily in the technology of basic science and clinical science, and we have revolutionized the way we deliver health care.

But we have paid insufficient attention to the mechanisms and the systems by which we actually provide that care.

As a result, it is impossible for me to provide the information that patients want when they come to see me. It’s absolutely impossible, even though I’d like to do it, as would virtually all physicians. It is also impossible for patients to make good decisions about their care without this kind of information.

What is this information that is lacking and so necessary? We need a movement that says: It is to the advantage of everybody to put their medical information in a secure database so that we can benefit from each other’s experience.

– Dr. Robert Brook, 2000

If the patient asked “Is the surgery we do today the same as that done 30 years ago,” the answer would be no.

If the patient asked the final question – “If the surgery has changed and the medical therapy has changed, how do you know I should have surgery as opposed to medical therapy?” - the doctor would probably have said, “Hey, maybe we don’t know that.”

Data to answer these kinds of questions are not collected and evaluated in a systematic way. We haven’t kept up to date with information about therapies and what they imply for patient care as the therapies change over time.

Here are three key questions that patients ask:

• What treatment is best for me?
• What will happen when I get that treatment?
• Where should I go for it?

When patients ask these questions, they aren’t interested in what happens to the average person. They want to know, “What’s going to happen to me?” It doesn’t really matter what the averages or probabilities are.

What is “me”? “Me” is made up of a lot of things – demographics, social circumstances, knowledge, attitudes, expectations, and the things that each person values in life. If we are going to produce more knowledge to help patients and physicians make better decisions, we must collect this kind of information about people.

Then we must put it in an accessible database so people can get information tailored to them, not to the average person.

What is this going to require? To provide information that is relevant to many different individuals, we need large databases. We need detailed clinical information. We need new analytical methods to improve our understanding of the data.

The information has to be useful, on a real-time basis. People should have, in their home, a system that allows them to get answers to questions such as those above.

Making this information available will change the balance of power between physicians and patients. As a physician, I am not worried about that. I think most physicians are beginning to be not worried, knowing that if patients are more equal to us in power, together we will achieve better health outcomes.
To make these databases valuable, we will need as close to 100% participation as possible—from both patients and physicians. And we will need significant financial support, probably from the federal government, because the database will only be useful if the information in it is of high quality.

Let’s imagine how these data could be used. Suppose we have research showing that if a patient over 65 is admitted to the hospital with a heart attack, the likelihood that the patient will die is 15% in hospital A and 20% in hospital B. Obviously it makes a big difference which hospital the patient chooses. It’s conceivable that the kinds of databases described above could help patients decide not only what treatment to choose, but also where to get it.

Here’s another situation where data from patients would help: I will bet not one of you who has had surgery didn’t experience more fatigue and difficulty getting back to normal activities than what the doctor predicted. The doctor is not trying to provide incomplete information. The doctor believes in what he or she is doing. But that commitment sometimes produces an exchange with patients that is misleading.

The doctor is not trying to provide incomplete information. The doctor believes in what he or she is doing. But that commitment sometimes produces an exchange with patients that is misleading.

So we need data from patients as kind of a counter force to produce realistic estimates of what will happen to them if they get a procedure, experience illness, etc. For example, it would be nice to know that the average woman reports being tired for three to five months after a hysterectomy, as opposed to one month, which may be what the treating physician told her. Information from such a database could provide reassurance and support for other patients. How are we going to change this situation? It’s going to take a quiet revolution. It’s going to take a radical change in the way we think about medical information.

We are so concerned about the confidentiality of our information that we are not willing to share it. We need a movement that says: It is to the advantage of everybody to put their medical information in a secure database so that we can benefit from each other’s experience.

So there is a whole set of exciting things we can do in this area. In order to move ahead, we need a constituency, we need everyone’s cooperation, and we need to make developing these kinds of data central to our efforts to improving our health system so that everyone benefits and lives as long and healthy a life as possible.

I often tell people what Bob Brook told me years ago: “I can’t give quality care to my patients, and neither can any other physician, because we lack the data. That’s why we need more outcomes data and a national health outcomes database.”

– Joe Kanter

In April 2004, President Bush set a 10-year goal of creating personal medical records for most Americans and an interoperable system of medical data available to providers and patients.

– George W. Bush

If you want to be part of this constituency call 202-349-9853 or email www.healthlegacy.org with your contact information.
Independent Board Needed to Oversee Data

Speech by Dr. Paul Elwood of the Jackson Hole Group to HELP Conference on Jan. 14, 2005:

Every facet of our health system – cost, quality, access and even our vaunted research enterprise – is falling dangerously below its potential. It’s time we rethink how we approach health care reform.

One significant problem is that our outmoded health system fails to routinely measure and analyze health outcomes and to apply the results in caring for patients. The Vioxx controversy and other widely publicized clinical surprises like it involving post-menopausal hormone therapy, antidepressants for children and the Atkins diet are symptoms of that failure.

Paradoxically, medical inflation and uneven quality are the result of contemporary health care’s success treating chronic illnesses and prolonging life. This has been achieved largely with powerful drugs that are designed to influence critical biochemical processes. Most of us outwardly “healthy” seniors are mini-biochemistry laboratories testing and exceeding the limits of today’s health science.

All of these blockers, enhancers and inhibitors have unintended influences and unpredictable effects beyond the purview of clinical trials and the average practitioner. The confounding impacts of aging, drugs, surgery and lifestyle changes can only be sorted out by keeping track, pooling and analyzing what works for patients and clarifying the odds of undesirable side effects.

Progress has outstripped medicine’s historical way of doing business. Catching up is going to involve continuously measuring, managing and using clinical methods that are consistent with what we learn.

The health system will continue to be out of control until we establish a permanent independent, quasi-governmental institution whose responsibility is to guide the behavior of the health system without directly participating in its operations. One possible model for this approach is the Federal Reserve System.

– Dr. Paul Elwood

Our health system teaches tough lessons to those who try to rely on traditional methods of reform. Here are some of those lessons:

Restructuring the massive health enterprise takes far longer than anticipated. It does not follow prescribed patterns. It requires decades of continuous and pragmatic leadership. Since 1979, Medicare has had 22 chief administrators or acting administrators. Each has had to learn on the job how to run a $400 billion insurance company that is supposed to serve as a model for the rest of the health system.

Health reforms are increasingly imperiled by the power and ruthlessness at every level of the medical-industrial complex constantly pressing for the indiscriminate use and pricing of their products and services while blocking or subverting needed reforms. The resources and skill of health industry lobbyists and marketers has sharpened to the point that voices of ordinary citizens and patients have been drowned out by the voice of health commerce.
Until recently I was convinced that consumers, given adequate information about their choices, could effectively influence both the cost of health insurance and the quality of health care. As a practicing physician interested in health policy, I was absolutely against some remote bureaucrat telling me how to practice medicine. I was wrong!

The original HMO/managed care theory was that if consumers were given the opportunity to make informed choices between health plans that were competing on price and quality, they would choose a plan that best suited their needs. Consumers were exceedingly sensitive to price differences between health plans. Despite our convictions about informed consumers having sufficient influence on the overall quality of healthcare, the health system and consumers have not adequately responded to quality concerns.

Patients said they wanted to know about the quality of their own doctor, a question that proved to be impossible to answer in the absence of a process or outcome data on the performance of individual physicians. Shortly after the collapse of the Clinton health plan, it became obvious that effectiveness of any health reform depended on parallel success in controlling costs and assuring quality. The managed care plans had lost their legitimacy in assuring quality.

Uncertainty about what constitutes effective health care, lack of accountability for results, and piece-work incentives add up to uneven provider performance.

Despite advances in therapeutic and diagnostic capabilities, repeated studies over the past 30 years confirm that best practices are followed slightly over half the time. Patients experience widely varied care based on where they live, who they consult and their perceived diagnosis. Professionalism and peer pressure forces have not eliminated poor care.

After 40 years of pushing patient power and physician autonomy, I concede the situation in health care is deteriorating so rapidly that it is unwise to continue to rely on appealing but failed theories about the magnitude of consumer influence on the quality of our health care.

We need to shift our focus to clarifying what works and the consistent adherence to evidence-based methods by providers and their patients. The extensive collection and sharing of health outcomes data will allow patients to become more informed and active participants in the management of their health, but they are going to need outside help to make sure they get appropriate care.

The integrity of the entire medical system depends on those making clinical decisions choosing interventions that work and are worth it. The HealthFed should be given the responsibility to develop and reinforce evidence-based clinical standards as their principal tool for managing the health system.

The HealthFed will need the power to demand and interpret essential health outcomes data for guideline development on all significant clinical conditions. The increasing demand for data based on patient and clinician experience and the greater ease in applying guidelines with electronic medical records will drive the use of information technology. But electronic systems will not be the norm in physicians’ office until they are needed to practice medicine.

The HealthFed will require leaders and experts who have no conflicts of interest to produce unassailable evidence-based guidelines. Its challenge will be to collect the data and assure adherence to those appropriate guidelines.

The HealthFed must enhance the competitiveness of those carriers and providers who adhere to its standards. The concept I like best for justifying and motivating the
routine collection of outcome information and reliance on evidence-based practice guidelines is taken from another page of the banking system playbook: The Federal Deposit Insurance Corporation’s protection of bank deposits up to $100,000.

The deposit guarantees are extended to the depositors in banks that meet Federal Reserve and FDIC standards. Like the banking system, the health system could benefit from federal insurance or reinsurance of high-cost patients. Federal health reinsurance might cover health care costs for an individual exceeding $50,000. To be eligible for federally guaranteed reinsurance, patients, providers and insurers would have to meet the data collection and evidence-based clinical quality standards of the HealthFed.

If the costs of the federal health reinsurance program exceed congressionally-determined health budgets, the HealthFed would have the responsibility to determine the cause of the cost overruns and have the option of expanding or tightening the health care clinical guidelines.

Federal reinsurance of health care has an additional potential virtue: helping to prevent “genomic cherry picking.” Health insurers have become increasingly adept in a competitive environment at avoiding people with the greatest health risks - a practice labeled “disciplined underwriting.” We need some other means of insuring high risk individuals and making certain that everyone has access to health insurance regardless of their health status. Federal reinsurance could protect high risk individuals.

Our proposed theory, tools and powers for the management of the health system by a HealthFed is to let the market determine the prices of health insurance and the structure of health care organizations, but to assure quality through federally-specified standards.

The HealthFed would guide the health system with consistent leadership, outcome information and quality assurance tools.

HHS Secretary Mike Leavitt in promoting his 500 Day Plan said, “The President of the United States has given me a very clear mission to help Americans live longer, healthier and better lives, and to do it in a way that protects our economic competitiveness as a nation.”
Quality initiatives are now focused on reducing the under use of effective care. While paying providers to do things they should do will very likely improve the quality of care and save lives, it is unlikely to have a major impact on rising costs. Only a relatively small proportion of the health care dollar is influenced by effective care. However, because under use of effective care is not associated with overall Medicare spending, one should not assume that doing the right thing will of itself lead to a reduction in per capita spending. To have a significant impact on Medicare costs, pay-for-performance strategies must be directed to the other two categories of care.

Most health care dollars, at least for Medicare, go to categories where the problem is not under use. More than 50% of Medicare spending is used to buy visits to physicians, diagnostic tests and hospitalizations, mostly for patients with chronic illness, an area where the important problem is overuse because more is not better. Unless pay-for-performance focuses on rewarding providers who are efficient in the delivery of supply-sensitive services it will have little impact on overall costs and poor quality associated with too much care.

A significant proportion of Medicare spending is for discretionary surgery, where the quality problem is misuse of care. Unless pay-for-performance can reward providers who improve the quality of patient decision making for these services, it will have little impact on the cost and quality of preference-sensitive care.

The impact on cost and quality of care of high deductibles and medical savings accounts will also depend on the type of care. If targeted to influence patient decisions that involve expensive treatments such as discretionary surgery, making sure that patients have a financial stake might improve the quality of decision-making as patients seek information on treatment options and reward providers that offer high decision quality.

However, as a tool for addressing the use of care among the chronically ill, the strategy is problematic. The volume and costs of such care becomes progressively higher as illness progresses, reaching a crescendo toward the end of life. Even well-endowed savings accounts would be exhausted relatively early in the course of serious chronic illness and would have little influence on costs. Moreover, when the goal is to increase appropriate utilization, as it is in the case of immunizations, it is hard to see how financial considerations that discourage patient access can help improve quality.

Effective care interventions are medically necessary care - on the basis of clinical outcomes evidence, preferably from randomized clinical trials. The benefits are thought to so outweigh the risks that virtually all patients with a specific medical need should receive the service. Most effective care is under-used. Recent research found that patients received recommended care only 54.9% of the time.

The Dartmouth Atlas Project has had only limited success in measuring effective care using claims data, either because the population at need cannot be accurately defined in the claims, or the item of necessary care is not paid for by Medicare. For those we have been able to measure, we have found extensive underuse of effective care. For example, in several hospital referral regions in 2001, fewer than 50% of Medicare enrollees with diabetes had recommended eye examinations. The underuse of effective care relates in large part to the lack of the infrastructure necessary to support systematic compliance with guidelines.

Organized group practices such as Kaiser Permanente have achieved guideline compliance that exceeds that of fee-for-service medicine. Enrollees in traditional Medicare in regions or states with fewer specialists and more family practice physicians (and less Medicare per capita spending) are more likely to receive effective care. Patients with chronic illness who live in high-spending regions also tend to have many more physicians involved in their care, raising questions about who is in charge and responsible for assuring that needed care is provided.

Geographic variations in rates of surgery that reflect physician practice style will persist until patients are actively involved in the decision process and there are incentives for physicians to adopt shared decision-making.

– Dr. John Wennberg
A remedy for unwarranted variation will depend on finding ways to change the economic incentives, most specifically to change the behavior of patients and providers. Changes need to be specific to the category of care. For effective care, where physicians are paid to do more, incentives are well aligned and the effects on the health care economy would be minimal as these services themselves cost little. Identifying patients in need will become easier and easier as electronic medical records become more widely used, and the process may be accelerated by pay-for-performance.

Preference-sensitive care comprises treatments that involve significant tradeoffs affecting the patient’s quality and/or length of life. The surgical options for the treatment of early stage breast cancer, for example, usually include mastectomy or lumpectomy. The Dartmouth Atlas has noted striking variations in the proportion of early stage breast cancer patients who undergo lumpectomy. In an early study (1992-93), we found regions in which virtually no Medicare women underwent lumpectomy, but one region in which almost 50% did. Sometimes, adjoining regions had strikingly different rates. For example, in the Elyria, Ohio, hospital referral region, 48% of Medicare women had breast-sparing surgery for early stage breast cancer, while in Cleveland 23% did and in Columbus 12% did.

Idiosyncratic practice style is the major source of such variation in rates of discretionary surgery. A common counter argument is that patient preferences dominate decision-making, and that rates of surgery vary in proportion to variations in preferences. Under this theory, the interpretation would be that 48% of women with early stage cancer in Elyria preferred lumpectomy, while in Columbus only 12% did, and in Rapid City, S.D., only 1% did. The question is whether in “usual practice” the physician’s recommended course of treatment corresponds reasonably closely to the patient’s informed preference.

Experimental evidence that physicians’ opinions and patients’ preferences for treatment might not be well correlated comes from clinical trials of shared decision-making, aided by patient decision aids. Shared decision making is the process of interacting with the patient to help him or her make informed, values-based choices among two or more medically reasonable alternatives, and patient decision aids are standardized, evidence-based tools designed to facilitate that process. They are designed to provide: benefits of available options and, if appropriate, a discussion of the limits of scientific knowledge about outcomes; values clarification to help patients in sorting out their values and preferences; and guidance or coaching in deliberation.

There have been clinical trials of patient decision aids for a number of conditions that involve discretionary surgery, including the choice between lumpectomy and mastectomy for early stage breast cancer; the choice between invasive cardiac treatment or more conservative medical management for chest pain due to coronary artery disease; and the choice between surgery and conservative management for patients with back pain due to disc disease. The trials show that, compared to a control group, patients who use decision aids are better informed about the risks, benefits and clinical uncertainties associated with the treatment options. Moreover, the choices patients make in the shared decision-making environment (aided by patient decision aids) are “better” decisions: they more closely reflect the patient’s own values.

Finally, most clinical trials show a net reduction in demand for the more invasive surgical options. A recent study by Gillian Hawker and her colleagues in Canada speaks to this point. The researchers conducted a population-based interview study to screen for patients with pain that might signal arthritis of the knee. The patients were then examined by physicians and X-rayed to define a patient population that would benefit from knee surgery. The number of patients defined as clinically appropriate for surgery exceeded the rate of surgery for the corresponding age and sex groups by a factor of more than ten. The most important finding was the striking contrast between need for surgery as defined by physicians and need as defined by patient preferences. When these patients were interviewed concerning their preference for treatment, only 14% indicated a preference for surgery.

Knee replacement, hip replacement, and back surgery vary remarkably. Knee replacement and hip replacement are four and five times more variable than hip fracture repair, respectively, and back surgery is about seven times more variable. There are sometimes remarkable differences among neighboring regions. In 2000-01, the rate of knee surgery in Fort Myers, Fla., was three times higher than the rate in Manhattan. The rate in Sarasota was 2.5 times higher, and the rate in Fort Lauderdale was 1.8 times higher. Among these same communities, the rates of hip replacement were twice the rate in Manhattan, and back surgery rates were more than three times higher in Fort Myers and Sarasota, and two times higher in Fort Lauderdale, than in Manhattan. By contrast, the rates for Miami were much closer to those of Manhattan than to the other South Florida medical communities: Hip replacement rates were 11% lower in Miami while the rate of knee surgery was 26% higher and the rate of back surgery was 39% higher. In theory, the differences among these communities in rates of knee and hip replacement and back surgery could reflect differences in patient preferences about treatment, or the incidence of osteoarthritis and/or herniated discs. In light of the evidence, this seems unlikely. Moreover, there is no epidemiologic evidence that illness or informed patient preferences vary as sharply according to the boundaries of health care markets as does surgery.
The behavioral basis of the surgical signature phenomenon rests in the propensity of local surgeons to specialize in a particular subset of the orthopedic surgical workload and in the workshop’s ability to find candidates that meet clinical appropriateness criteria. In Fort Myers, surgical workloads are oriented toward knee and back surgery; in Sarasota, back surgery is favored over knee and hip replacement; and in Fort Lauderdale, the rate of hip replacement is higher than the United States average. If surgeons of a particular specialty were allocating their time and surgical effort among a prioritized list of indications based on patients’ needs and preferences, regions with more surgeons should have higher rates of surgery for common conditions. But, in fact, there is very little association between the supply of orthopedic surgeons and the rates of hip, knee, and back surgery. For example, although the per capita supply of orthopedic surgeons varies more than 4.7-fold among regions, there is no relationship between the supply of orthopedic surgeons and rates of knee replacement, and there is little relationship with hip replacement. The relationship between the supply of orthopedic surgeons and rates of back surgery has an R2 value of .02.

There is remarkable consistency in local rates of surgery over time. Over the decade, the surgeons working in Fort Myers performed 7,250 more back operations, 7,000 more knee replacements, and 2,600 more hip replacements than would have been done had the Manhattan rate prevailed in those communities. Compared to Manhattan, over the 10-year period Miami “produced” 870 more back surgeries and 1,400 more knee surgeries — but 56 fewer hip replacements. The absence of a strong association between the per capita supply of orthopedic surgeons and rates of knee and hip replacement and back surgery is also true of other surgical specialists and procedures performed on the Medicare population. Although the supply of cardiovascular surgeons, cardiologists, urologists, general surgeons, and vascular surgeons vary by factors of more than three among regions, there is little association between the per capita supply and the rates of common procedures performed by those specialists. The R2 statistic ranged from .00 for the association between urologists per capita and transurethral prostatectomy to .09 for the association between vascular surgeons and lower extremity bypass grafting. The stability of the surgical signature of orthopedic procedures in Florida is typical of the nation as a whole. The R2 correlation between knee replacement rates in 1992-1993 and 2000-2001 is 0.75 — that is, 75% of the variation in rates of knee surgery in 2000-01 is “explained” by the rate in 1992-93. The United States average rate of orthopedic surgery in 1992-93 increased by 40%. The supply of orthopedic surgeons increased about 9%. Similar patterns were evident in hip replacement and back surgery.

Spending levels for care in the last six months of life provide a case-mix adjusted profile of the efficiency of a health care organization in managing chronic illness — one that is untainted by differences in illness severity. Is more better? The implementation of shared decision-making, supported by decision aids, should offer the opportunity to establish valid measures of the actual demand for a given treatment option. In the early 1990s, a decision aid for patients with enlarged prostates was introduced in Denver and Group Health Cooperative in Seattle. After the implementation of shared decision-making, the population-based rates of prostatectomy fell 40%, providing a measure of demand when patients are informed and involved in the choice of treatment. (Rates in the control group did not change.) The rate that resulted from shared decision making was at the extreme low end of the national distribution, suggesting that the rates of prostate surgery in most regions of the United States might substantially exceed the amount that informed patients actually want.

It is not clear what the demand for discretionary surgery would be if shared decision making were fully implemented. We know relatively little about these possibilities, since shared decision-making supported by patient decision aids has not yet been systematically implemented, even in pre-paid group practices such as Kaiser Permanente. What is safe to conclude is that current patterns of practice do not reflect demand based on patient preferences, and that geographic variations in rates of surgery that reflect physician practice style will persist until patients are actively involved in the decision process and there are incentives for physicians to adopt shared decision-making. Over the ten-year period from 1992-2001, we estimate that Medicare spending (in 2001 dollars) for knee and hip replacement and back surgery in Fort Lauderdale and Fort Myers was $137 million and $135 million, respectively, more than would have been spent if the Manhattan rates had prevailed. In Miami the excess spending amounted to $25 million. A change in utilization that more accurately reflected “true” patient-driven demand is potentially disruptive to both surgeons and hospitals. If shared decision making were implemented at the hospital level, pay-for-performance strategies would could end up disproportionately rewarding regions and hospitals with high rates. For preference-sensitive care, HSAs could conceivably lead to better decisions. The introduction of economic considerations would presumably have an additional impact on patient choice, particularly in situations where one treatment is much more costly than another.

Most supply-sensitive care (at least 50% of medical spending) is provided to people with chronic illnesses. The conditions that generate the most spending are congestive heart failure, chronic lung disease, and cancer, reflecting frequency of physician visits, hospitalizations, intensive care, and the use of diagnostic tests. Rates of primary care visits vary by a factor
of about three, visits to medical specialists by more than six, and hospitalizations for cancer, chronic lung disease and congestive heart failure by more than four.

Medical theories and evidence play little role in supply-sensitive services. Medical textbooks contain no evidence-based clinical guidelines for scheduling patients for return visits, when to hospitalize or admit to intensive care, when to refer to a medical specialist, and, for most conditions, when to order a diagnostic or imaging test. The supply of resources governs the frequency of their use for patients with supply-sensitive conditions. The Dartmouth Atlas Project has consistently shown a positive association between the per capita supply of staffed hospital beds and the hospitalization rate for medical conditions. More than half of the variation in discharge rates is associated with bed capacity.

The effect of hospital bed supply on hospital use is known as “Roemer’s law.” The effect is primarily on patients with medical conditions; hospitalizations for major surgery are not correlated with overall beds per capita. The use of hospitals for the treatment of people with medical conditions is particularly intense during the last few months of life. Patients living in the lowest rate regions spent about six days of their last six months in hospitals, while those in the highest rate region spent twenty days. There is a similar relationship between the supply of physicians and visit rates, particularly for those specialties that spend most of their time treating chronic illness. About half of the variation in rates of visits to cardiologists is associated with the per capita number of cardiologists. A similar relationship exists between the supply of internists and numbers of visits to internists. Physician visit rates among people who are in their last six months of life vary substantially. In the highest-rate region, these people had an average of more than 55 visits during their last six months; in the lowest-rate regions the average was about 14 visits.

The bottom-line question is whether populations receiving more supply-sensitive care have better outcomes. Do they live longer? Do they have higher quality of life? Are they more satisfied with their care? This question has received virtually no attention. The issue of the appropriate quantity of supply-sensitive care is only beginning to emerge. A recent study by Elliott Fisher and colleagues at Dartmouth examined the outcomes of three patient cohorts, comparing those living in regions with greater care intensity to those in regions with less intensity. The study showed increased mortality rates in regions with greater care intensity. High-rate regions had 32% more hospital beds per capita, 31% more physicians, 65% more medical specialists, 75% more general internists and 37% more surgeons. The low-rate regions had 25% more family practice physicians than the high-rate regions.

Although the hip fracture, colon cancer and heart attack cohorts were comparable in baseline morbidity, those living in the high-rate regions had higher mortality rates: 1.9% higher for hip fracture patients, 1.2% higher for colon cancer patients, and 5.2% higher for heart attack patients. The study found no difference in high-rate regions in level of decline in functional status or satisfaction, but lower access to care. A study of patients who received their initial care at academic medical centers found that those in high-intensity regions received more supply-sensitive services than those in low-intensity regions.
During the first six months following their hip fractures, patients using academic medical centers in high-spending areas had 82% more physician visits, 26% more imaging exams, 90% more diagnostic tests and 46% more minor surgery. Compared to low-intensity regions, patients with hip fractures, colon cancer and heart attacks who were loyal to academic medical centers in high-intensity regions had higher mortality rates and worse “score cards” on measures of quality.

How well do well-known academic medical centers manage severe chronic illness? We compared 77 hospitals from the 2001 list of the “best” hospitals for geriatric care and for heart disease, cancer and pulmonary disease in U.S. News and World Report. Most of these hospitals are well-known academic medical centers. Efficiency measures include use of hospitals, ICUs, physician visits and Medicare spending. The quality measures include the proportion of deaths occurring in ICUs and the proportion of the population 40 months of life. Resource input variables included FTE physician inputs.

The average number of days spent in hospitals during the last six months of life ranged from 9.4 to 27.1 per decedent. Hospitals that had high rates of utilization among cohorts with one chronic condition tended to have high rates for cohorts with other chronic conditions. For example, the average number of days in hospital for patient cohorts with CHF and cancer were highly correlated, even though, on average, cancer patients tended to be hospitalized less. There were similar correlations between the rates of hospitalization for COPD and CHF, and between rates of hospitalizations for COPD and cancer. The most important finding was the striking contrast between need for surgery as defined by physicians and need as defined by patient preferences.

We also analyzed racial differences in end of life care at the 50 “best” hospitals with 100 or more black patients. At the same hospital (controlling for case mix) black patients tended to use slightly more care than white patients. Hospital days among blacks – as among whites – varied by a factor of about 2.5 among the 50 hospitals, and the rates were highly correlated. What really mattered in determining the risk of hospitalization was not race but the hospital to which the patient was assigned, not whether they had cancer or CHF.

Another perspective on the quality of care is the quality of death, which ideally should be as free as possible from overly aggressive, futile care. We see striking differences among academic medical centers in the chance of dying in an intensive care unit. Greater intensity of terminal care, with its negative impact on the quality of dying, is thus not a price the dying must pay to assure overall greater survival among those with chronic illnesses.

In view of the Fisher findings, the problem is not under use in low-rate regions and hospitals, but overuse and inefficiency in high-rate regions.
The patterns of practice and Medicare spending in the last six months of life are an indicator of the relative intensity of care delivered to the chronically ill during previous stages in the progression of their disease. This is evident from the high correlations between Medicare spending during the last six months of life and spending for the same patient cohort during previous periods prior to death. The overall average per-decedent spending for Part A inpatient care and Part B physician and laboratory services for the 77 U.S. News and World Report “best” hospitals in the last six months of life was $22,000, more than five times higher than the $3,900 average for the same cohorts in the 18th – 24th months prior to death.

However, Medicare program spending varied almost three-fold among the 77 hospitals cohorts, from $11,500 to $37,200 per decedent during the last six months and from $2,200 to $8,100 during the 18th – 24th months prior to death. The spending patterns were very highly correlated. Spending levels for care in the last six months of life provide a case-mix adjusted profile of the efficiency of a health care organization in managing chronic illness — one that is untainted by differences in illness severity.

SUMMARY: THE PROBLEM OF UNWARRANTED VARIATION

- There is under use of most kinds of effective care, such as the use of beta-blockers for people who have had heart attacks and screening of diabetics for early signs of retinal disease. The causes of under use include discontinuity of care (worse when more physicians are involved in the care) and lack of infrastructure to assure outreach and the timely use of these services. Pay-for-performance should lead to reduction in under use.

- There is misuse of preference-sensitive care, where treatment options involve significant tradeoffs that should be based on the patient’s own values. The causes include failure to accurately communicate the risks and benefits of the alternative treatments and the failure to base choice of treatment on the patient’s opinion rather than that of others. Adjustment of economic incentives to reward adopters of shared decision-making could lead to a reduction in unwarranted variation. Medical savings accounts may make patients more involved in active participation in decision-making.

- There is over use of supply-sensitive care, particularly in the management of chronic illness. The causes include overdependence on acute hospital care and lack of infrastructure to support continuous management of chronically ill patients in other care settings. Hospital-specific measures profiling performance in managing chronic illness can help identify efficient providers. Pay-for-performance and related strategies to reward efficient providers and pay for infrastructure for managing chronic illness could promote reform.

America needs to move much faster to adopt information technology in our health care system. Electronic health information will provide a quantum leap in patient power, doctor power and effective health care. We can’t wait any longer.

– Tommy Thompson, secretary of Health and Human Services in 2004
Speech by the Hon. Paul Rogers, former Florida congressman and longtime leader on health care issues. Jan. 14, 2005; Fifth Annual Health Legacy Conference:

I commend Joe Kanter and Dr. Carolyn Clancy for this initiative to focus attention on health care problems and the exchange of ideas which will bring the means of improvement to the fore.

I am also pleased to join Research America’s President, Mary Woolley, who continues to do a truly spectacular job in advocating for medical research, prevention of disease and quality of health care. I call her the “Florence Nightingale of advocacy.”

Research has already shown us the importance of information technology with its medical record systems for obtaining outcome results in order to establish best practices and quality for the delivery of health care. Prevention, of course, is a goal to constantly strive for. All of the above will have a positive impact on the continuing rising costs of health care.

Tight budgets, the Iraq war and terrorism have reduced attention on the health care of our citizens and the support and funding of programs to provide answers to improve the care of Americans.

Dr. Carolyn Clancy has stated: “We pay for and receive excellent care one third of the time – unnecessary care one third of the time, and one third of the time our care is characterized by mistakes, errors or under-use of clinically appropriate treatments.”

Even with the significant advances achieved through our national commitment to research, more than 4,200 Americans die every day of five major diseases: heart disease, cancer, stroke, diabetes and Alzheimer’s disease. That’s 1.5 million deaths each year. There are more deaths in our country in one year, from just these five diseases than the total of all deaths our nation has suffered in World War I, World War II, the Korean War, Vietnam War, Gulf War and the Iraq War. We need to do more here at home to fight the war against disease.

We need to take actions to prevent health care for the American people from being crowded out of the national agenda.

It is essential, given our nation’s current fiscal and policy climates, that as advocates we work together not only to raise awareness of research as an imperative for health, but also as directly linked to the economic destiny of our nation.

Medical and health research is a driver for U.S. global competitiveness and contributes to health care cost containment. Health-related research has created and supports hundreds of thousands of skilled jobs at companies, academic medical centers and research institutions across the nation.

We have so many stories to tell regarding the return on national investment in health research. For example:

- For every $1 dollar spent on technologies that improve heart attack care, $7 comes back to the economy through saved lives
- Vaccinating children against chicken pox saves the nation $100 million a year.
- Treatments resulting from research that just delay the onset and progression of Alzheimer’s disease by five years could save $50 billion a year in health care costs.
- A 5-year delay of heart disease: $69 billion each year.
- A 5-year delay of cancer: $60 billion each year

You know messages that will strike a chord in 2005 are those that show economic benefit. As stakeholders, we must convey research’s ability to save lives and improve the quality of life, but also to create jobs, spur industries, maintain U.S. global leadership and contain health care costs.

Businesses are warning about health care costs. The chairman of the Ford Motor Company has stated that his company cannot compete with companies from countries who provide workers’ health care. With health insurance continuing to rise in double-digit figures, more and more industries will be dramatically affected. Business leaders are beginning to speak out.

Seeking Allies, Advocates in Push for Better Care

- Hon. Paul Rogers
They can become health care advocates when efforts are made to connect with them. Good advocacy would make the effort to include them when decision-makers listen to the health and economic problems we face.

Finally, I want to emphasize the importance of outreach at the local level. We have heard time and time again the adage that “all politics is local.” We hear this as often as we do because, simply put, it is true. It is critical that all stakeholders in research collaborate to “bring research closer to home” so that elected officials and the media understand and appreciate the life-saving and economic benefits health research offers.

Our job, along with the hundreds of health organizations, is to make the case. The facts are with us.

-- Claude Allen, deputy secretary of HHS, spoke to the 2003 HELP conference. In 2005, he became President Bush’s top domestic policy adviser, when he spoke about medical research.

Dr. David Kibbe of the American Academy of Family Physicians speaks to the 2003 HELP Conference.

Dr. Gary Filerman of Georgetown University.
Many Health Organizations Launch Own IT Efforts

Speech by Janet Marchibroda, CEO of eHealth Initiative, to HELP Conference on Jan. 14, 2005:

Health information organizations are cropping up in every state. I’d like to share with you what we know about these emerging and operating health information networks.

And we can begin to think how we might leverage these networks to improve patient outcomes and to truly create this voluntary sharing network of which Joe Kanter speaks.

I run a little organization that’s a nonprofit, eHealth Initiative, and every day when we wake up and go to work, we focus on improving the quality, safety and efficiency of health care which we think can be accelerated through the use of information technology.

We’ve got a very diverse membership. It’s a good feeling to work with so many different stakeholders in the system, whether they’re health plans, patient groups, practicing clinicians, public health agencies that are all trying to move towards some of the same goals in health care. And we bring them to the table and talk about what actions can all of us take to move this ball forward.

An initiative called Connecting For Health released a roadmap for electronic connectivity, and I’m delighted to say we were able to provide a little bit of seed funding to about nine communities across the United States that are actually making this happen.

Rather than just talk about HIT, or health information applications, I’d like to take you down a road about mobilizing that information across organizations. You know more than me how fragmented our health care system is, and the fact that it’s paper-based and siloed, creating real issues about using that data to support better patient outcomes.

Doctors who take care of us spend a lot of time looking for charts and when they find them, because they’re on paper, it’s hard to get all the information they’d like to have when delivering health care to patients. And look at the waste in our system as a result - 20% of lab and radiology tests are performed because the prior tests were unavailable. We couldn’t find them. So we had to do them again. And one in seven hospitalizations occurred because we couldn’t find information that was available but somewhere else. And not at the point of care.

The Center for Information Technology Leadership is releasing a study that shows if you begin to mobilize information across organizations in a standardized way, we’re going to save billions of dollars.

I really caught a wonderful glimpse of what’s happening in different pockets of our country. I would say we get about three calls or messages a week from another community that’s saying, “I think we’re going to start doing this. We’ve got some plans at the table. Some of the medical societies, the big hospital CEOs. We want to start exploring ways for us to exchange data across our organizations.”

This is no longer a short list of states. It’s nearly every state across the country where we’re seeing communities engaging. So why are these different stakeholders getting together and saying, Let’s begin to explore health information exchange? There are a lot of reasons.

We had about 75 representatives from about 60 communities in America doing this. A lot of them told us they were just trying to improve the amount of information that doctors and clinicians have at the point of care.

Some were doing this for public health reasons. Some folks were saying they were trying to better measure the quality of care and improve access.

About 134 responded to a survey a year ago, and we did a quick, informal survey this past December. And about 59 responded to an informal survey from community health organizations.

This is what they told us. The most highly rated function was just results delivery to the doctor’s office. Lab test results, reminders and consultations were also of great interest.

A large majority of the health care organizations were saying they were looking at patient provider communication, and I think that speaks well to Joe’s agenda around improving patient outcomes and assuring better decision making at the point of care.
Person-centered Care: Let’s Use Best We Have

Speech by Gary Christopherson, senior advisor to the Department of Veterans Affairs, to HELP Conference on Jan. 14, 2005:

“Person-centered health” is different than almost any care provided today by any health provider or system. But if “health” is really what we want to achieve, then “person-centered health” is how we need to operate.

It is different in attitude, culture, design and operation. It is different in using the term “person” rather than terms like patient, consumer, or enrollee. It is different in that it views the person and his or her “self care” as necessary to the successful achievement of health. It is different in using the term “health” rather than the term medicine. It is different in its focus on “health” rather than illness and disability. Health is the end goal.

Health status could be everywhere from well to being very sick to being moderately sick, to being chronically ill, to living with a disability. And we can sometimes have more than one of those at the same time. And it will change over time. We have to understand not just their health dimension, but also what are their abilities, motivations and behaviors.

Health care is not the simple world that we’ve been used to and thinking about. We have introduced all kinds of tools and techniques, including the electronic health record and behavioral interventions. We’re also bringing into play the community and “care in the community,” the real future.

Let me emphasize, by the way, I’m using the term person very consciously. Using consumer, patient or enrollee makes a certain presumption about the role. When we think that we’re dealing with conception through death, person’s a pretty good term to use.

When we look at the person we have to understand there’s a whole other non-health care world that’s impacting health big time. There are time and location dimensions. We as persons change over time.

If we really want to be person-centered, it’s an extremely complex world. With the modern world of computers, we actually can begin to address this issue.

Multiply the individual person times nearly 300 million to cover all people in the United States. Internationally, we start multiplying times billions of people. We are a very diverse people.

The Institute of Medicine’s studies on quality looked at how people, consumers, enrollees, patients, think about this. How am I going to stay healthy? How am I going to get better if I’m feeling sick today? How do I deal with living with an illness or disability for the rest of my life? And how do I deal with the end of life?

Coupling that with the six aims of the IOM – safety, effectiveness, patient-centered, timeliness, efficiency and equity, we’ve got to somehow bring this personal dimension together with the quality dimensions. And if we’re really going to do it right, we’ve got to do all of this.

The real question is how do we create a self-perpetuating system to keep health care quality, outcomes and status high. This is complex and gets us deep into the question of behavior.

Let’s stop the bad things that reduce health. Stop the treatments that are bad. Stop the bad safety problems. Stop denying people access to care.

Let’s get people off the bottom and help lift them up. They are some of our most vulnerable. But let’s go further and take the reasonably decent care and really make it great care.

– Gary Christopherson, senior advisor to VA

Let’s stop the bad things that reduce health. Stop the treatments that are bad. Stop the bad safety problems. Stop denying people access to care.

Let’s get people off the bottom and help lift them up. They are some of our most vulnerable. But let’s go further and take the reasonably decent care and really make it great care.

– Gary Christopherson, senior advisor to VA
“Care in the community” is the concept that says if it is true we don’t spend most of our time in health care settings, then maybe we should start spending more time supporting people when they’re out in the community. With computers, we now have the ability to potentially reach everybody.

This can include “mass personalization,” where we integrate the best medical evidence with what we know about the person, both medically and behaviorally, to gain the ability to reach millions of people.

We need a “virtual health system”, which David Brailer and I and many others have been working on for several years, to connect all the dots. We must be interconnected with standardized ways of communicating and passing data using the Internet as the backbone. We’ve got to have electronic health records (EHRs). We should have personal health systems that each of us owns, controls, uses and feeds into. We’ve got to make it a living, breathing system that goes on all the time.

But we don’t yet have enough highly functional EHRs in operation. We need good EHRs in every doctor’s office, hospital, nursing home and home care setting in the United States.

We don’t yet have enough personal health systems (PHS/R) to support the person with a a copy of their health record, quality health information, self-entered information, appointments, prescription drug refills, behavior reinforcement and ehealth care.

We need to connect with other providers and other health organizations. The Centers for Disease Control and the Centers for Medicare and Medicaid need information to do their job. There are non-health organizations, like Social Security, that need health information.

So when we have a virtual health system, we get to what Joe Kanter is trying to put together here. With that virtual system in place, feeding from potentially 288 million people and 3 million health providers across the United States and with careful privacy, we’re talking about some serious power to make big, positive change.

We can really start to look at what the health of the US population is, almost in real time. We can talk about best clinical practices. We can use them to inform us on outcomes, treatments and how they apply to unique persons with their unique characteristics.

We can talk about it from a public health perspective. We can address naturally occurring diseases or bioterrorism by finding, attacking, and controlling them earlier and better.

For improving quality, we will have current health care practices and can create a better health practice and the glide path to achieve it. One example that the Institute of Medicine and we have been discussing is prescription drugs. We have the potential to see how well a drug works on particular individuals and in off-label use. We can quickly adjust as safety or efficacy information flows in and then back to the provider.

Quality should improve as we pipe all this health information back to persons and their clinicians.

Why person-centered health? The U.S. is making a $1.7-trillion-a-year investment. Our payoff on health status is very disappointing. Compared to many other countries, it’s even more disappointing.

To do this, we can’t just treat the provider and the person in isolation. We must look at the world they’re walking through and its impact on them.

We need to improve person and provider behavior. The future of health care is more about behavior than technical medicine. One model to use is BEM, the behavioral effectiveness model. If you want to achieve a behavior, BEM helps you figure out how to get there by looking at the person-by-person level. And BEM helps you figure out how to achieve this with thousands of individuals, whether providers or the person themselves.

We need to move from our current health status to what should be our “best health” status. Looking at Institute of Medicine and other studies, we’ve got far too much of “worst health”. If we want “best health,” we must stop the things that push people down into worse health.

Let’s stop the bad things that reduce health. Stop the treatments that are bad. Stop the bad safety problems. Stop denying people access to care. Let’s get people off the bottom and help lift them up. They are some of our most vulnerable.

But let’s go further and take the reasonably decent care and really make it great care.

We go back to Joe’s point about outcomes. We’ve got real data in real time to tell us how we are doing on key health and vulnerability status indicators.

How do we turn the health status indicators green? This is the test of us as a country. We know how to do it. We just haven’t done it yet and not for 288 million people consistently over time.

The promise of person-centered health is a nation of people, or potentially larger than a nation, using the best that we’ve got consistently over time. Just imagine what it would feel like if all the health and vulnerability status indicators turned “green” and never changed back?
 Achieving a National Outcomes Database

The Role Of Archimedes

How does an outcomes database actually work? Archimedes is a pioneering health modeling program now available to diabetics (at www.diabetes.org). Dr. David Eddy, a member of the creative team, described it in a presentation to the 2005 HELP conference:

Dr. David Eddy

The vision

- A patient (or physician) goes to a source (e.g. a website).
- Pulls up a section on his or her disease,
- Types in a question.
  - (e.g. “What are the available treatments for...”)
- A form pops up that requests more specific information about the patient
  - (e.g. age, sex, family history, stage of disease, comorbidities, ...)

The vision...

- The patient provides the information
- The source presents a list of the treatment options
- ...and the chances of all the important outcomes for each treatment.
- The patient takes the printout to his or her physician
- They discuss the options and make a final decision.

Call this the “Outcomes Website”

Achieving a National Outcomes Database: The role of Archimedes

David M. Eddy MD PhD

2005 HELP Conference
Washington, DC
January 14, 2005

The problem

- We lack good information about the outcomes of different treatment options
  - Information exists, but is difficult to access
  - Information does not even exist
- Many people have to make treatment choices without really knowing the consequences

An example: Mary

Mary is an 18 year old black woman who was diagnosed as having type 1 diabetes three years ago. At the time her FPG was 250. Currently her A1c is controlled to 8.6 with metformin (Glucophage 30 mg 1/day). Her triglycerides are high at 400. LDL is 110, HDL is 20, Total cholesterol is 210. Her BP is OK at 125/80. She does not smoke. She has no retinopathy, and her urine albumin is 15. She has no family history of diabetes. She is currently taking Lopid (50 mg 2/day). She is having foot exams, but no eye exams.
Mary wonders…

- I’m only 18 and I have diabetes. What are my chances of having complications in the future, like
  - A heart attack or stroke
  - Kidney failure
  - Blindness
  - Foot ulcers, amputation

Mary wonders…

- And what can I do about it?
  - Lose weight?
  - Control my blood glucose level better?
  - Have eye exams?
  - I have heard about aspirin, beta blockers, and ACE inhibitors. What about those?

Today’s questions

For Mary
- When will Mary be able to get answers to those questions, tailored to her specific situation and needs?
- How will she get access to the information?
- How much will it cost her?

For us, to make this happen for Mary
- How did we do it (technically)?
- How do we check the accuracy?
- How are we making it better?

Briefly,

- Archimedes is a mathematical representation of human physiology and disease
- Begins with anatomy and biology
- Includes
  - Occurrence and progression of diseases
  - Signs, symptoms
  - Behaviors
  - Tests
  - Treatments
  - “Outcomes”

“A mathematical representation of human physiology and disease”

- Archimedes is built up from the underlying anatomy and physiology
- Illustrate this by looking inside a typical simulated person in the model

Let’s try it

- How will she get access to the information?
  - Go to diabetes.org, the American Diabetes Association website. Click on “Diabetes PHD
  - How much will it cost her?
  - Nothing

And there are thousands of simulated people, each with their own individual characteristics, physiologies, genetic propensities, behaviors,…
We hope this brochure has memorialized what has been accomplished so far – BIPARTISAN SUPPORT FOR A NATIONAL HEALTH OUTCOMES DATABASE – and helps galvanize efforts for what still needs to be done. Our next goal is an independent government-private organization, Federal Health Reserve System (FRESH), which could be patterned after the Federal Reserve Banking System to oversee the collection and evaluation of medical data. Our “virtual” Board is in formation and we have already recruited important National Leaders. This “oversight” Board could serve as a model for the creation of the health care system of the future.

– Joe Kanter
The Health Legacy Partnership
Co-founded by the
Joseph H. Kanter Family Foundation and the
Agency for Healthcare Research & Quality (AHRQ)

Outcomes Research
Knowing what works best in healthcare

Senate Majority Leader Bill Frist (R-TN)
Former Senate Majority Leader George Mitchell (D-ME)
Joseph H. Kanter, Joseph H. Kanter Family Foundation Chairman
Former Senate Majority Leader Robert Dole (R-KS)

Bipartisan Support for National Health Outcomes Database

William Novelli
Mark McClellan, MD, Ph.D.
David Brailer, MD, Ph.D.
Carolyn Clancy, MD

Joseph H. Kanter, Chairman