1999 AHSR Presidential Address

Better Health Care Decisions: Fulfilling the Promise of Health Services Research

Jack Hadley

Two years ago, Bill Roper challenged us with an agenda of ten major research issues for the new health care environment created by the growth of forprofit and private sector activities in health care. Last year, David Kindig encouraged us to think beyond health services research—to focus not just on medical care and medical care financing, but also on taking on the really big issue of what determines health.

I would like to follow in the same vein as those thoughtful and provocative addresses, but from a different vantage point. I think we have more than enough big issues to tackle, so I don't intend to offer any new ones. Instead, I would like to talk about the view from the trenches. What do we need to do and what needs to happen for us to deliver on the promises of health services research?

As background, let me tell you two apocryphal stories from my days as a graduate student. By apocryphal, I mean that as I get older I have a harder and harder time remembering whether these events actually happened. But if they didn't, they should have.

The first took place in the graduate student coffee room. One of the fourth-year students, who later became an editorial writer for the *New York Times*, was expounding on the nature of research. He declared that "research is not about making great discoveries. It's the painstaking process of reducing how much we don't know; it's shrinking the size of the black hole by nibbling away at the edges."

Jack Hadley, Ph.D., President of the Association for Health Services Research in 1999, is Professor in the Institute for Health Care Research and Policy, Georgetown University. This address was presented on June 27, 1999 at the 16th Annual Meeting of AHSR.

The second event occurred a year or two later. The Nobel Prize in Economics had just been awarded, and the chairman of the department was asked—by the alumni magazine, I believe—if training Nobel laureates was one of the goals of his department. He said, in effect, that winning the Nobel Prize has much more to do with talent, lots and lots of hard work, and luck than with training per se. "Champions are born, not made." His goal was to produce economists who can solve problems and fix things, who are good mechanics and plumbers. (Just to be clear, he used the word "plumber" in an honorable sense. This was before the original Watergate scandal, and for those of you too young to remember, the word plumber will always have a pejorative connotation to the Watergate generation.) By the way, he won the Nobel Prize about ten years later.

Please keep these stories in mind as I continue.

In a way, I think we suffer from a kind of envy in comparison to our brethren in biomedical research. After all, they search for the cure. Their goal is to eradicate disease. They look for the magic bullet or the Holy Grail. And, you know what? Sometimes they succeed. That's the promise of biomedical research.

But what about our science, health services research? What are the promises we can hope to fulfill? A good starting point is the famous IOM definition (Figure 1). I won't try to read it—my breath would give out before I got to the end—but it's all there, just a little hard to see through the words. I want to emphasize three phrases: field of inquiry, to increase knowledge, and effects of health services.

Since a picture is worth a thousand words, Figure 2 depicts my vision of the IOM definition. It posits HEALTH to be a function of (1) genetics

Figure 1:

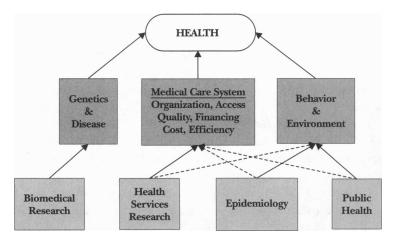
Health Services Research is a "... Multidisciplinary field of inquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes and effects of health services for individuals and populations."

and disease, (2) the medical care system, and (3) behavior and environment. We'll cede the first box to the biomedical researchers, and while we ought to spend more time thinking about the third box, our bread and butter is the relationship between the medical care system and health. (The solid lines indicate primary areas of inquiry or causation, and the dashed lines represent secondary relationships. I omit the feedback loops from HEALTH to the second-tier boxes to keep the picture relatively simple.)

So, what is health services research? First and foremost, it is scientific investigation. It is a branch of science. We're right there—at the base of the pyramid, just like biomedical research, epidemiology, biostatistics, and public health. We produce knowledge. We reduce the amount we don't know about how medical care and behavior and environment affect health and about how much those things cost. However, we are not "looking for the cure." The kinds of problems we tackle don't have cures or once-and-for-all solutions. Instead, we try to make temporary gains, until the system responds and we have to start again.

Our goal is to produce information that will help us—society—improve health and the health care system. And we care about how much those improvements cost and how to provide them efficiently. After all, the relationships between behavior and environment and health also involve money. If we can save a few dollars in the medical care box and spend it on fostering healthier behaviors or improving the environment, or simply letting people buy more of whatever else they want, those are good things.

Figure 2:



How do we do our research? How do we provide the information that can be used to make decisions about improving health and the health care system?

We collect data—all kinds of data—from structured and unstructured interviews, from surveys, from demonstration projects, from medical records, from administrative files, from case studies, and, every once in a while, from real, live experiments, with randomization and everything. By "data" I certainly don't mean to imply only numbers. Some of my best friends are political scientists and sociologists, and I've learned from them. We also do interviews with key participants and describe organizational and institutional structures.

We analyze those data using some very sophisticated techniques to adjust for problems like observational data bias, categorical variables, and variables with non-normal or other funny distributions. As far as statistical methods go, I think we're way ahead of the other disciplines that share the bottom of the pyramid with us.

To some, it appears that we have an overabundance of data. In the words of Al Gore, "We have generated vast mountains of data that never enter a single human mind as thought" (Gore 1992). In spite of sentiments like this, however, I don't think we have anywhere near enough information to answer the kinds of detailed questions people have when they're trying to make decisions about improving their health or the health care system.

The simple fact of the matter is that collecting data is enormously expensive and, relative to the implied promises we've made, our field is terribly underfunded. I don't think we're addressing the wrong questions. We have more than enough good questions to go around. We just don't have enough data to answer them with enough precision for people to use in making decisions.

Let me give you a couple of examples. We know that pure fee-for-service reimbursement of providers is suboptimal because it leads to excessive costs, especially if the fees are too high. We also suspect that pure capitation is suboptimal because it creates too strong an incentive to underprovide services, especially in a for-profit environment. But do we know what the right level of fees might be, or the right combination of fee-for-service/cost reimbursement and capitation? And do we know how the answers to those questions might vary with the type of service or the particular conditions of the local marketplace? Unfortunately, we haven't kept our promises here. It's not that we don't know how to answer them. We just don't have the information to do the analysis properly.

Here's another example. We desperately want to be able to tell people that health plan A is x percent better than health plan B, or that hospital A is y percent better than hospital B. Yet, with all due respect to my friends at NCQA, our current efforts may not be much better than the rating scale depicted in Figure 3—probably neither very useful nor very fair to the institutions we're rating.

Moreover, the answer to the question depends on whether you're healthy or sick. If you're sick, what's the problem you have? And health plans and hospitals are hardly uniform, homogenous organizations. Health plans offer many different products that vary in terms of coinsurance, deductibles, the costs of going out of network, the composition of the network, the benefits covered, and the procedures for obtaining approvals for service use. We want to be able to tell people that if a person like you chooses a health plan with the following characteristics, what the chances are or what's the probability that you'll have an adverse outcome, or that you'll die.

We want to be able to say that if you have condition x or need treatment y, and if you go to a major teaching hospital instead of your local community hospital, here are the odds that your outcome will be better, and here's how much more it will cost you. I believe we have the tools and the know-how to answer these questions, to fulfill our promises. What we don't have are the necessary data.

Unfortunately, there appears to be a social tendency to resort to legislative bans to prohibit types of care or methods of payment that are thought to have lower quality or to be more risky—in part, perhaps, because we are unable to specify the variations in risks and the variations in costs that would allow people to make their own, informed decisions.

As an illustration of the point where society is willing to tolerate variations in risks when they are known, consider the following. We know that people who ride in small cars face a significantly higher risk of death in an

Figure 3:



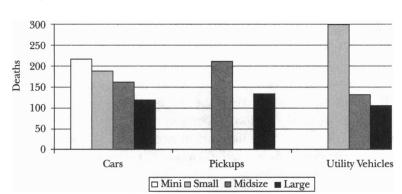


Figure 4: Deaths per Million Registered Passenger Vehicles 1-3 Years Old, 1997

automobile accident than people in large cars. As shown in Figure 4, the differences can be quite stunning.

Yet we don't ban small cars, which make up almost 25 percent of registered vehicles, nor do we require everyone to ride around in armored personnel carriers. Instead, we let people make the trade-off between the increased risk of a small car versus a few hundred dollars a year less for car payments and gas, and easier parking. Could we let people make the same choices about types of health plans or treatment options at various premiums and prices? With the data we have now, the answer is generally no. Inadequate data terminated HCFA's publication of hospital-specific mortality rates, and, with the possible exception of Medicare, we cannot calculate the risk-adjusted mortality experience of different health plans.

Inadequate data and analysis also limit our ability to manage our major public health insurance programs, Medicare and Medicaid. Medicaid programs around the country are trying all sorts of variations in how they structure benefits, how they pay providers, and how they cover people. Do program administrators really know what works and what doesn't, and at what costs? Are we able to learn very well, to find out what doesn't work, from these experiences? I don't think so.

Does the Medicare program fully understand the consequences of all the changes it is making? The increasingly heated arguments over what explains Medicare's recent, miraculous, reduction in annual spending suggest not. And while there are lots of anecdotes, there's very little rigorous research on the effects of these changes on beneficiaries' health.

Last year, HCFA's Office of Research and Demonstrations had a budget of \$61 million, compared to HCFA's annual spending of over \$414 billion. That's 0.015 percent, and I'm rounding up. The ORD budget is barely a footprint on Figure 5. It's one sixty-eighth of one percent of HCFA spending going to research on organization, financing, payment systems, access, satisfaction, and quality of the Medicare and Medicaid programs.

The country of Israel, where I've been a visiting researcher for the last year, has a per capita income about two-thirds that of the United States, and it spends about 60 percent as much of its GDP on health care, roughly 8 percent compared to almost 14 percent for the United States. Yet, by law, it sets aside one-tenth of one percent of its health budget to support health services research, just on its health insurance system. If ORD's budget were based on the same formula, it would be spending over \$400 million this year, an increase of almost 700 percent.

How badly underfunded is health services research? To help put this in perspective, this year's budget for the National Institutes of Health is just under \$14 billion, which is about 1.3 percent of the just over \$1 trillion the nation spent on all health care (Figure 6). Recent calls in the Congress to double NIH's budget over five years can be thought of as trying to attain a target of about 2 percent of health spending devoted to biomedical research, and some people think that's not enough.

Federal spending on health services research this year is \$491 million, slightly more than half of which is allocated to NIH (\$206 million) and VA (\$42 million), with the balance going to AHCPR [now the Agency for Health-

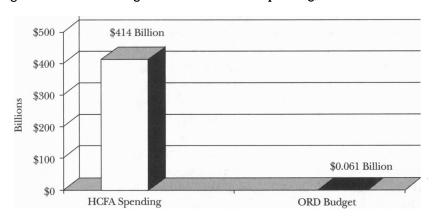


Figure 5: ORD's Budget Relative to HCFA Spending, 1999

Figure 6: National Health Care Spending and Federal Spending for Health Care Research, 1999

	\$ Billion	% of Total Health Spending
National Health Care Spending	1,060.000	-
NIH Budget	13.800	1.300
Federal Spending for Health Services Research	0.491	0.046

care Research and Quality, or AHRQ] (\$182 million) and ORD/HCFA (\$61 million). That's just under five-hundredths of one percent, or roughly one twenty-eighth the size of the NIH budget. Remember these numbers, one twenty-eighth the size of the NIH budget and five-hundredths of one percent of national health spending, and remember that Israel spends proportionately twice as much, one-tenth of one percent on health services research.

Do people value or want what we implicitly promise we can do? The answer is clearly yes, as suggested by Figure 7, which I borrowed from last year's Presidential Address by David Kindig (Kindig 1999). Even with the usual qualifications about survey questions like this, that's a pretty darn good approval rating.

Tomorrow, Bill McInturff will present work he's doing for AHSR on people's understanding of health services research. As part of this project, he conducted two focus groups of well-educated people who discussed health services research and how much ought to be spent on it. He asked them, "How would you divide \$100 among six health-related activities?" As shown in Figure 8, it's no surprise that "Medical Care—making sure more people have health care," and "Medical Research—the discovery of new treatments and cures for diseases," received the greatest allocations, as they should have.

What is surprising, though, is the relative weight people gave to health services research. Even if you combine the three categories of medical research, developing new medical procedures and technology, and research to develop new prescription drugs, these panels of well-educated people would assign a quarter to two-thirds as much money to health services research as

Figure 7: Public Values Health Services Research "Health services research seeks to understand why there are differences in quality of care and for patients. How do you perceive the value of this kind of research?" (Percent saying great/some value)

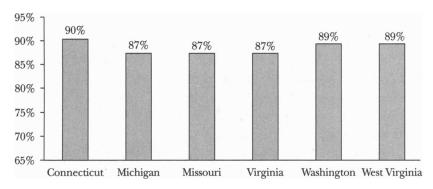


Figure 8: Focus Group Answers to . . . "How would you divide \$100 among six fields of health care?"

	Group 1	Group 2
1. Medical Care	\$40	\$40
2. Medical Research	\$20	\$30
3. Health Service Research	\$10	\$20
4. Developing New Medical		
Procedures and Technology	\$10	\$ 0
5. Research to Develop New		
Prescription Drugs	\$10	\$ 0
6. Medical Education	\$10	\$10

to medical research. Recall one of those numbers I asked you to remember: currently, health services research receives about one twenty-eighth as much federal support as biomedical research.

Returning to my opening observations about the nature of research and being plumbers and mechanics, I don't think it's helpful to portray ourselves as NIH researchers looking for the cure. We can't keep those kinds of promises. In some ways, I think their job is actually easier. It's true that the submolecular world is really tiny and very complex, especially for someone with bad eyesight and big hands like me. But it's relatively static. Once you've

decoded the gene, you've got the answer. It's not going to change while you're trying to figure it out. It will be the same tomorrow as today.

In contrast, the social universe, which is our research domain, is constantly changing. When we finish a study, will we have the answers for all time? No, because medical technologies change; the organizational structures for providing care change; attitudes and values change; government policies change; and underlying resource costs and prices change.

For us, cracking the CPT and ICD codes should be the equivalent of cracking the genetic code. For different medical services and different diseases in different market and institutional circumstances, we want to know what determines—and therefore how to influence—supply, cost, access, use, quality, outcomes, and effectiveness.

My point is not that such studies are futile. In fact, I would argue quite the contrary: we need to keep doing these studies on a continuous and ongoing basis, so that as technology, organization, values, policies, incomes, and prices change, we can revise and update our answers and give people information they truly can use.

Rather than trying to model ourselves after NIH researchers, I believe we should aim to be much more like agricultural economists. They go out and measure the weather, and the conditions of the soil, and the types of fertilizers and machinery available, and the costs of storage and transportation, and interest rates, and the weather and harvests in other countries so that they can give farmers timely, up-to-date advice on what crops are likely to yield the best returns for them. And they do it season after season after season in almost every state in the country. It's not glamorous work, but it produces useful information for people who have to make decisions.

What can the Association for Health Services Research do about this situation? First, we have to make the case—clearly and loudly—that health services research has the capability to make very useful contributions, to provide very helpful information for improving health and the health care system. We have the capability, but not the capacity.

Collecting data is expensive. We can't provide helpful answers on the cheap, from a few scribbles on the back of an envelope. To paraphrase an unknown sage: "Every complex problem can be described by simple correlations, which at best are misleading and usually are wrong." Without in any way demeaning the power and influence of the two-by-two table, we need to be more sophisticated about what numbers we put in the boxes and how we got them.

In this time of budget surpluses and looking for areas where marginal investments will have big payoffs, I would like to call for a quadrupling over the next five years of the money allocated to health services research by the federal government. Perhaps as much as half of that amount should be targeted to collecting the data we need to fulfill our promises.

If Israel, with all of its domestic and international problems, can afford to allocate one-tenth of one percent to health services research, then I think the United States, with its greater wealth and much more complex and troubled health care system, should spend at least twice that amount. A quadrupling of federal spending for health services research would increase the allocation to about two-tenths of one percent of national health spending or, alternatively, ten percent of NIH's budget. Just in case you've forgotten, the federal government currently spends five one-hundredths of a percent of national health spending on all health services research, including NIH and Veterans Affairs, which equals about one twenty-eighth of the NIH budget.

Second, if we are going to mount a campaign to increase funding for greatly expanded data collection and for analyses of those data, we have to establish clear and strong standards with regard to privacy, confidentiality, and the uses of those data. If the public doesn't trust us and fears that information they provide will be misused, then we might as well give up the game. We need to be sure that researchers follow appropriate procedures and standards for collecting and storing data. We need to help develop those procedures and standards. And we need to assure the public that we, as researchers and scientists, take these issues very seriously.

Third, we need to make it clear that health services research is a science. We produce knowledge to help people make decisions about their health and their health care system. We need to work diligently to promote and support the development of our science through training and education programs. Without proper analysis, we will have tons of data, but little information. Al Gore is right about this point. We have to ensure that future generations of health services researchers are fundamentally grounded in the appropriate theoretical and statistical methods.

Fourth, we need to do a much better job of educating the public about health services research and its benefits. As a first step in this process, I am very excited about the work the Association is doing on developing a program and campaign for **B**uilding **U**nderstanding of and **S**upport for the field of health services research—the BUS project.

Ken Kesey and his Merry Pranksters used to say, "You're either on the bus or off the bus" (Wolfe 1968). We're now in the process of building the bus, and we'd like to get as many people as possible on board. Over the next months and years, the new AHSR will be calling on many of you to help and to contribute to these efforts. I look forward to seeing all of you on the bus.

Thank you very much.

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