

# REAUTHORIZATION OF THE AGENCY FOR HEALTH CARE POLICY AND RESEARCH

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## HEARING BEFORE THE SUBCOMMITTEE ON HEALTH AND ENVIRONMENT OF THE COMMITTEE ON COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED SIXTH CONGRESS FIRST SESSION

APRIL 29, 1999

**Serial No. 106-29**

Printed for the use of the Committee on Commerce



U.S. GOVERNMENT PRINTING OFFICE

56-608CC

WASHINGTON : 1999

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## REAUTHORIZATION OF THE AGENCY FOR HEALTH CARE POLICY AND RESEARCH

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THURSDAY, APRIL 29, 1999

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON COMMERCE,  
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT,  
*Washington, DC.*

The subcommittee met, pursuant to notice, at 10 a.m., in room 2322, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Deal, Ganske, Cubin, Bryant, Brown, Deutsch, Green, Barrett, Capps, and Eshoo.

Staff present: Jason Lee, majority counsel; Thomas Giles, majority counsel; Penn Crawford, clerk; John Ford, minority counsel, Karen Folk, minority professional staff.

Mr. BILIRAKIS. The hearing will come to order.

Good morning. I now call to order this hearing on reauthorization of the Agency for Health Care Policy and Research. Today we will hear testimony from the administrator of the agency as well as experts from both the public and private sectors. I would like to thank all of our witnesses for their willingness to testify on such short notice and for the cooperation of the ranking member, Mr. Brown, and the minority staff in helping us prepare for this hearing.

Working on a bipartisan basis, I am hopeful that we can pass legislation to reauthorize the agency this year. This agency serves a critical function in efforts to improve the quality of health care in our Nation. It directly funds the collection and analyses of critical health data needed by Congress to make sound decisions on health care access, quality and cost effectiveness issues. And equally important, it provides technical assistance to private sector organizations that seek its expertise to support their initiatives.

I would note that one of our witnesses today played a key role in the agency's creation. As minority counsel of the Ways and Means Health subcommittee, Chip Kahn spearheaded the legislative effort to establish this agency through the Omnibus Budget Reconciliation Act of 1989.

And I want to extend a special welcome to Dr. Mahan, dean of the College of Public Health at the University of South Florida in Tampa. He is also the director of the Lawton and Rhea Chiles Center for Healthy Mothers and Babies. Dr. Mahan will describe the Chiles Center's efforts to overcome barriers to access to preventive health care through a public-private partnership. He will also ex-

plain the potential role of the Agency for Health Care Policy and Research in achieving that objective.

Again I want to thank all of our witnesses for their time and effort in joining us. I look forward to their testimony on how reauthorization of this agency can improve the quality of health care nationwide and would now yield to Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman, and special thanks to John Eisenberg and our other distinguished panelists. Tapping into an expanding agency, AHCPR, is an opportunity to do something legislatively that is unequivocally positive for the future of health care in this country. Success or failure of health care financing and delivery hinges on three variables, access, quality and cost. These variables are obviously interdependent.

Optimizing access and quality is a process of spending limited dollars in ways that reaches as many people as possible with the most effective, efficient care as possible. The work that AHCPR does is fundamental to this process. It is the agency that evaluates the current systems so that we can improve it. With health care dollars as scarce as they are, this is a crucially important role. AHCPR conducts and supports health services research and communicates the results of that research to the health care community and to the public.

It sounds dry, but it translates into tangible improvements into public health, fewer wasted dollars in policy changes grounded in knowledge rather than simply wishful thinking. Through initiatives such as Friendly Access, which Dr. Mahan will discuss, AHCPR also helps the Nation expand its reach to deliver care to disenfranchised populations.

We know that an estimated 2 to 3 million children eligible for Medicaid coverage have not been enrolled in the program. These children fell through the cracks. AHCPR's research and collaborations like Friendly Access, that help us get care to these children and our hard-to-reach populations, are a solid investment for the Nation. I am pleased to be working with the chairman on legislation to reauthorize AHCPR and look forward to hearing from our witnesses this morning.

Mr. BILIRAKIS. I thank the gentleman. The gentleman from Tennessee, Mr. Bryant.

Mr. BRYANT. Thank you, Mr. Chairman. I have no formal statement, but I do want to thank both you and the ranking member Brown for the work you have done in this, and I understand that you will be introducing a bill reauthorizing the Agency for Health Care Policy and Research. There will be a companion bill filed in the Senate by my colleague from Tennessee, Senator Frist.

I do have other commitments, as all members do; and I look forward to hearing the testimony of the panel here. If I am not here reviewing their testimony, I might lay out—I understand that there is an increase in your budget of \$250 million, and certainly it would be welcome if you could explain the needs that are there—the justification for this increase—and certainly I will review that. I have some understanding of why, but, again, for the record I would appreciate, in my absence, if you would answer that question.

Again, I thank the distinguished panelists that are coming, and again thank our chairman and ranking member.

Mr. BILIRAKIS. Thank you. There appear not to be any other opening statements from the members of the subcommittee. They will be made a part of the record with unanimous consent.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. TOM BLILEY, CHAIRMAN, COMMITTEE ON COMMERCE

Mr. Chairman, thank you for calling this hearing today. I am pleased to see so many distinguished leaders in health policy before us to share their views on the value of the Agency for Health Care Policy and Research, commonly referred to as AHCPR. It was a decade ago that Congress created this Agency to enhance the quality, appropriateness, and effectiveness of health care services and access to care.

AHCPR plays a vital role in empowering consumers with the objective information they need to make informed health care purchasing decisions. Informed consumers are what drives the private market to provide quality services and products. The role of AHCPR as a nonpartisan agency able to provide evidence-based science to the market place is an invaluable resource from which all Americans will benefit.

We take great interest in what AHCPR has to say about the best practices in medicine, and want to ensure that any legislation that moves through this Committee reflects the latest advances in science and medicine. In the prevention and early diagnosis of breast cancer, an area this Committee has given a great amount of work and attention, AHCPR recommended that both physicians and their patients receive written notification of the results of mammograms from the facilities performing them. When it came time to reauthorize the Mammography Quality Standards Act last year, we put the AHCPR recommendation into law. As of yesterday, all women will receive letters, or e-mail notices about test results as soon as possible, and are encouraged to follow-up with their physicians for conditions that cannot be detected by mammography.

This Committee excels in reviewing public laws within its jurisdiction in light of advances such as electronic commerce. The Committee's approach to AHCPR demonstrates as well. We plan to seek authorizing legislation that would give the agency more direction in using new technologies including electronic commerce to enhance the latest medical breakthroughs in the public and private sectors, to help ensure that patients receive high quality, effective and appropriate care.

Once again Mr. Chairman, I applaud you for holding a hearing on the reauthorization of AHCPR. I look forward to hearing from our distinguished panelists.

PREPARED STATEMENT OF HON. GENE GREEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Thank you for scheduling today's hearing on the reauthorization of the Agency for Health Care Policy and Research. I believe their research efforts to improve the standards for care will be critical as this Committee and Congress moves forward with reforming different parts of the health care system.

I hope today's hearing will lead to legislation that will update and strengthen the agency's core mission. Not only should the agency retain its research and grantmaking focus to improve knowledge about health quality and practices, but we must improve its role and ability to disseminate information to health care providers as well.

The value of the research will only be as great as the number of providers who know about it and can apply those results in the examination and treatment rooms of America's doctors offices and hospitals.

Clearly, there is a great potential upside to having an agency solely dedicated to improving and updating the "best practices" standards for care. However, I think it is even more important to recognize that these developed and widely accepted standards must serve as a model or a guide—not an inflexible rule.

One thing I have learned about health care during my brief tenure on the Health and Environment Subcommittee is that there is no such thing as always or never. All health care providers must have some basic flexibility to model the care of a particular patient to the needs of that patient.

I believe we have an opportunity to substantially improve the quality of health care by strengthening the agency to serve as a valuable resource and guide to doctors who can then apply the research results to the individual needs of their patients.

Again, thank you for scheduling today's hearing. I look forward to hearing from the distinguished witnesses.

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PREPARED STATEMENT OF HON. ANNA ESHOO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Thank you Mr. Chairman.

There are few things that American people care about more than good, quality health care.

People need to feel confident that they are getting the best medical care available by the most knowledgeable, competent professionals.

The Agency for Health Care Policy and Research (AHCPR) helps to ensure that they do.

We've seen it time and again.

Because of AHCPR research, certain pneumonia patients can now be treated in the comfort of their own homes.

AHCPR research has significantly reduced complications from diabetes.

AHCPR research has improved diagnosis of chest pain, resulting in fewer heart attack patients going undiagnosed and a whopping 55% reduction in hospital admission rates.

We are fortunate to live in a country where medical innovation is a given. AHCPR is a critical part of the development and application of these innovations to create the highest quality health care system in the world.

Thank you Mr. Chairman. I look forward to hearing from the witnesses.

Mr. BILIRAKIS. Dr. Eisenberg, would you come forward. The good doctor is the administrator of AHCPR located in Rockville, Maryland. Your written statement is already a part of the record. We would appreciate your supplementing it. We will set the clock at 10 minutes.

**STATEMENT OF JOHN M. EISENBERG, ADMINISTRATOR,  
AGENCY FOR HEALTH CARE POLICY AND RESEARCH**

Mr. EISENBERG. Thank you, Mr. Chairman. Thank you for enabling us to come and talk to you about the reauthorization of the Agency for Health Care Policy and Research. This is our 10th anniversary year for AHCPR, and in those 10 years the agency has matured, I think; and our approach to our plan and our approach to our responsibilities has evolved.

If I were to summarize the entire testimony in one sentence, I would say that we are a science partner and that we work in collaboration with the public and private sector to build the science, the knowledge and information that is going to help improve access, the quality and cost of care, and the functioning of the health care system in the United States.

Because my written testimony outlines the details of the agency's activities, I would like to focus on four goals. One of them is to put our research and our goals into the context of what is going on in health care in our country; the second one is to discuss the agency's role in health care quality; third, outline an example of one new approach to getting health care research done and translating it into practice; finally, to share some observations on what the appropriate role of our agency might be in the future.

Let me start by talking about how our research fits into the context of health research in general. There is a broad continuum of health research, and we need a balanced portfolio from the most fundamental research to health services research. The kind of research that we support, health services research, is a companion to the biomedical research agenda.

Biomedical research in general focuses on mechanisms of disease, including basic science. It focuses on clinical interventions to understand how well we can translate those understandings of basic mechanisms of disease into interventions, prevention and treatment and often uses a clinical trial, which is an idealized setting, to test whether these interventions can work.

We need to collaborate with our basic science colleagues to be sure when the basic science advances are made that we can go the next step; that we can assure patients and the Nation that it reaps the full rewards of that basic science investment in four ways: first, to develop the scientific evidence about when those interventions work best in daily practice; second, to identify the types of patients for whom those interventions work—treatments or preventive or diagnostic services—third, to compare their effectiveness and their cost effectiveness with existing practices; and last, to translate those research findings into improved patient care.

This research has already started to have an effect on the way people in America get their health care. For example, urologists in the United States worked with researchers we had funded to develop some new ways in which men who have enlarged prostates could make decisions about their surgery. This research helped the clinicians working with these men to take into account the men's assessment of their function, more than just physiologic assessment, but what it meant to them as individuals, what their health status was, what the likelihood was of the risk of surgery, what the likelihood was of a benefit from surgery.

The early results of that study, having been translated already into practice, show that men are getting less surgery when they use the results of this research, but that they are more satisfied and that the costs are down. It is a wonderful example of better quality care costing less.

We have also funded research in the area of clinical prevention that has started to make a difference, like the assessment of the effectiveness of different kinds of pap testing or studies on diagnosing attention deficit disorder in children. We support the U.S. Preventive Services Task Force's activities as a way of translating those advances in prevention through the Prevention Into Practice Program.

In a nutshell, what we are trying to do is to help the practice of health care catch up with the science of health care. In addition to the clinical focus that I have been emphasizing, the clinical focus on outcomes or the effectiveness or the quality of health care, our research also helps to develop and translate scientific knowledge about the most efficient and effective ways of organizing and financing the care and delivering care to people.

One of the ways that we do this is by supporting a major survey called the Medical Expenditure Panel Survey which provides the only nationally representative data on expenditures and the services that people get, including their insurance coverage as well as their out-of-pocket costs.

These data are already being widely used in the public and private sector from think tanks like the Heritage Foundation to CBO. We are seeing people recognizing this data base as one of the best



that the country has to understand what is happening in the delivery of health care in this country.

Anchored to the work that we do, in many ways is the comment that Mr. Brown made in his opening statement, when we think about our major emphases, we think about three topics: one is the outcome of medical care, one is the quality of medical care, and one is the cost and use and access to medical care.

We believe that good research can help to inform those topics by helping us to understand what works best, under what circumstances, with what kind of patients, and determining how it compares with existing alternatives.

If we can answer those questions, then it is going to be possible for the practice of health care to catch up with the science of health care.

When we think about who is going to use this information, who are our customers, we think about three groups. We think about people who need research to make clinical decisions: doctors, nurses and other professionals who need the best evidence available to guide informed decisions.

We also think about public policymakers like you who need better evidence to drive the decisions that they make, and then we think about a third group, and those are the people who work in large systems. They may be people in plans or purchasers of care, but they are people who need the kinds of evidence that we can deliver to help them make better decisions so they can get better quality for less cost.

Mr. Chairman, we think the entire spectrum of health services research can contribute to this goal to improve the quality of health care. As a clinician, I think about the challenge that faced me before I came to the agency in taking care of individual patients who came into the exam room. About every patient I would ask am I doing it in the right way and for the right person, and at the right time.

I was seeing patients, and like every clinician, there were instances when some question would come up and I would ask myself, is it that I don't know what is known, or is it that nothing is known. Whichever of those two questions a clinician asks, our agency can help answer each of those questions. For those in which the answer is we really don't know; we don't know at all what the answer is to your question, Doctor, we think that our agency's research can help to build that knowledge base, to close that gap between what we need to know and what we know. In addition to that, we can close the gap between what we know and what we do. Those are the gaps that we think are so important for our agency to close.

But it is not just clinical questions that our research can answer. It is nonclinical questions as well. For example, what happens when we offer different kinds of incentives to clinicians? How do they respond? How do patients respond when they have different kinds of financial incentives or services that are available to them? How do we make decisions on what kinds of services that we are going to offer?

Those are questions that we are asking and our researchers are answering. Consistent with the Senate's reauthorization language,

we think that we can provide information to the country about how we are doing as a Nation, whether the health care that we are providing is getting better, worse, or more specifically, in which regions of the country is it getting better or worse, and what can we do about it.

Let me tell you a story about one specific project that we do which I think depicts the whole pipeline of research that we are concerned about, all of the way from getting new knowledge and tools to translating it into practice. It is something we call the Consumer Assessment of Health Plan Survey or CAHPS.

This is a survey that came out about a year ago in its first iteration. It is available to plans and purchasers so they can collect and compare information on health plans, compare them, and make decisions about which ones they would choose. Or if you are a plan, determine how you rank compared to other plans.

The story of CAHPS is the story of our working in partnership with our customers, asking them what they want and need, delivering that and seeing what impact it has.

So about 4 years ago, we listened to people who make decisions about health care plans and we said, what do you need to know that you don't currently know about making these decisions.

In a very careful way, we analyzed what needed to be known, what was available, and where the gaps were. We then developed grants and contracts to organizations outside the agency, including some of the best minds in the country, from Harvard School of Public Health, the Research Triangle Institute in North Carolina, and the Rand Corporation in Los Angeles. We asked them to work together as a team, not separate investigators, but together as a team to develop this survey, this tool, this way of finding out how you can compare plans. They came back to us with a sample. We tested it. We evaluated it.

We then made that available to the public, and within a year we now can brag that we have Medicare using it, NCQA, which is the National Committee for Quality Assurance, the Office of Personnel Management, 22 States in their Medicaid plans, and a large number of private corporations that are using it.

When we add up the number of people who can compare their plans based on how they do in terms of performance for consumers, there are over 90 million Americans who have more information than they had before. They can now make a decision among the plans available to them based on real evidence rather than just gossip or anecdote.

Let me conclude by making five quick observations about the reauthorization that is in front of us and the reauthorization which the Senate HELP Committee has moved on.

The first is that we believe that our agency must remain a credible scientific research agency, and the Senate language helps us to do that. The provisions in that language that help us to govern scientific review of our research are critical. We use the same system of scientific peer review that our colleagues at the NIH use, which helps us to assure that the funds we have to support research are going to scientific excellence. About two-thirds of our funding goes in grants and contracts to researchers around the country, and we

think they are the most talented people that our Nation has to offer.

The second point is that we think that it is clear that the agency's research needs to help inform decisions at the clinical, system, and policy levels, but we don't make policy. For that reason, we are comfortable with the idea of taking "policy" out of the name of the agency because it really has led to confusion to some who think that we make policy decisions rather than help inform policy researches.

The Senate Health Committee deleted the word "policy", added the word "quality" to the agency's name, which we think is both symbolically important and practically important in helping people understand us.

Third, we believe that our agency should not be a standard-setting agency. We should support the research that others will use in establishing standards. We should not be mandating clinical practices. We should not be setting individual standards of quality, but we should be, as I mentioned before, a science partner.

The fourth, consistent with the notion of being a "science partner," is that we need to develop public-private partnerships in every aspect of our work. Our budget does not allow us to do anything other than to have partnerships. We need to leverage the research that our grantees and our contractors get done in order to provide the type of objective information that can make our competitive health care marketplace function better, and can help the people who don't have access to care to get it. When they do get access, our research can help ensure that it is high-quality care.

Finally, we believe that the agency's mission should be amended to direct us in the way that the Senate bill does, to develop and advance the science of quality measurement and quality improvement.

There are a host of other provisions that I would be happy to address now or later. But I principally want to thank you for having this hearing and letting us talk about AHCPR's reauthorization. Thank you.

[The prepared statement of John M. Eisenberg follows:]

PREPARED STATEMENT OF JOHN M. EISENBERG, ADMINISTRATOR, AGENCY FOR  
HEALTH CARE POLICY AND RESEARCH

*Introduction*

Mr. Chairman, thank you for giving me the opportunity to address the Subcommittee on the programs and activities of the Agency for Health Care Policy and Research (AHCPR). AHCPR's mission is to provide good and objective science-based information that will improve decision making at all levels—from patients, to clinicians, to health care system leaders, to public and private policymakers. AHCPR's goal is to ensure in an increasingly market-based health care system that state-of-the-science information drives informed decision making.

AHCPR was established by Congress in 1989 "for the purpose of enhancing the quality, appropriateness, and effectiveness of health care services and access to care." While we have met this objective during the past nine years, we recognize that health care in 1998 is very different from 1989, and the Agency has adjusted its agenda and priorities to meet the new challenges we face, while continuing our charge set forth by Congress. Here are our priorities:

- To conduct and support research on the outcomes and effectiveness of treatments.
- To ensure that clinicians, patients, health care system leaders, and policymakers have the information that will enhance quality of care.

- To identify gaps in access to and use of health care services, achieving value for the Nation's health care dollar, and helping the market and policymakers find ways to address those gaps.

#### *Research That Helps Patients*

Mr. Chairman, before turning to our programs and the way we conduct our work, I want to emphasize that this research has already had a profound effect on the quality of care patients receive. After all, that is the bottom line for our Agency: improving patient health. A welcome side benefit, for programs over which you have jurisdiction such as Medicare and Medicaid, is that these quality improvements, in a surprising number of cases, have also led to lower costs and more appropriate use of health care resources. For example:

- **Pneumonia.** Approximately 450,000 Medicare patients are hospitalized for pneumonia each year. With AHCPR support, one group of researchers developed a way for clinicians to determine which patients with pneumonia can be safely treated at home. This option avoided hospitalization entirely. Studies of health systems that have implemented this decision tool found that it not only reduces hospitalization rates (and, consequently, Medicare costs by 26% in one major hospital) but also that home treatment is preferred by many patients.
- **Diabetes.** A significant advance in diabetes treatment during recent years has been the demonstration that tight control of blood sugar, using intensive management strategies, reduces the risk of long-term complications from the disease. The intensive monitoring and self-care needed to achieve this, however, is costly and time-consuming for patients and clinicians alike. AHCPR's sponsored research has helped provide the information that diabetics and their health professionals need as they choose the best long-term management strategy for each individual. For type 1 diabetics, for example, AHCPR-funded research has shown that using continuous insulin infusion, a newer mode of insulin delivery, to achieve tighter control can decrease the incidence of ketoacidosis and low blood sugar crisis.
- **Heart Attacks.** About 1.5 million Americans are admitted to hospitals yearly for serious chest pain. However, of those admitted to inpatient cardiac units, only 30 percent end up with a diagnosis of threatened or confirmed myocardial infarction (MI). This means that 70 percent undergo an expensive workup before they know that they have not had a MI, which translates to more than \$3 billion of unnecessary expenditures per year. One group of AHCPR-funded investigators has tested the effectiveness of a chest pain observation unit, located within a hospital emergency department, for patients experiencing a possible MI. This intervention has revealed some very positive effects: fewer heart attacks go undiagnosed compared to hospitals with only inpatient observation units; fewer patients are mistakenly sent home without being observed; there is a 55 percent reduction in hospital admission rates; and there is a 25 percent drop in the average length of stay when an exercise electrocardiogram (ECG) is added to the evaluation procedure. Savings in total hospital costs are calculated at \$567 per patient. In addition, patients who receive treatment in the chest pain units are more satisfied with their care, compared to those actually admitted to inpatient cardiac units for observation.

This research has also had a significant but unexpected impact on the way that medical research is conducted and clinical decision making takes place. For example, urologists, working with researchers we funded, found new ways of determining which men with enlarged prostates should have surgery. Health services research shifted the views of clinicians by emphasizing the importance of taking into account the patient's assessment of how the prostatism affected his ability to function, and his assessment of the risk of surgery. Our work has broadened the focus for evaluating the success or outcomes of medical care from only physiologic measures (such as urinary track pressure measures) to include important clinical outcomes, such as patients' perceptions of, and preferences for, their ability to function after treatment. This research has provided the foundation for truly informed patient choice among alternative clinical treatments and higher patient satisfaction, as patients become involved to the extent they want to be in making these choices. Plus, we have funded the translation of this research into practice, and we are already seeing reduced costs along with better outcomes through partnership with urologists and their patients. We are now funding similar research in other fields, such as breast cancer and the care of children.

#### *Quality*

Health care quality is very much in the news and a major issue for the Congress. I want you to know that our Agency has played a pivotal role in the effort to im-

prove the quality of patient care. We have worked closely with all of the major organizations committed to improving the quality of patient care, such as the American Medical Association (AMA), the Foundation for Accountability (FACCT), the National Committee for Quality Assurance (NCQA), the Joint Committee on Accreditation of Healthcare Organizations (JCAHO), and many others. And we are using every aspect of health services research to address the challenges we face.

But let me start with a basic question: what do we mean when we say “quality?” At the most basic level, quality means doing the right thing, at the right time, in the right way, for the right person. As someone who recently left clinical medicine, I am personally sensitive to the challenge clinicians face every day in knowing what the right thing is, when the right time is, and what the right way is. We are using our clinical research, often referred to as outcomes and effectiveness research, to address those three questions. And we are undertaking efforts, equally as important, to provide clinicians with the information they need most: syntheses of what we already know so that they can provide care to their patients that takes into account the latest findings.

We are working to develop better information on the quality implications of the way we organize, deliver, and reimburse health care services. We are developing the measures and tools that will help us to assess, compare, and improve the quality of care in different plans and settings. And we are working to provide you with a better sense of how quality is faring over time, much like the “leading economic indicators” that provide you with a touchstone for how the economy is faring.

We recognize that our focus on the quality and outcomes of care needs to be paired with a focus on issues related to access to that care. And we have a special responsibility to address the needs of vulnerable populations, who are most likely to face barriers to access. Our research has demonstrated that a growing percentage of the population are not offered health insurance; that of those offered health insurance, a growing number of Americans decline insurance coverage; and that even with health insurance, access to quality health care is not assured. And the reasons for this lack of access can be surprising and disturbing. For example, the Washington Post highlighted on its front page several weeks ago an AHCPR-funded study that found that primary care physicians were prepared to recommend very different courses of treatment for patients of different races and gender who outlined identical symptoms. These physicians recommended referrals for cardiac catheterization only 60% as often for black patients than white patients, and there was a clear impact of gender as well. Black women were referred only 40% as often. These results are disturbing and suggest that we have a broad array of issues to address in ensuring access to quality care.

#### *The Conduct and Planning of our Research.*

Mr. Chairman, let me know turn to how we conduct and plan our research and our specific research activities. As you well know, AHCPR is not a regulatory or enforcement agency, but a scientific research agency that sponsors, conducts and translates research. We follow the same rigorous evaluation and peer review standards for awarding research grants as does the National Institutes of Health. Three-quarters of AHCPR's research funds are used to support researchers throughout the country.

Since I have been at the Agency, we have been going through an extensive planning process. We are consulting our National Advisory Council, seeking input from our stakeholders, and welcome advice from the Subcommittee. We hope that the reauthorization process will provide an opportunity to gain additional insight from you and the other witnesses at this hearing as well as strengthen the relationship between AHCPR and this Subcommittee. The planning process has focused our priorities on four primary customers: clinicians, patients, health care systems leaders, and policymakers, each of whom need information to enhance their contribution to improve the quality of care in this country. In the rest of my testimony, I will describe how we are serving our customers with research on outcomes, quality, cost, use, and access.

#### *Providing Information that Helps Clinicians Provide Better Care and Patients Receive Better Care*

I see AHCPR's clinical research as a continuum. First, we build the science base by conducting health services research that serves as the foundation for improved care. Second, we translate and disseminate the research in a format that can be used in clinical practice. Third, we evaluate the translation and dissemination of that research to make sure that it has reached the relevant audiences and is used appropriately.

### *Measuring Health Outcomes*

First, let me concentrate on how we serve decisionmakers with information on outcomes of clinical care. AHCPR's sponsored research attempts to answer these questions for a wide variety of medical conditions and treatments. The findings of this research have been translated into useful tools for every day clinical practice. For example, AHCPR sponsored research at John Hopkins University developed a visual function index—the VF-14—that measures the effects of cataracts on patients' ability to perform 14 everyday activities, including reading and driving. The index also allows for comparisons of patients' visual function before and after removal of a cataract.

The VF-14 index is a sensitive and reliable measure of the impact of cataracts on visual function. As a result, it can be used to help determine the value of cataract surgery for specific patients. In a study of more than 500 patients 4 months after cataract removal, changes in patients' ratings of satisfaction with their vision correlated more strongly with changes in VF-14 scores than with traditional ways of measuring changes in visual acuity. Compared with other outcome measurements, a changed VF-14 score was also the strongest predictor of changes in patients' satisfaction with their vision.

Another tool developed by AHCPR-supported research should have a great impact on the quality of care provided to patients who suffer heart problems. An outcomes project funded by AHCPR recently found that many patients with heart attacks do not receive thrombolytic therapy (drugs to dissolve clots inside coronary arteries). Another research project at the New England Medical Center led to the development of a new tool to care for patients having a heart attack. The tool estimates whether a patient is likely to benefit from potentially lifesaving treatment with thrombolytic therapy in the emergency room. The information is provided to the doctor in "real time." The tool also calculates the patient's likelihood of developing serious complications, such as hemorrhagic stroke or major bleeding, if given thrombolytic therapy.

A trial to assess whether this instrument, which plugs into an existing electrocardiograph machine, will increase the proportion of eligible patients receiving recommended treatment is in progress. The researchers are also working with the major manufacturer of EKG machines to make this tool widely available.

### *Understanding Variation in Health Care*

AHCPR's research emphasis has been on conditions that are common, costly, and for which there is substantial variation in practice. This research includes many of the conditions that represent a major expenditure for Medicare.

The issue of variation is not new to you. Dr. John Wennberg's work has shown that medical practice varies widely in this country. AHCPR has sponsored a substantial portion of Dr. Wennberg's work in the area of prostate disease. His research team found that the rate of radical prostatectomy for Medicare patients in Clearwater, FL is nearly twice the rate in Medina, OH (the national average is 2.0 surgeries per 1000 Medicare beneficiaries while the rates in Clearwater and Medina are 2.8 and 1.5 respectively). These variations can vary region to region, State to State, or within States. For example, the rate for radical prostatectomy for Medicare patients in Baltimore, MD, is approximately three times the rate in Salisbury, MD.

Variation provides us an opportunity to study what care is appropriate, how much is enough, and what is fair. This involves understanding when variation is due to issues of uncertainty, issues of access, and issues of overuse or under use. I would like to note that variation isn't inherently bad. The research that AHCPR supports and conducts helps us understand whether variation in medical practice should be celebrated or eliminated. In some cases, variation is caused by geographical, epidemiological, or cultural preferences. For example, we expect to have a higher rate of skin cancer in the South, and therefore more treatment for skin cancer.

Outcomes research—which provides the basic knowledge of what works and what doesn't work—is the foundation for all efforts to improve the quality of health care services. We can use this knowledge to determine what the right thing is, when the right time is, and what the right way is, and whether we are getting value for what we spend.

### *Supporting Evidence-based Practice*

A key issue in variation is professional uncertainty. If clinicians don't know what works and what doesn't work, they may be inadvertently providing inappropriate or ineffective care. AHCPR supports 12 Evidence-based Practice Centers (EPCs), which provide the scientific evidence that others will use to reduce unnecessary variation by reducing uncertainty. The 12 Centers develop scientific analyses, known as "evidence reports," of the evidence of the effectiveness of a particular treatment, tech-

nology, or procedure. These analyses are then used by health care organizations, medical societies, physician practices, and others to develop their own quality improvement tools, including guidelines, quality improvement programs, and performance measures.

For example, the Agency developed an evidence report on the findings on colorectal cancer screening. The information contained in AHCPR's evidence report led to a clinical practice guideline that was developed by the American Gastroenterology Association on colorectal cancer, which in turn, contributed to Congress' decision to expand Medicare coverage for colorectal cancer screening.

An important component of AHCPR's Evidence-based Practice Initiative is collaboration. The EPC topics are nominated by public and private sector organizations which will use and help us disseminate the information. The nominators are our partners. For example, the American Academy of Pediatrics and the American Psychiatric Association nominated attention deficit/hyperactivity disorder as a topic, and they have incorporated AHCPR's evidence report into a guideline they developed. Similarly, a consortium of patient and provider groups nominated management of urinary problems in paralyzed persons as a topic, and they will also create a guideline from it. And the Health Care Financing Administration asked us to evaluate swallowing problems in the elderly to help them determine their coverage policy for this area.

#### *Translating Research into Practice*

In addition to providing information on outcomes to clinicians and patients, we want to help them use the information to enhance the quality of care provided and received. Obviously, developing the information isn't enough. We need to make sure that it is available in a useful format to anyone who needs it. To achieve that goal, AHCPR, the American Association of Health Plans, and the American Medical Association worked together to provide one-stop-shopping for best practices in clinical care. We developed the National Guideline Clearinghouse that makes clinical practice guidelines available to every clinician, health system leader, patient, and policy-maker who can use a computer.

AHCPR also is looking at the effectiveness of clinical preventive services, and the potential they have for saving lives and reducing health care costs. The medical literature increasingly recognizes that some clinical preventive services provide enormous benefit. We need to know which services are most appropriate and effective for which patients and when. The Balanced Budget Act expanded Medicare coverage for prevention services. The information AHCPR develops will be invaluable to you as you deliberate about further expansions in coverage for preventive services.

As a central component of these efforts, AHCPR will support renewed activities of the U.S. Preventive Services Task Force. Their 1996 report provides clinicians with the information on the effectiveness and appropriateness of the full range of preventive care—screening tests for the early detection of disease, advice to help people change their risky health-related behaviors, and immunizations to prevent infections. AHCPR will support major new assessments of preventive services and updates of priority topics by the Task Force. As requested in the Balanced Budget Act, the Task Force will also work with the Institute of Medicine to evaluate the implications of including new preventive services under Medicare.

Supporting the U.S. Preventive Services Task Force will continue a long and productive partnership between the government and the leading primary care medical and nursing organizations. Our activities complement the major investment being made by the Centers for Disease Control and Prevention (CDC) in the study of preventive services in community-based settings. We look forward to working with the CDC on integrating our research in this area.

Finally, I want to thank the Subcommittee for providing the Agency with its authority to support Centers for Education and Research Therapeutics or CERTS, under the Food and Drug Administration Modernization Act. We expect to announce to announce funding for several centers before the end of this fiscal year. The CERTS will improve the effective use of medical products, such as pharmaceuticals. This new authority builds on our existing research in this area. For example, clinicians can receive the information they need to help reduce the costs of medical care through AHCPR's research on pharmaceuticals. With funding from AHCPR, Michael Fine of the University of Pittsburgh and colleagues found that using the antibiotic erythromycin for treating community-acquired pneumonia in most outpatients aged 60 and under significantly reduces treatment costs compared with the use of other antibiotics (\$5.43 versus \$18.51) and has no adverse effect on medical outcomes. About 600,000 of the 4 million Americans who develop community-acquired pneumonia are hospitalized each year. This research could lead to significant savings.

### *Improving Decisionmaking in Health Care Systems*

The health care system has gone through some significant changes over the past several years. These changes have created new structures, processes, and settings in which care is delivered. These changes have also raised a number of issues such as what is the impact on quality, what happens to patients' access to services, the cost of those services, how they are used, and the outcomes of patients who use the services. For example, some of the questions we can ask are: What happens when patients are discharged quickly from the hospital? How are managed care and traditional insurance changing and how are the new arrangements affecting access to care and the quality of that care?

Unfortunately, these changes are happening quickly and we have little scientific evidence regarding their impact on the health care system, generally, and on quality specifically. AHCPR is conducting and supporting research to fill this void.

### *Providing Research on Market Changes*

I believe that outcomes research is more than measuring the outcomes of clinical treatments. Our customers need to understand the outcomes of the organizational and financial structures in the way medical care is delivered. It isn't enough to know that clinical services are safe, effective and appropriate if the structure for delivering that care is shaky or untested.

The journal *Health Affairs* featured AHCPR's research that presents the first comprehensive look at what is currently happening in the health care marketplace. The articles form an invaluable evidence-based core of information for current discussions of policy options by all health care system participants—both public and private.

These studies, which had a 2-year turnaround from funding to report, provide fundamental knowledge about the link between the financing and delivery of health care and the quality of services. These studies empirically and rigorously examine issues of how current, incentive-driven market decisions of multiple participants—hospitals, physicians, health plans, employers, employees, and public, private and individual purchasers—determine who gets health care, what kind of care, how much care, who pays and how much it costs.

### *Supporting Research To Improve Primary Care Systems*

Issues of systems of care are not strictly limited to hospitals or other institutions. We need to understand how patients gain access to the system. AHCPR is the only agency that has an expressed responsibility to study the structure and delivery of primary care services. This research is increasingly important as more care is delivered beyond the hospital walls.

More than half of all Americans are now covered by managed care plans, which often require the use of a primary care physician or gatekeeper to manage the referral of patients from primary to specialists. Access to specialists is a major concern among the public, and has been the subject of much debate. To strengthen the scientific base underpinning the referral policies of health plans, AHCPR funded ten grants on physician referrals, and will be hosting a conference in Washington this September where the results will be presented.

### *Preventing System Errors*

AHCPR-supported research has demonstrated that the processes and systems used to provide care are often faulty and can lead to avoidable accidents. One conclusion of the research is that many of these accidents are not the fault of individuals, and therefore can be prevented by evaluating and improving the system.

In an AHCPR-funded study, Dr. Lucian Leape, a pioneer in research on how to reduce errors in medicine, estimated that the number of injuries caused by medical errors in hospitals alone could be as high as three million annually, resulting in costs as much as \$200 billion each year. In his work on drug-related errors, Dr. Leape concluded that 70 percent of these errors are avoidable, and can be prevented by re-engineering the hospital systems which allowed the errors to occur. Other organizations, such as the Department of Veterans Affairs and the American Medical Association, are using this research to develop programs to reduce preventable errors.

AHCPR is also examining how changes within systems of care affect the delivery of services and their quality. The Health Resources and Services Administration (HRSA), the National Institute of Nursing Research (NINR), and AHCPR in 1996 convened a joint meeting of experts to set a research agenda on the impact of nurse staffing levels on the quality of care in hospitals. We will be supporting additional research in this area during the current fiscal year.



*Developing the Science and Tools to Measure and Improve Quality*

AHCPR is working to refine existing measures and develop new measures that accurately reflect the changing health care system. An important component in our effort to develop and test valid measures is to anticipate future measurement needs. The goal of our efforts is to begin to identify and develop the "next generation" of quality measures for certain conditions and population subgroups—particularly vulnerable populations such as the chronically ill—and in the full spectrum of treatment settings such as rehabilitation and home care.

The Agency is involved in collaborative projects with private sector organizations to develop their own quality measures. For example, AHCPR research found that elderly patients who receive beta blockers following a heart attack are 43 percent less likely to die in the first 2 years following the attack than patients who do not receive this drug. That same study found that patients who receive beta blockers are rehospitalized for heart ailments 22 percent less often than those who do not get beta blockers. However, only 21 percent of eligible patients receive beta blocker therapy.

The National Committee for Quality Assurance (NCQA) used the findings of this study as the basis for changing the performance measurement for beta blocker use after acute myocardial infarction to include patients over 75 years of age in the most recent version of the Health Plan Employer Data and Information Set (HEDIS 3.0). An important component of improving the quality of health care services is giving patients the information they need to make informed choices about their health care coverage, physicians, and treatment options.

AHCPR's Consumer Assessments of Health Plans (CAHPS) survey consists of a series of questionnaires designed to be used by public- and private-sector health plans, employers, and other organizations to survey their members and employees. The information from CAHPS questionnaires, presented in the CAHPS tested report formats, can help consumers and group purchasers compare health plans and make more informed choices based on quality.

The CAHPS materials are designed for use with all types of health insurance enrollees (Medicaid and Medicare beneficiaries as well as the privately insured) and across the full range of health care delivery systems, from fee-for-service to managed care plans. In addition to a core set of items designed for use with all respondents, some additional questions are targeted for use with certain subgroups such as persons with chronic conditions or disabilities, Medicaid and Medicare beneficiaries, and families with children.

We are not suggesting that all providers and plans in every clinical setting and every region in this country be evaluated using the exact same measures. Measures and instruments should not be one-size-fits-all, but should reflect the diversity of needs and uses. We are advocating a "department store" of accepted quality measures, all based on science and validated for reliability and usefulness, where users of measures can pick the set that fits their need, whether that need is to compare health plans or providers, or to conduct a hospital quality improvement project.

*Supporting Policymakers with Data and Information*

Policymakers need to understand how dramatic growth of managed care, changes in private health insurance, and other dynamics of today's market-driven health care delivery system have affected, and are likely to affect, the outcomes, quality of, cost of, and access to the health care that Americans use.

*Developing and Improving Information Technology*

Informatics is another important tool for improving the quality of health care services. There has been an explosion in the use of information technology in medicine, such as telemedicine and computerized medical records. These technologies have greater potential to improve the quality of, outcomes of, access to, cost of, and use of care. To achieve this potential, we need research to determine what works and what doesn't work in "high tech" health care.

Informatics is an area of research that is critical to every aspect of AHCPR's work. Let me explain. First, the revolution in information technology is critical to the ability of health care delivery systems to measure and improve the quality of care that they provide their patients. They need seamless information systems—linking administrative, financial, and clinical data—that can follow patients no matter where or from whom they receive care. I am delighted to note that much of the pioneering work in developing the prototypes and evaluating their usefulness in daily practice was supported by our predecessor, the National Center for Health Services Research. AHCPR has an important and continuing role to play in evaluating the impact of informatics on the cost, access, and quality of clinical care and health care systems. Last year we funded eight projects to do just that.

Second, the type of research that AHCPR conducts and supports—to assess what works best in clinical practice and how we organize and manage the systems in which care is delivered—relies upon information technology at every step. The type of rapid analysis and dissemination of data on patient outcomes envisioned by some of the quality of care proposals under consideration by the Congress will not be possible if we do not advance the state of the technology and develop the common language that will let systems from various providers, plans, purchasers, and payers communicate with one another.

For both of these reasons, we have recently taken steps to integrate our informatics work into our other substantive research centers. This step will strengthen our commitment to informatics in the long run.

Because the Secretary believes that health informatics is critical issue to the health care system, she asked me shortly after I joined the Agency to co-chair the Department-wide Data Council, which has become an increasingly important forum for decisionmaking in the area of information technology and carrying out the Department's statutory responsibilities. AHCPR's experts in informatics will help the Data Council as it addresses issues of advancing a common language for information technology systems and addressing questions of their appropriate use.

AHCPR's Medical Expenditure Panel Survey (MEPS) provides policymakers and others with up-to-date, highly detailed information on how Americans as a whole, as well as different segments of the population, use and pay for health care. This ongoing survey also looks at insurance coverage and other factors related to access to health care. MEPS is the only survey that collects expenditure data from the non-Medicare population.

MEPS data is used by Congress and Federal agencies, including HCFA and other components of the Department of Health and Human Services, Office of Management and Budget, and Department of the Treasury. If MEPS data were available during my tenure on the Physician Payment Review Commission, it would have been an invaluable source of information in helping to make recommendations to Congress on payment for physicians.

These data also are used widely in the private sector by researchers at The Heritage Foundation, Lewin-VHI, Urban Institute, RAND Corporation, and Project Hope, as well as by health insurance companies, pharmaceutical firms, and other health-related businesses.

Using MEPS data on the first 6 months of 1996, AHCPR researchers Philip F. Cooper and Barbara Steinberg Schone have found that as many as 6 million Americans choose not to accept health insurance when offered it by their employers. The study found that the number of workers declining employment-based health insurance increased by 140 percent between 1987 and 1996 while the number of employers offering health insurance increased during those years. Those most likely to turn down insurance are young (under age 25), single, Hispanic or black, and work for low wages. Possible factors driving this trend include the decline in real wages, higher employee contribution rates, and State legislation aimed at enhancing insurance coverage which may have increased costs.

AHCPR's assistance is not limited to Federal policymakers. An important AHCPR program is the User Liaison Program (ULP), which plays a critical role in providing technical assistance to States and local policymakers on a wide range of issues. For example, the ULP program conducted a workshop geared toward State policymakers to examine the latest research findings on the uninsured and what State governments have been doing to solve the problem. In 1998, the ULP will provide technical assistance to help State legislators and executive branch officials plan for and implement the State Children's Health Insurance Program (CHIP) recently enacted by Congress.

One of AHCPR's statutory responsibilities is to conduct assessments of new technologies for the Medicare program (HCFA) and the Department of Defense. This information is invaluable to Federal policymakers and in some case drives coverage policy in the private sector. A case in point is AHCPR's technology assessment on lung volume reduction surgery (LVRS). This technology assessment concluded that there was insufficient evidence upon which to make a scientific judgment regarding the effectiveness of LVRS. AHCPR recommended that coverage be granted within the scope of a clinical trial, which is now being conducted by the National Institutes of Health. AHCPR is supporting the cost-effectiveness component of that trial. It is our hope that the collaborative efforts between the agencies will yield the information needed to make an informed coverage decision on LVRS.

AHCPR's new Evidence-based Practice Centers will continue to produce timely technology assessments that will assist Federal, State, and private sector decision-makers make difficult coverage decisions. Private-sector policymakers also use our research to make informed health care decisions. Recently, the Pharmaceutical Re-

search and Manufacturers of America included AHCPR's research finding on atrial fibrillation to promote the use of blood thinning drugs in an advertisement touting "three ways pharmaceuticals are ganging up against health care costs."

AHCPR's research and data give policymakers the "big picture" on the cost, use, and access to health care in this country for them to use in making decisions about clinical policy, coverage, quality improvement, and spending.

#### *Conclusion*

In order for health services research to fulfill its potential to improve the quality of the health care system, the foundation on which it rests must be strong. This foundation includes the tools that can be used to improve health care, the training to nurture and promote the best researchers, and the teams that foster partnerships and collaborations among the public and private sectors.

All of these elements will enable AHCPR to meet the challenges we face. Mr. Chairman and members of the Subcommittee, I respectfully request that you reauthorize AHCPR so that we can help our Nation's health care system by:

- Conducting and supporting research on the outcomes and effectiveness of treatments.
- Ensuring that clinicians, patients, health care system leaders, and policymakers have the information that will enhance quality of care.
- Identifying gaps in access to and use of health care services, achieving value for the Nation's health care dollar, and
- Helping the market find ways to fill those gaps.

These issues are critical to a sound, high quality health care system. I look forward to working with the Subcommittee in the months ahead to find ways to improve health care decisionmaking.

Mr. BILIRAKIS. Thank you very much, Doctor. Doctor, let me just go right to the point raised by Mr. Bryant before he left on the appropriations. Last year the agency received a 17 percent increase, and you are seeking an even larger increase for the coming year. Why are additional funds necessary, and would you do more of the same activities you do now, or would you expand the effort into entirely new areas?

Mr. EISENBERG. When the agency was established in the late 1980's, the Physician Payment Review Commission offered a recommendation to the Congress that some agency like this ought to be established, and it said in the report from PPRC to the Congress that the budget ought to be hundreds of millions of dollars. That was in 1989 dollars. I think ever since then people have felt that the agency's budget should be substantially higher than it has been.

In 1995, in fact, we had a cut in our budget. If you were to take the budget that we had before 1995 and project it in real dollars today, we still have not caught up with that budget. So part of our effort is to catch up with where we would have been before.

But more exciting is what could be done with more funding that would be available for this kind of research. We are funding now a very small fraction of the grants that our study sections tell us would help to improve the quality of care and access to health care. We believe that there is a lot of research that could be done that we are not benefiting from because we have not had sufficient dollars to do so.

But in addition to that, there are some big projects that we would like to do. We would like to undertake, for example, projects such as those described in this year's budget request of getting a better handle on what is happening to the quality of care in this country through surveys and through the analysis of the data that is currently available, and that will cost a substantial amount of money for us to do.

So the request for the budget increase is in part a reflection of the fact that the agency's budget is small. And as you said, we had a 17 percent increase in our budget last year; but in terms of absolute dollars, that was the smallest increase in any agency in the department. So part of this is catch up and part is to help fulfill the potential that the agency has.

Mr. BILIRAKIS. All right. You gave us the example of some of the work that you do; and you have mentioned managed care, the information made available for better decisions in plan selection.

Let us take an individual family, mom and pop, and they are trying to make a decision on managed care, on what kind of plan to choose. Now, they would not come to you directly, would they?

Mr. EISENBERG. No, they would not.

Mr. BILIRAKIS. They would go to partners with whom you work and to whom you furnish information and research?

Mr. EISENBERG. Well, we provide our partners with the capacity to do these measures. We don't go out and collect the data. We neither have the funds, nor frankly do we think that it is appropriate that we be collecting information on health plans, but rather our partners do that.

They may be a purchaser like a company, Ford Motors, General Motors for example are using instruments like this. If you are a Medicare recipient, it would be the plan. Or maybe your State collects this kind of information. The State of New Jersey collected data using the survey that we developed, and presented it to all of the people in New Jersey to help them make decisions about which plan to join.

So the individual that you are describing would, depending on the way that he or she gets insurance, get the information from that organization and compare the different plans that are available, if they are lucky enough to have multiple plans offered to them. They would compare them on a set of different characteristics, including the characteristics of the physicians and the hospitals in the plan, as well as the way in which the plan meets the needs of its members. The plans would be compared in a way that looks familiar because the data are arrayed in easily-understood formats, like a lot of other consumer surveys where people can compare their options.

Mr. BILIRAKIS. Frankly, I am convinced of the good work of the agency, but could there be any claims made of duplication of effort? In other words—this was created back in 1989. If you were not in existence, is any of this being done elsewhere?

Mr. EISENBERG. Some of it is being done, but most of it isn't. Let me be specific.

The NCQA had a survey that was trying to get at the same issues that this survey gets at. Most of the other people using this survey did not have anything that they could use. We did not want to see duplication, and so we reached out to the partners, customers, and asked them what their needs were. We worked with NCQA and Medicare to ask them what their needs are so each of them now is using the CAHPS survey, but modified to their own needs so there is collaboration with the private and public sector. So neither Medicare or NCQA had to reinvent the wheel. NCQA

has an adaptation of CAHPS and Medicare has an adaptation of CAHPS.

For a small plan or purchaser, they do not have the resources to adapt the methodology, so they will use it just as it was produced.

Mr. BILIRAKIS. Thank you, sir. Mr. Brown.

Mr. BROWN. In some of the AHCPR publications, one of your research priorities is improving the quality of children's health and you look at the—you list eight indicators, low birth weight, pediatric asthma, child diabetes. Are you considering in your children's health research, are you including estrogenic substances and endocrine disrupters and what that does to the next generation both in terms of women's health and children's health? Is that something that your agency is looking at, or should be looking at, in your children's research?

Mr. EISENBERG. We could. I don't recall that that is on the list now, but let me explain how we come up with the list and then suggest a way in which we could look at that specific issue.

We have a set of evidence-based practice centers which are the first step in our developing ways of measuring and improving health care. We ask several times a year people like clinicians and consumer groups and policymakers what they think the most burning issues are and where more data or information is needed. Then we have 12 of our evidence-based practice centers around the country analyze those particular issues and come back with what we call an evidence report, which is a synthesis and analysis of data that we then give to that partner. The American College of Obstetrics and Gynecologists and the American Academy of Pediatrics are two of our partners and they come in with a list. I don't recall what was on their list. But what we have asked them to do is identify the thorniest issues that they need advice on. I can get back to you on that.

Mr. BROWN. Because of the public-private partnership that you mentioned, you will typically look to organizations like that on whether it is on children's issues or minority issues or any other kinds of health care issues, you will look to the sort of experts in the field and generally accepting their advice on directions to take your research?

Mr. EISENBERG. Exactly. The reason for that is we have a commitment to what we are calling "user-driven research." We start the way that I described, which is asking where the gaps are that we can help to close. But we also believe that if we don't start that way and we fund research that does not meet anybody's needs, it is going to fill some journals; but it is not going to get translated into practice. So we don't just ask these people what they want, we also say if we do this work, are you going to do something with it. We expect them to say yes, in which case we can close the circle of research and make it meaningful.

Mr. BROWN. Is the issue of estrogenic substances and endocrine disrupters and synthetic chemicals that mimic naturally occurring hormones that may cause birth defects and some sort of genetic problems 1 and 2 generations later, is that more of, possibly, an NIH issue than one for you?

Mr. EISENBERG. If the question is what its mechanism is, what is the biologic mechanism, the physiology or other characteristics, yes, it would be much more in keeping with an NIH study.

If the question is to do a clinical trial with randomization to see what the effect is in an idealized setting, the answer again is yes, that is more an NIH issue.

If the NIH or others have done research that answers those biologic questions and the question is for which patients might this be effective and how can we help improve the quality of the use of those services, what effect do they have on people's functional status, we see it more in our bailiwick. Or how can you develop measures of the performance of physicians and others in delivering those services.

Mr. BROWN. So the indicators that you discussed in one of your fact sheets in HCUP, quality indicators, low birth weight, child diabetes, pediatric asthma, if it is possible that you could look at that in terms of endocrine disrupters as potential causes of some of those indicators?

Mr. EISENBERG. Yes.

Mr. BROWN. Can you tell me some of the—give me a couple of examples of your private-public partnerships that you have worked on?

Mr. EISENBERG. Maybe I can give you two. One is at the beginning, and the other is at the end of the research cycle. At the beginning of the cycle, we felt that we could use our public dollars more effectively if we could use them to stimulate some spending on the private side to fund research, so we have partnerships with some foundations. For example, we are working with the Packard Foundation, AAHP, the Association of American Health Plans, the Johnson Foundation, to cofund projects that neither alone could do, or because we fund different parts of it where our mission is one part and their mission might be another part of the agenda. In this way, we get projects done that, as I said, probably would not be done if either of the two parties could not come to the table. That is one way in which we have partnerships.

Another partnership at the beginning of the cycle reflects my response to your previous question which is our agenda setting. We are having meetings from the private sector asking where should we invest and spend our research dollars on. At the back end we also need those partnerships to be sure that it gets delivered, so that we can be sure that the product actually gets out there. NCQA and the use of the Consumer Assessment Health Plan Survey is an example of that one.

We also have some partnerships with organizations who are taking the results of the Put Prevention Into Practice products. Some health plans who are taking the template that was developed as a public good with public dollars, printing it at their own expense, and translating the information so it can improve the care of patients who are in those plans and the performance of the physicians who are practicing in those plans.

So that is where we have emphasized our partnerships, setting our agenda, understanding where the gaps are and closing the gaps, to ensure that the research does not just sit on a shelf. Those are a couple of examples.

Mr. BROWN. Thank you.

Mr. BILIRAKIS. Mrs. Cubin.

Mrs. CUBIN. Thank you, Mr. Chairman. I want to follow up on the subject that the chairman brought up last in his questioning, but first I need a little information, and bear with me because even though I was on this subcommittee last year, it is such a huge jurisdiction of medical issues, I don't know as much as others do.

I think you said in the late eighties the Physician Payment Review Committee recommended the establishment of AHCPR?

Mr. EISENBERG. That's right.

Mrs. CUBIN. What did they want you to do at this time? What I am getting at is this. Sometimes, and I am not saying—I think that your agency does valuable—provides valuable services. And where I am going is do we really need a separate government agency to provide those services or could they, whether in one organization or multiple organizations, be provided without having a separate government agency? So that is where I am going.

In the beginning why did the physician payment—what did they ask the agency to do?

Mr. EISENBERG. Well, first, truth in advertising, I was on the Physician Payment Review Commission at the time, and I remember the discussions well. The argument went like this: if we are going to change the way that physicians are paid so we have this new payment system and we are trying to get doctors to practice on the basis of what works best for the patients, rather than how they get paid for those services, then we need to be able to be sure that physicians know what works best for their patients.

So there were chapters in the PPRC reports in 1989 and, in fact, in preceding years about effectiveness in outcomes of medical care. At that time the outcomes agenda and the effectiveness agenda was just starting to be identified as a major agenda for the research community.

And so PPRC looked around and said where is this research going to come from and concluded that there wasn't a place. There was a gaping hole in the research agenda, and it was not being done in the private and public sector, and the PPRC said some Federal agency is needed to meet this need. Congress then created it. And it was their judgment that something was needed to provide evidence for practice, to improve quality and decrease costs.

Mrs. CUBIN. My concern is that—is the growth of government and in the late eighties government was growing exponentially with programs and so on. And you know, we are trying, as you do know, to define what are the real legitimate functions of the Federal Government, State government, and local government in as efficient a model as we can.

And so it seems in a way that AHCPR, instead of need driving the agency, the existence of the agency is driving a larger need. So it is the growth, I guess, of what is going on inside AHCPR that I am questioning because it seems to me that between NIH and CDC, AMA, universities, medical schools, it seems to me that the information other than what you just said, should be there. And so I don't understand why you are the ones that are giving grants for research around the country and that sort of thing.

Mr. EISENBERG. I think it is the right question for us to ask, and we ask it every day: Where is our value added? If we didn't exist, what would not happen so we can focus on those areas where we make a contribution and a difference?

I would love to think that the agency is influential enough so we can drive the agenda, but I think the agenda in the areas that I described, the desire to contain the increase in health care costs, the concern that the country has about health care quality, and the concern that the country has about the outcomes of care is very external to our agency. Whether we exist or not, I think that agenda is going to exist, and I think the Nation's concern about those issues will continue.

Mrs. CUBIN. I agree.

Mr. EISENBERG. I would like to think that if we exist, the Nation's concern will be moderated because some of the research will help to address those problems. But we ask ourselves and our constituency groups all the time whether or not we are meeting a need that they have that wouldn't be met otherwise. We are small and we need to be sure that our resources are used in a way that does not duplicate what other sectors would do.

I have concluded that those issues about concern about outcome, concern about quality and cost would not be adequately addressed were the agency not present and that those concerns would be on the minds of every American whether we exist or not as well. So my conclusion is that we exist in order to solve or help to solve those problems that Americans are concerned about.

Mrs. CUBIN. Permission just to ask one more question.

Mr. BILIRAKIS. Without objection.

Mrs. CUBIN. Thank you. In the reauthorization legislation, one of the responsibilities of the agency will be to support primary care research and access in underserved areas. Can you tell me how you plan to do that. I represent Wyoming, which tends to be very underserved in primary care especially.

Mr. EISENBERG. Yes. We start by asking questions about who it is that is relatively underserved and who might have insurance but not be able to get access to care. We know that having insurance does not automatically translate into access to high quality care. Certainly rural America is one of those areas that is relatively underserved. We have some reports to help us focus and address the needs of rural Americans. We are collaborating in several different ways in order to meet those needs. We will continue to collaborate with other agencies to fund activities in telemedicine to see whether or not the impact of telemedicine on quality and outcomes of care is one that will help people who live in rural areas. Working on issues related to the relationship between different health professionals so we can understand what the most appropriate deployment of different kinds of health professionals in rural areas is another issue that we have dealt with.

Transportation is a big area for rural America in terms of getting its health care. And we have an agenda for research related to rural America. There are two problems there. One is setting the agenda, and the other is stimulating researchers to be interested in those problems because many of the States who are most interested in rural issues don't have a substantial number of investiga-



tors who are capable of doing this kind of research and competing successfully for it.

So that is a second agenda, to be sure that there is a pool of talented researchers who are interested in and looking at the problems that rural America has. I hope that we can make a difference there.

Mrs. CUBIN. Thank you.

Mr. BILIRAKIS. To hitchhike on the gentlelady's question, you mentioned in response to Mr. Brown that you meet with representatives of the private sector to help determine your agenda in terms of the areas where they do need some help regarding research. How does that take place? Is that done periodically? Is that at annual meetings? Who determines who these private sector people are?

Mr. EISENBERG. It goes on in several different ways. One is that we respond to people who come to us and say we heard about your agency, we would like to talk to you. There was a group from Cleveland. They called up and said what do you do. And we said, let's talk about what we can do together. All of us spend a fair amount of time inviting people to Rockville and meeting with them.

The second is that we have an outreach to organizations when they have their annual meetings or executive board meetings. I enjoy and am as responsive as I can be to invitations to talk to their members and their leadership about what we are and listen to them about what we should be.

Third, we have initiated this year a more proactive approach to this, where we have taken sectors of our user community and invited in people who are representatives of that user community to meet. Two days ago we met in Washington with about 15 people from the hospital community, rural hospitals and urban hospitals, private and public. The whole range of hospitals were represented around the table, and we just said what do you need. And then we listened to people for 3 hours. We are doing that seriatim with different user groups so we can get them together to help us set an agenda.

Mr. BILIRAKIS. Thank you. Mr. Green to inquire.

Mr. GREEN. Thank you, Mr. Chairman, and I would like to first ask unanimous consent to place a statement into the record.

Mr. BILIRAKIS. Without objection the statement of all members of the subcommittee will be made a part of the record.

Mr. GREEN. On page 6 one of your funded studies points out that where it says: "Physicians recommended referrals for cardiac catheterization only 60 percent as often for black patients than white patients," I want to follow up on my colleague from Wyoming's question. Have those results been verified by other studies, by the government, public or private agencies?

Mr. EISENBERG. That study was only published about a month and a half ago, so there has not been that much time for verification. Let me explain what we tried to do with that study is to look at what people know happens, which is that there are disparities among different groups in the population, including racial and gender differences.

This study was intended to ask why does that happen, not just does it happen. So it got into the clinical decisionmaking issue and

tried to understand the degree to which we as physicians are part of institutional racism and gender bias. We do need to validate it, and we need other studies to make sure that other studies confirm it. We are also looking at what we can do to decrease those biases and decrease those disparities.

Mr. GREEN. I know that is one of the functions of your agency, to look at racial and geographic disparities, and in your testimony you talk about the differences in treatment geographically based.

You mentioned at the end of your statement that the agency's research should be used as a guide and not as a rule. Are you concerned that some of the managed-care providers would deny doctors' recommendations based on your research results? And what could Congress do to ensure that your research is used only as a guide and not as a fixed rule?

Mr. EISENBERG. I think you should give us clear instructions that that is the case. Our research ought to be aimed at delivering evidence for decisionmakers so that they can make decisions based on the best science that is available. The language that the Senate has drafted gives us very clear and unequivocal instructions that that is the role of this agency, to get the best evidence out there, and that is what we intend to do.

One of the things that you might find interesting is our guideline clearinghouse where we have taken the guidelines that are developed by public and private sector organizations and put them on a website. We have had abstracts written, and this is the kind that would never happen if it weren't for a public agency who could do it; but you can go in and click your mouse to a website to see what the recommendations are that are based on evidence—we accept evidence-based guidelines—but what the recommendations are of different groups. And you would conclude in looking at that that there are multiple ways of taking care of patients and that they need to be individualized to the individual needs of a patient.

Mr. GREEN. On page 20 you are quoting another study of your researchers. It is mentioned that 6 million Americans chose not to accept health insurance that was offered by their employers. Hopefully that was not employer-paid insurance that they refused.

Mr. EISENBERG. Actually it was. That is startling. What it told us was just offering people insurance isn't enough. We found that the individual said I am not going to get sick; I don't want to pay my share of the premium.

It also happens in Medicare and Medicaid. We have found when Medicare offers certain services to individuals, that a substantial number of people don't pick them up. With the CHIP program, we know that one of the major efforts we need to undertake is an outreach program so that the people eligible for CHIP will sign up for CHIP.

I found that piece of research profoundly important in changing the way that I think about insurance. We have got to get insurance for Americans, but we also need to collaborate with those who are offering insurance to be sure that people know that they have insurance and that they know the importance of getting insurance so that they are covered. In this way, we can translate the availability of insurance to the acquisition of insurance, and translate that to better quality care.

Mr. GREEN. I understand that under 21, particularly single and minority, and having a 23-year-old who thinks that he is bullet-proof I understand, but it just boggles the mind that they would not accept insurance.

Mr. EISENBERG. I have a 21-year-old the same way. You are right. It is very difficult to explain to people that they are vulnerable and having insurance will help deal with that vulnerability. It is not just young people, but it is many young people who don't accept the insurance that is offered to them.

Mr. BILIRAKIS. I thank the gentleman. Dr. Ganske.

Mr. GANSKE. Dr. Eisenberg, how are your research processes different from HMOs' guidelines and HMOs' population-based studies?

Mr. EISENBERG. They are quite different. The research that we do generates the evidence that people can use to try to influence or improve health care. For example, we have these evidence-based practice centers that review the literature and analyze the available evidence about certain problematic issues in health care, and they will come back with a report that we then make available. That report might be translated into a continuing education program by one professional society, a manual by another one, a guideline by another one or by a managed-care organization.

We want to partner with them so they can use the evidence most appropriately, but we see ourselves as a partner with them. We are not going to write the guidelines. We are going to help generate the science-based evidence so that health care is based upon good research.

Mr. GANSKE. My point is that your processes require peer review?

Mr. EISENBERG. Yes.

Mr. GANSKE. And they are public?

Mr. EISENBERG. Yes.

Mr. GANSKE. And they are nonproprietary?

Mr. EISENBERG. Yes.

Mr. GANSKE. And they are available?

Mr. EISENBERG. Right.

Mr. GANSKE. Thank you.

Now, to what extent do your guidelines take into consideration individualization for a practitioner treating an individual patient?

Mr. EISENBERG. Let me emphasize that the agency produced 19 guidelines prior to 1995 and at that time made a decision that we should not produce more guidelines, but rather we should produce the evidence that helps others develop guidelines if they choose to do so. Once they have, we help people gain access to them through something like the National Guideline Clearinghouse, if they are evidence-based.

So we really are not producing guidelines any more. So it would be hard to answer your question since we are not doing the production of guidelines any more, but helping others to be sure that their guidelines are based on good evidence.

Mr. GANSKE. But as a physician, you would agree that when you are looking at a prevailing standard of medical care, that the type of work that you produce is something that should be taken into consideration along with peer-reviewed literature, NIH consensus

statements, and the physician's individual examination of that individual patient?

Mr. EISENBERG. Absolutely on every point. And I would even add one, which is to say that we would hope that the evidence that is generated by the research that we sponsor about what works when and for whom would help to influence what the prevailing standard of practice is since none of us wants it to be constant.

Mr. GANSKE. And since your work is public and it is peer reviewed, there would be nothing that would prevent that from being considered as part of a prevailing standard of medical care?

Mr. EISENBERG. That is an essential premise of the way that we operate. It is a public good, and it is available to everyone.

Mr. GANSKE. I thank you. I thank the chairman.

Mr. BILIRAKIS. Mr. Deal?

Mr. DEAL. I don't have any questions. I am learning by listening.

Mr. BILIRAKIS. Doctor, thank you very much.

Panel two, if you would come forward. Ms. Mary Woolley, president of Research! America based in Alexandria; Mr. Charles Kahn, president, Health Insurance Association of America; Dr. Charles Mahan, College of Public Health, University of South Florida; and Mr. Brian Lindberg, executive director for Consumer Coalition for Quality Health Care based here in Washington, DC.

Thank you very much. Thank you for honoring us with your presence and complementing the testimony of Dr. Eisenberg. Your written statement is already a part of the record and we would prefer that you supplement that orally, but obviously the time is yours. We are setting the clock at 5 minutes.

**STATEMENTS OF MARY WOOLLEY, PRESIDENT, RESEARCH!AMERICA; CHARLES N. KAHN III, PRESIDENT, HEALTH INSURANCE ASSOCIATION OF AMERICA; CHARLES S. MAHAN, DEAN, COLLEGE OF PUBLIC HEALTH, UNIVERSITY OF SOUTH FLORIDA; AND BRIAN W. LINDBERG, EXECUTIVE DIRECTOR, CONSUMER COALITION FOR QUALITY HEALTH CARE**

Ms. WOOLLEY. Thank you, Mr. Chairman.

Mr. Chairman and members of the subcommittee, my name is Mary Woolley; and I am the president of Research!America, which is a nonprofit alliance of nearly 400 organizations, industries, societies, institutions, and individuals committed to making medical and health research a much higher national priority.

Among the things we do are to commission polls to assess public attitudes toward research and researchers. Also, we have a number of programs designed to help researchers become more accountable and more accessible to the citizens who support their work. Like the Agency for Health Care Policy and Research, Research!America marks its 10th anniversary this year and like the AHCPR, Research!America is committed to making sure that the full continuum of research can sooner, rather than later, deliver on its promise of better health and quality of life.

Without the AHCPR, the public benefits of research, in fact, may be needlessly delayed or never fully realized. Just last week I testified before the House Labor HHS subcommittee reaffirming the public's support of doubling our commitment to medical research

over 5 years. You can see our survey results from the last three rounds of surveying on the chart that is displayed. And it shows, among other things, that just in the last 9 months or so, public support for doubling our Nation's commitment to research has increased from 60 to 68 percent. And importantly, the percentage of people who have no opinion has been reduced dramatically.

Now today as I testify before your committee, I bring with me evidence of the public support for the work that is performed under the auspices of the AHCPR. In our most recent public opinion survey, which we will show you now, we asked whether citizens value research which seeks to understand why there are differences in quality of care and outcomes for patients. As you can see here, 92 percent, 9 in every 10 respondents said that they do indeed value this research. It is the AHCPR that champions this value on behalf of the public.

We also regularly ask what concerns people have about research. At or near the top in survey after survey is the need for more information. Again, the AHCPR addresses this need. We have found that quality information is, in fact, essential as we advance research from the bench to the bedside through clinical trials. One of the top factors in the public's willingness to participate in clinical trials is their concern regarding the competence of the institutions and the people conducting the research. The AHCPR helps both practitioners and institutions evaluate and maintain their own competence and disseminates guidelines which help people make informed assessments about institutional and practitioner competence.

The AHCPR's goals are the goals of all Americans concerned about health. In just 10 years, the AHCPR has charted, explored, and helped us all understand the new landscape of quality. It has done so with a very modest commitment of public funds, and the agency is one of this Nation's great bargains. For the expenditure of just  $\frac{1}{100}$  of 1 percent of our Nation's health care costs, the AHCPR enhances quality measurement, improves outcomes for the elderly and chronically ill, strengthens the quality of children's health, expands clinical prevention services, furthers education on therapeutics, informs consumer decisionmaking, improves access, and champions cost savings. Remarkably, considering the limited budget of the agency, the AHCPR has had a substantial impact on every one of those items.

By reauthorizing the AHCPR, you will be able to report to your constituents that you helped reduce the rates of surgery, provided for healthier babies, saved health care costs, and improved coverage.

Your committee support of the AHCPR is greatly appreciated. With your continued commitment to the agency, America's greatest bargain will be something every authorizer, every appropriator, and every Member of Congress can take pride in supporting.

Let me conclude with this thought: as more public dollars are spent on research as well as on health care, the public and its decisionmakers rightly demand more accountability. By helping the practice catch up to the science, as Dr. Eisenberg has said, the AHCPR in many ways epitomizes public accountability. It is help-

ing us all make smarter, more cost effective decisions about health care. Thank you, Mr. Chairman.

[The prepared statement of Mary Woolley follows:]

PREPARED STATEMENT OF MARY WOOLEY, PRESIDENT, RESEARCH!AMERICA

Mr. Chairman and members of the Subcommittee, my name is Mary Woolley and I am President of Research!America, a non-profit alliance of nearly 400 organizations, industries, societies, institutions and individuals committed to making medical and health research a much higher national priority. Like the Agency for Health Care Policy and Research, Research!America marks its 10-year anniversary this year. And like the AHCPR, Research!America is committed to making sure the full continuum of research can—sooner rather than later—deliver on its promise of better health and quality of life. Without the AHCPR these public benefits may be needlessly delayed or never fully realized.

Just last week I testified before the House Labor/HHS Subcommittee, reaffirming the public's support of doubling medical research, and in particular the budget of the National Institutes of Health, over five years. (Figure 1) Today I testify before your committee with evidence of the public's support for re-authorizing the work that is performed under the auspices of the AHCPR. The continuum of medical and health research extends from basic through clinical research. Health services research then closes the gap between what we know and what we do, by asking what works, what is most cost-effective, and what is the best way to ensure quality in health care delivery. Our nation leads the world in the conduct of basic, clinical and health services research; we must lead also in assuring that health care delivery is thoroughly grounded on our world class research.

Research!America has been commissioning public opinion surveys since 1992, exploring attitudes toward medical and health research, researchers, and the agencies, institutions and industries that conduct research. We know that the public strongly supports research and is willing to pay for it. In our most recent survey we asked whether citizens value research which seeks to understand why there are differences in quality of care and outcomes for patients. Nine in every 10 said they perceive value in such research (Figure 2). The AHCPR champions this value.

We also regularly ask what concerns (if any) people have about research. At or near the top in survey after survey is the need for more information. The AHCPR addresses this need.

We have also found that quality information is essential when we advance research from the bench to the bedside through clinical trials. One of the top factors in the public's willingness to participate in clinical studies is concern regarding the competence of the institutions and people conducting the research. The AHCPR helps institutions evaluate and maintain their own competence, and provides guidelines which help people make assessments about institutional competence.

In other words, the AHCPR's goals are the goals of all Americans concerned about health. In just ten years the AHCPR has charted, explored and helped us all understand the new landscape of quality. It has done so with a very modest commitment of public funds. Indeed, the agency is one of this nation's greatest bargains.

For the expenditure of just  $\frac{1}{100}$  of 1% of our nation's health care costs, the AHCPR enhances quality measurement, improves outcomes for the elderly and chronically ill, strengthens the quality of children's health, expands clinical preventive services, furthers education on therapeutics, informs consumer decision-making, improves access, and champions cost-savings.

Remarkably, considering the limited budget of the agency, the AHCPR has had a substantial impact on every item I have listed. As this nation increases its commitment to NIH and CDC, a multi-fold increase for the AHCPR is warranted as well. And it all begins with the re-authorization decisions this committee will make on behalf of the American public. By re-authorizing the AHCPR, you will be able to report to your constituents that you helped reduce rates of surgery, provided for healthier babies, saved health care costs, and improved coverage.

You and your colleagues are well aware of weekly polls conducted by the networks and papers that show health care remains a top public concern. Citizens often talk about quality of care, access to delivery and the importance of excellence in health care. No one is exempt from these concerns—especially when a friend or family member needs care. The AHCPR addresses these concerns on our behalf, bringing quality, access and excellence to health care in America.

In summary, I reiterate that the AHCPR is a vital component of the medical and health research continuum. In survey after survey, Research!America's polls affirm the public's recognition of both the economic and health benefits of the full con-

tinuum of research, including the research conducted under the auspices of the AHCPR. Moreover, the public is willing to pay more for research.

Your committee's support of the AHCPR is greatly appreciated. With your continued commitment to the agency, America's greatest bargain will be something every authorizer, every appropriator, every budgeteer, indeed every member of Congress can take pride in supporting. As more public dollars are spent on research as well as on health care, the public and its decision-makers rightly demand more accountability. The AHCPR in many ways epitomizes public accountability by helping us all make smarter, more cost-effective decisions about health care—decisions for the individual, for institutions, and for all of us, via public policy. As the AHCPR enters a new decade on the edge of a new millennium, it enters with both the capability and intent to meet public demand for accountability even as it assists the nation to deliver on the promise of better health and well-being.

## Support for Doubling Is Increasing

Do you support or oppose a proposal to double total national spending on government-sponsored medical research over five years?

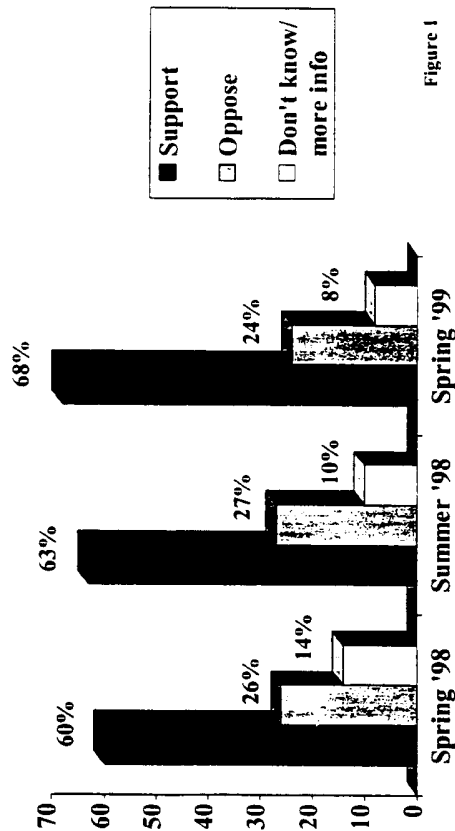


Figure 1

Aggregate 1998, 1999  
Charlton Research Company

*Research America*

## Health Services Research Is of Value

How important would you say research is which seeks to understand why there are differences in quality of care and outcomes for patients?

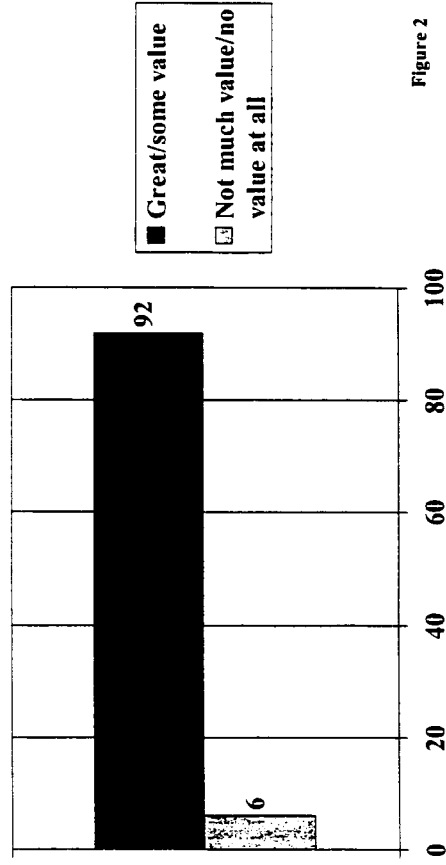


Figure 2

Aggregate, Spring 1999  
Charlton Research Company

*Research America*  
A CHARLTON RESEARCH COMPANY



Mr. BILIRAKIS. Thank you. Mr. Kahn.

**STATEMENT OF CHARLES N. KAHN III**

Mr. KAHN. Thank you, Mr. Chairman. I am president of the Health Insurance Association of America. I appreciate the opportunity to testify today about the AHCPR and the unique contribution it makes to improving health care for Americans. I have personal involvement in the development of AHCPR as minority health counsel to the Ways and Means Committee. I helped draft the authorizing legislation establishing AHCPR in 1989.

By the 1990's, however, AHCPR became embroiled in controversy during the initial budget and appropriations process in the 104th Congress. The agency came under fire for its role in the Clinton administration's health care reform effort.

Further questions were raised about the AHCPR's involvement in the development of medical guidelines. This situation was fueled by a particular physician group which felt that it had been treated unfairly in the establishment of certain medical guidelines. Eventually, congressional concerns were allayed by a reorientation of the agency's role in medical guideline development and a significant education and outreach effort by the agency itself to inform Members of Congress on its activities.

In early 1998, I wrote an article for the policy journal *Health Affairs* which suggested criteria for determining whether or not funding of AHCPR should continue. The criteria I recommended was, first, does the agency have an agenda that cannot be replicated by the private sector; second, does the AHCPR provide value added to help policy and medical decisionmaking uniquely attributable to its role as an independent public agency. I have attached a copy of the article to my testimony.

Today, both as a contributor to the development of the agency and as a representative for a major sector of our private health care system, I can unequivocally say that the AHCPR is meeting these goals. It is fulfilling a purpose that no single private company association or foundation can assume. Put simply, the agency is making health care in this country work better. In my written testimony I have outlined examples of distinct AHCPR activities and products that support this assertion.

I want to stress, however, that these are only illustrations and only barely scratch the surface. For example, since 1994 United Healthcare Center for Health Care Policy and Evaluation has used the AHCPR's clinical classification system to categorize administrative claims data for research purposes. As Dr. Eisenberg pointed out, the Consumer Assessment of Health Plans Survey is providing a tool to help Americans decide what health plan or insurer best meets their health care needs. It is being used by 90 million Americans, the Health Care Financing Administration is using it for Medicare and the Office of Personnel Management is using it for the FEHB program for the Federal employees. With AHCPR's assistance, Aetna U.S. Health Care has founded the Academic Medicine and Managed Care Forum, which is examining better approaches to collaborations on health services research and its dissemination.

Congress recently reauthorized AHCPR to establish centers for the education and research on therapeutics to fund research and education on the use of approved drugs, the prevention of adverse drug reactions, elimination of pharmaceutical errors and the appropriate use of dosage of drugs for special groups.

As these examples illustrate, the AHCPR plays a significant role in helping Americans covered by the private market and by public programs such as Medicare. It enables the building of evidence of what works and doesn't work in everyday medical practice, as well as helping the consumer navigate the health care system; and it helps use this evidence to create the knowledge to measure and improve the quality of care.

It is important to point out that AHCPR is neither a regulator, a payer, nor a standard-setting body. It is at its core an evidence-based science agency that works collaboratively with both public and private sectors to develop tools and information that they need to improve health care and its delivery.

In my view the agency meets the objectives it has set for itself as well as the goals that I offered in my health affairs article. HIAA is happy to assist this subcommittee in any way as you develop reauthorization legislation for AHCPR. HIAA supports the goals of the bipartisan AHCPR reauthorization legislation in the Senate.

In my written testimony I have included comments on that legislation that may be helpful to you as you move forward. Again, thank you, Mr. Chairman, for the opportunity to share my views on the work of the AHCPR. I would be happy to answer any questions.

[The prepared statement of Charles N. Kahn III follows:]

PREPARED STATEMENT OF CHARLES N. KAHN III, PRESIDENT, HEALTH INSURANCE  
ASSOCIATION OF AMERICA

#### *Introduction*

Mr. Chairman, members of the Committee, I am Charles N. Kahn III, President of the Health Insurance Association of America. HIAA represents 269 member companies providing health, long-term care, disability income, and supplemental insurance coverage to over 115 million Americans. I am pleased to speak to you today about the important role that the Agency for Health Care Policy and Research (AHCPR) plays in improving health care for millions of Americans.

#### *The Critical Role of AHCPR*

I have a long history of personal involvement with AHCPR. In the mid-1980s, when I worked on the staff of Senator David Durenberger, I helped the Senator draft one of the early pieces of authorizing legislation on health outcomes research; that legislation was a precursor to the establishment of AHCPR. Later, I served as Minority Counsel to the Ways and Means Health Subcommittee where I worked for Bill Gradison, one of the original sponsors of legislation establishing AHCPR in 1989. In that role, I contributed to the drafting the agency's authorizing legislation.

While I served as Staff Director to the Ways and Means Subcommittee on Health in early 1998, I wrote an article that appeared in *Health Affairs* outlining the role of AHCPR and setting forth criteria for assessing its value.

Through my service on Capitol Hill, I had become keenly aware of the agency's promise and the important role it had come to play in fostering, undertaking, and implementing health services research. By 1995, however, AHCPR became embroiled in a series of controversies that threatened its existence. During the budget and appropriations process in the first session of the 104th Congress, the agency came under attack for its involvement in the Clinton administration's 1993-94 health care reform effort. The House Budget Committee's report on the budget resolution for fiscal year 1996 stated: "The agency is supposed to support research and information dissemination on health care services and technology, medical effective-

ness, and patient outcomes, but performed an advocacy role in the health care debate the past 2 years while its funding increased from \$125 million in 1992 to \$163 million in 1994.<sup>8</sup> Congressional opposition to AHCPR funding also was fomented by complaints by some practitioners, who saw themselves as losers under practice guidelines developed by the agency.

More fundamentally, AHCPR's opponents questioned the need for the agency. Critics believed that whatever worthwhile functions the agency did perform could be replicated by other government agencies or in the private sector.

Eventually, Congressional concerns were allayed by significant education and outreach efforts, as well as a reorientation of the agency's role in medical guidelines development. In response to Congressional pressure, AHCPR sidestepped conflicts with medical specialty groups and other providers by redirecting medical guideline activities to the development of methodologies, promotion of guidelines use, and synthesis of the literature on treatments rather than actually establishing guidelines. In addition, the agency's senior staff and health services researchers spent a great deal of time discussing the unique role and contributions of the AHCPR with Congress.

In the *Health Affairs* article, I outlined two major objectives that the agency must meet to continue to fulfill its mission and, thereby, justify its existence. First, it must maintain an agenda that meets the nation's health policy and research needs in ways that cannot be replicated in the private sector. Second, it must continually demonstrate added value to health policy making and medical decision making uniquely attributable to its role as an independent public agency.

Today, as a representative for one of the most important segments of the private health care industry, I can say unequivocally that AHCPR is, in fact, meeting these goals. It is fulfilling a purpose that no private company, association, or foundation could. The agency plays a unique and significant role in helping to make the private health care market work. Private markets are driven by informed consumers. As a partner with the private market, AHCPR is playing a leading role in developing information and measures to help both employers and individual health care consumers better understand the value of what they are purchasing. And unlike other state and federal government agencies, AHCPR is neither a regulator nor a standard-setting body. It is, at its core, an evidence-based science agency. It is not a policy-maker, but informs policy makers in the public and private sector. The agency works collaboratively with both the public and private sectors to develop tools and information they need.

In addition to providing tools to help consumers choose health plans and providers, AHCPR plays a three-step role in developing and disseminating quality improvement measures. First, it builds the evidence base for measurement through outcomes and effectiveness research. Second, it develops measures and works with other public or private researchers to develop measures. Third, and critically important, the agency helps disseminate these measures into real-world practice.

#### *Examples of Private Sector Collaboration with AHCPR*

The Health Insurance Association of America has first-hand knowledge of how the AHCPR can provide valuable information not only on health practices but on the financing and delivery of health care. In 1996 and 1997, AHCPR worked with HIAA to produce *Choosing and Using a Health Plan*, a booklet that explained managed care in clear, concise language, and that was made available in English and Spanish. Development of the guide required skillful coordination among various constituencies in the world of health care. (Consumers, commercial insurers, various managed care plans, and providers all "vetted" the booklet.) This project is exactly the kind of low-cost, consumer-friendly publishing venture that AHCPR is extremely good at; we were proud to be the agency's private sector partner, and a number of our companies were happy to distribute the booklet to their policyholders.

A number of individual health insurance companies who are members of HIAA also have worked collaboratively with AHCPR.

For example, United Healthcare uses the Agency's Clinical Classification Software (CCS), which was developed as part of the Healthcare Cost and Utilization Project (HCUP), in its plans' medical management. United also has worked with Dr. Jose Escarce on two funded grants. One studied referrals from primary care to specialists in different types of managed care arrangements. The other involves study of the quality of care by eye specialists and patient outcomes in relation to the features of managed care contracts.

Since 1994, United Healthcare's Center for Health Care Policy and Evaluation has used the AHCPR's clinical classification system to categorize administrative claims data for research purposes. The International Classification of Diseases (ICD) coding system, the health care claims classification system, consists of over 20,000

codes. The Center has used the AHCPR's clinical classification system to aggregate the claims of Medicaid and employer insured members, and to compare health status and health services utilization. This classification system has been integrated into risk adjustment models, and served as a baseline from which to compare other classification systems, risk adjustment applications, and episode groups. Ingenix, a part of United Health Care's Knowledge and Information business segment, provides a software application to United's health plans which use the AHCPR clinical classification system to group claims for measuring the performance of delivery systems and providers, and to profile populations and purchasers.

The Consumer Assessment of Health Plans (CAHPS), one of the most widely used of AHCPR's products, is providing people with a tool to help them decide what health plan best meets their health care needs. The CAHPS will make information on the quality of health care available to 90 million Americans in 1999. According to AHCPR, it is being used by 20 States, 10 employer groups, a wide range of health plans, and at least one large employer. The Health Care Financing Administration (HCFA) has also used CAHPS to survey Medicare enrollees in managed care plans to assess their experiences. The Office of Personnel Management will use CAHPS to report consumer assessments of their health plans to federal employees.

With AHCPR's assistance, Aetna U.S. Healthcare has founded the Academic Medicine and Managed Care Forum, which is examining better approaches to collaborate on funding and dissemination of research. Aetna also has adopted guidelines developed by AHCPR for the treatment of low back pain in both its disease management program and its continuing medical education monograph for practitioners. In addition, Aetna uses AHCPR's evidence-based guidelines (e.g., cataract surgery) to help establish clinical policy.

AHCPR also was instrumental in developing the National Guideline Clearinghouse (NGC) in collaboration with the American Medical Association and the American Association of Health Plans. The NCG, which went live on the Internet on December 15, 1998, will serve as a comprehensive resource on evidence-based clinical practice guidelines. To date, it contains over 500 clinical practice guidelines submitted by over 67 guideline developers.

AHCPR has taken significant steps to close the gap between what we know about appropriate treatments and what we need to know to further improve care in the future. For example, despite the large number of studies and guidelines defining the management of heart attacks, many patients (often patients of vulnerable populations) still receive sub-optimal care. AHCPR research found that elderly patients who received "beta blockers" (drugs used to lower the heart rate) following a heart attack were rehospitalized 22 percent less often than nonrecipients and the mortality rate was 43 percent lower. However, only 21 percent of eligible patients were using beta blockers.

The National Committee for Quality Assurance (NCQA) used the findings of this study as the basis for changing the performance measurement for beta blocker use after heart failure to include patients over 75 years of age in the most recent version of the Health Plan Employer Data and Information Set or HEDIS 3.0 (a set of standardized performance measures designed to assure that purchasers and consumers have the information they need to reliably compare the performance of managed care plans). HEDIS 3.0 is being used by the Health Care Financing Administration to assess the quality of care provided by Medicare HMOs. It is also being used by a number of health plans in the private sector to improve outcomes for patients with heart failure.

One new role that the agency has been asked to take on by Congress highlights this. The Food and Drug Modernization Act of 1997 established Centers for Education and Research on Therapeutics (CERTS). These Centers will fund research and education on the use of approved drugs, the prevention of adverse drug reactions, elimination of pharmaceutical errors, and the appropriate use and dosage of specific drugs in special populations such as women, children, minorities, and the elderly. Too often patients are not aware of the dangerous side effects of misusing medication. For example, research has shown that the over prescribing of antibiotics can lead to resistance to an antibiotics therapeutic effects. Given the growing importance of pharmaceutical treatments, and their growing costs, information developed through this AHCPR project will be critical to helping HIAA's members ensure that patients receive appropriate medications at a reasonable cost.

Clearly, without the type of support from AHCPR outlined above, private health plans alone would have too few resources and too little capacity to produce these types of measures and evidence.

#### *Analysis of AHCPR Reform Legislation*

There have been several bills introduced and considered during the 106th Congress that would reform some aspects of AHCPR. Before concluding, I would like to briefly share HIAA's views on that legislation.

Earlier this year, Senator Frist introduced bipartisan legislation (S. 580) to reauthorize AHCPR. The legislation currently has 11 cosponsors, including Senator Jeffords (R-VT), Senator Kennedy (D-MA), Senator Mack (R-FL), and Senator Mikulski (D-MD). On March 17 and 18, the Senate Health Education Labor and Pension Committee marked up Patients' Bill of Rights Act legislation (S. 326) that contains a slightly modified version of S. 580.

Generally, HIAA supports the goals embodied in the Senate legislation. S. 580 would make a number of important modifications to AHCPR's statutory authority, clarifying its role as an evidence-based science agency and ensuring that it would continue to be a strong partner in improving the nation's health care system into the next century. For example, the legislation would expand the priority populations listed in the existing statute to encourage AHCPR to focus efforts on children and people with special health care needs, such as those with disabilities and those who need chronic care.

In addition, the bill expressly prohibits the agency from mandating "national standards of clinical practice or quality healthcare standards." This would reinforce that the agency has no regulatory authority and that its role should be limited, appropriately, to building the science of quality and letting private and public sector purchasers actually set quality standards. The legislation also includes several measures to ensure that promising research findings are translated more rapidly into improvements in daily practice by promoting the use of Healthcare Improvement Research Centers, Provider-based Research Networks, and similar innovative mechanisms.

To better help consumers measure, compare, and understand the health care options available to them, the legislation would require the agency to expand current data measurement activities and to report annually on national trends in quality. This report would be comparable to the "leading economic indicators" that now inform us about the health of our economy. Importantly, the legislation also would require the AHCPR to consider differences between types of health plans, delivery systems, and provider arrangements in developing data collection measures. As you know, Mr. Chairman, data collection and reporting standards that may be appropriate in an HMO setting are not always appropriate for PPOs or other types of delivery systems, and vice-versa.

#### *Conclusion*

Patients and health care practitioners need the best scientific evidence so they can make informed choices about treatment alternatives. Health plans, purchasers, and policymakers need to know the latest evidence on the most effective ways to organize, finance, and manage the delivery of health care. The pharmaceutical, biotechnology, disease management, and equipment and device industries need to know how to best focus their research investments and design new products. And we all need to know how to recognize and choose high quality health plans and practitioners.

As I have outlined above, AHCPR plays a significant role in helping the private market, and public programs (such as Medicare) that rely on private health plans in two basic ways: it builds the evidence of what works and doesn't work in everyday practice; and it helps use this evidence to create the knowledge to measure and improve the quality of care.

I strongly believe that the agency continues to meet the objectives it has set for itself and the goals I outlined in my *Health Affairs* article last year. I would be happy to answer any questions you may have at this time.

Mr. BILIRAKIS. Thank you, very much, Chip.  
Dr. Mahan.

#### **STATEMENT OF CHARLES S. MAHAN**

Mr. MAHAN. Thank you, Mr. Chairman. I am Dr. Charles Mahan. I am an obstetrician and dean of the College of Public Health at the University of South Florida in Tampa.

I strongly support the reauthorization of AHCPR, and I would like to introduce two recent articles just from the last few weeks into my testimony.

Mr. BILIRAKIS. Without objection, those will be made a part of the record.

[The articles are retained in subcommittee files.]

Mr. MAHAN. These show the importance of customer service on our ability to meet our Nation's health care goals. One is from Massachusetts showing 40 percent of the women who have babies that died stopped going for health care because of communication problems with their doctors; and another from Yale showing that our colleagues there have done some neat things for homeless veterans to figure out how to get them into health care by co-locating services.

I have been practicing in health care for 35 years, and my main area of practice has been trying to get better access for women into the health care system. Fifteen years ago, Florida started getting concerned about its infant mortality. We were last in the Nation, and one of the big parts of that is that we were last in the Nation in getting women into care.

We did the usual things for 5 years. We expanded the Medicaid program, hired more doctors and nurses at the health departments, and we were still last even though we were making slight improvements in infant mortality. At that time we did an extensive effort in all of our delivery hospitals around the State to interview women who had no prenatal care, expecting to find problems with these women.

To our chagrin the women on the average each had tried five times to get into care, and the enemy was us. Then I went for a week at the Walt Disney Company to their customer service program. I was one of the first health care people to ever go to that program. The other folks there were from General Motors and Kodak and IBM, and we incorporated Disney's customer service program into our State public health program along with quality improvement programs, key outcome indicators, and goals. And we saw some amazing turnarounds in the way we provided care, and now Florida is in the top third of all States in getting women into health care.

We certainly need to focus through AHCPR on national research and evaluation of why people are not using our health insurance programs in an appropriate manner. You can forget outreach, we found. You do not need to go door to door to get people into care. If you improve services, both prevention and curative services, you build it that way, and they will come. And we have seen places that had 10 to 12 percent of women not getting care shrink away to less than 1 percent within 6 months after the word got around in the community that that place was okay.

Dr. Eisenberg's definition of quality of care in his written testimony includes the words "in the right way for the right person." In the right way is a very important thing. Each person and each community has a different definition of what quality service is in health care, and it is heavily weighted by their perception of the kind of treatment that they got. Kind and considerate service is one of the most important parts of the attainment of good health, and that is what we are working on with the handouts and in cooperation with the Walt Disney Company and the National Perinatal Association. Thank you.

[The prepared statement of Charles S. Mahan follows:]

PREPARED STATEMENT OF CHARLES S. MAHAN, DEAN, COLLEGE OF PUBLIC HEALTH,  
UNIVERSITY OF SOUTH FLORIDA

Over the past 15 years, Florida has made the most rapid improvements in infant mortality and child health of any large state.

The most important step we took was to improve the accessibility by women and children to our caregivers. We were the worst in the nation in the number of women not receiving prenatal care. Since most of us blamed the women themselves for that, we decided to confirm our suspicions by extensive interviews of postpartum women who had no prenatal care. To our surprise and horror, we found that the enemy was us. The average woman had tried five times to access health services and had found enormous barriers to doing so. Barriers such as:

- five stops to determine eligibility, often with no
- transportation available;
- six hour waits at the clinics;
- unfriendly clerks and providers;
- unavailability of appointments;
- lack of translators, etc.

Why is getting people into care important? Wouldn't we save a lot of money if people just didn't use prenatal care or well-child care services unless they were very ill? The answer is no—we save an enormous amount of money if women and children use preventive services. We save \$3.00 for every dollar spent on prenatal care; we save \$11.00 for every dollar spent on childhood immunizations and we save \$16.00 for every dollar spent to help people space their pregnancies and more if they previously had a low birthweight baby. So it is in America's best interest to make access to health services as easy and welcoming as possible. It's just good common sense and good business. The health industry, the largest industry in the U.S., is the last industry to begin to wake up to the idea that excellence in customer service is key to improving our health outcomes.

Successful interventions: Using modern prevention marketing techniques (personal interviews, focus groups, etc.) and training precepts from Disney's famous customer service program, we instituted a state-wide "Golden Rule" program for public health providers. "Our health department services should be so friendly and so good that any of us would select them as provider of first choice for ourselves and our families." Key outcome measurements were tagged to the Goals for the Year 2000 and all counties were compared in their progress toward those goals. Shining examples of success were Lee County (Ft. Myers) where the "no prenatal care" rate went from 10% to less than 1% in one year with the establishment of teams of nurse-midwives. Another has been Seminole County (near Orlando) where services are the best I've seen anywhere, public or private—15 minute waits, maximum; all problems cared for at the same visit; and cheery, welcoming people and surroundings. While there are stellar examples of customer service by health care organizations—Moffitt Cancer Center and All Children's Hospital in Florida and The Mayo Clinic in Minnesota—those are, sadly, not the industry norm. My argument is, if public health departments can bring their customer service quality up to that of the Mayo Clinic, considering the vast differences in funding, anybody can!

Our college and The Chiles Center are joining with the Walt Disney Company, the National Perinatal Association, The National Public Health Leadership Development Network, the Department of Health and Human Services and private foundations and corporations to begin a national twenty year endeavor to improve access, quality and satisfaction in the U.S. health industry including public health. The program "Friendly Access" is outlined in your attachments.

We strongly believe that this approach will remove the many existing impediments to care for mothers and children of all walks of life and result in the establishment of a real system of care for this group—something this country has never had.

There is strong evidence that this approach works but, above all, it is the right thing to do. Thank you.

Mr. BILIRAKIS. Thank you very much. Mr. Lindberg.

#### STATEMENT OF BRIAN W. LINDBERG

Mr. LINDBERG. Good morning, Chairman Bilirakis and ranking minority member Brown and others on the panel.

The Coalition is a national membership organization of consumer groups committed to the goal of assuring and improving quality of health care for all Americans. Our work is guided by the empowerment principles of consumer rights, protections, choices, information assistance and self-responsibility and by the strong belief that our Nation must make the necessary investments in the evaluative infrastructure that can measure the impact of our health care delivery system on quality and the health status of Americans.

With these core principles and beliefs as our compass, the coalition is delighted to comment on the reauthorization of the Agency for Health Care Policy and Research. Over a quarter century ago, Dr. John Wennberg began his pioneering work documenting the variation in medical practice. Dr. Wennberg attributed variation to a high degree of medical uncertainty and the absence of clear scientific evidence demonstrating benefits to patients of various treatment interventions.

Not enough has changed in the intervening years. We know shockingly little about the effectiveness of the services we are paying for. The challenge ahead is to build the science of evidence-based medicine through a commitment to outcomes research.

Mr. Chairman, this is not our only challenge ahead. The diffusion in integration of new knowledge to the actual practice of medicine is an equally complex task. Mr. Chairman, where is the health care consumer in this equation? At present, most consumers have very little understanding of practice variation and how medical uncertainty can compromise effective medical decisionmaking.

Consumers generally assume good technical care and the clinical competence of physicians. But consumers need to be exposed to unbiased information about their medical care options and the potential outcomes for each option that are most relevant to them, including functional status, well being and quality of life. This information and this new dialog with health care consumers will promote a concept long advocated by Dr. Wennberg, the concept of shared decisionmaking between consumer and clinician.

Regarding the reauthorization of AHCPR, Mr. Chairman, today I want to request that this committee send a strong signal of your commitment to providing objective science-based information to patients and clinicians by supporting reauthorization of AHCPR. The consumer coalition supports AHCPR as an independent, unbiased nonregulatory Federal agency committed to building the science of evidence-based medicine.

Under the leadership of Dr. John Eisenberg, AHCPR has moved forward in the rapidly evolving health care environment and has staked out critical, broadly supported roles in the areas of outcomes, research, technology assessment, quality measurement, and quality improvement activities.

Consumers benefit directly from information created by AHCPR on the risks and benefits of various treatment options to support their health care decisionmaking. The availability of this information reinforces the central role of consumers in directing their own health care.

Consumers also benefit indirectly from the research that AHCPR does to assist physicians and other health care providers in doing a better job of providing appropriate and high-quality care.



AHCPR's roles in conducting health services research, disseminating that research and the findings and evaluating the use of the research in influencing practice behavior has a significant impact on improving the quality of patient care.

I also commend AHCPR on its new focus or research priorities for the coming year. AHCPR has proposed to fund research in several areas about which the coalition cares deeply. We believe that one of the critical measures of any health care system is how well it serves the chronically ill and the elderly. AHCPR will study how various system characteristics affect health outcomes, access and quality of care provided to these vulnerable populations.

In conclusion, I want to briefly address the issue of funding AHCPR. I believe that we need to pay closer attention to the direct and often immediate return on the investment that is made with funds provided to AHCPR. Their budget is simply not large enough to do all that could and should be done to improve the practice of medicine, improve the outcomes of treatment for patients and inform practitioners and patients of the effectiveness of their options.

Thank you again for including the coalition and our viewpoints in the hearing today, and I would be happy to answer any questions that you have.

[The prepared statement of Brian W. Lindberg follows:]

PREPARED STATEMENT OF BRIAN LINDBERG, EXECUTIVE DIRECTOR, CONSUMER  
COALITION FOR QUALITY HEALTH CARE

#### *Introduction*

Good morning, Chairman Bilirakis, ranking minority member Representative Brown, and other members of the Subcommittee on Health and Environment of the House Committee on Commerce. My name is Brian Lindberg and I am Executive Director of the Consumer Coalition for Quality Health Care. The Coalition is a national membership organization of consumer groups committed to the goal of assuring and improving the quality of health care for all Americans. The Coalition is an active forum for consumer groups to come together to develop policy positions on issues related to consumer protection, quality assurance and informed consumer choice in the health care field. Our work is guided by the empowerment principles of consumer rights, protections, choices, information, assistance and self-responsibility and by the strong belief that our nation must make the necessary investments in an evaluative infrastructure that can measure the impact of our health care delivery system on quality and the health status of all Americans. With these core principles and beliefs as our compass, the Coalition is delighted to comment on the reauthorization of the Agency for Health Care Policy and Research (AHCPR).

#### *The Challenge of Medical Uncertainty*

Over a quarter of a century ago, Dr. John Wennberg began his pioneering work documenting wide variation in medical practice. Dr. Wennberg attributed variation to a high degree of medical uncertainty and the absence of clear scientific evidence demonstrating the benefits to patients of various treatment interventions.

Little has changed in the intervening years. Medical care is America's largest industry, consuming over a trillion dollars annually, yet we know shockingly little about effectiveness of the services we are paying for. The health care system continues to pay for what has always been done and for new medical procedures and treatments without clear scientific evidence of the benefits for patients. The challenge ahead is to build the science of evidence-based medicine through a commitment to outcomes research. Evidence-based medicine will lead to an investment in health care services having a measurable *probability*, rather than an untested *possibility*, of improving health status.

Mr. Chairman, this is not our only challenge ahead. Even if we are successful in developing the science of evidence-based medicine, the diffusion and integration of new knowledge into the actual practice of medicine is an equally complex task. It is difficult for providers, much less consumers, to keep up with the ever-changing knowledge base as medical research produces new understanding of health, illness, treatment, and outcomes. For example, recent and clear scientific evidence that the

administration of beta blockers after a heart attack will reduce mortality risk and reoccurrence rates has not significantly changed the practice patterns of clinicians and low beta blocker use rates. Building the science of information transfer, quality improvement, and cognitive learning, while aligning economic incentives to encourage best practices, must become a necessary complement to our investment in outcomes research.

Mr. Chairman, where is the health care consumer in this equation? At present, most consumers have very little understanding of practice variation and how medical uncertainty can compromise effective medical decision-making. Consumers assume good technical care and the clinical competence of physicians. More often than not, they defer decision-making authority about their own health and medical treatment to physicians who “Know best.” Indeed, public opinion surveys suggest that consumers do not even define quality of care in the context of appropriate diagnosis, treatment and achievement of the best outcomes. Good quality care to consumers means convenient access to care, choice of provider, health professional interpersonal skills (“bedside manner”) and low out-of-pocket expenses.

Mr. Chairman, it is time to expose consumers to medicine's hidden secrets: medical uncertainty, practice variation, and the limitations of medicine. Medicine is not an exact science. Quality of care is not all the same. Clinical performance of plans, providers, physicians is highly variable. Perfect outcomes cannot be guaranteed. There is a range of treatment modalities for diagnosed illnesses. Most importantly, consumers need to be exposed to unbiased information about their medical care options and the potential outcomes for each option that are most relevant to them, including functional status, well-being, and quality of life. This information and this new dialogue with health care consumers will promote a concept long advocated by Dr. Wennberg—the concept of shared decision-making between consumer and clinician.

#### *Reauthorization of AHCPR*

Mr. Chairman, today I want to request that this Committee send a strong signal of your commitment to providing objective science-based information to patients and clinicians by supporting reauthorization of AHCPR. The Consumer Coalition Supports AHCPR as an independent, unbiased, non-regulatory federal agency committed to building the science of evidence-based medicine. Under the leadership of Dr. John Eisenberg, AHCPR has moved forward in the rapidly evolving health care environment and has staked out critical, broadly supported roles in the areas of outcomes research, technology assessment, quality measurement, and quality improvement activities. Consumers and patients benefit directly and indirectly from the work of AHCPR. We are, in the long run, AHCPR's most important customer.

First, consumers benefit directly from information created by AHCPR on the risks and benefits of various treatment options to support their health care decision-making. The availability of this information reinforces the central role of consumers in directing their own health care. Another direct impact that AHCPR has had on consumers is its collaborative work on the Consumer Assessments of Health Plans Survey (CAHPS) which has led to a widely accepted tool to provide consumers and others feedback from the patients themselves. An assessment tool like this is one of the necessary elements in the consumer information package that will eventually be available and enable more meaningful decision-making.

Consumers will also reap the rewards of AHCPR in the area of preventive services. With new assessments of preventive services, consumers will get more appropriate treatments, and may even find more preventive services covered in the future as a result of AHCPR research.

Second, consumers benefit indirectly from the research that AHCPR does to assist physicians and other health care providers in doing a better job of providing appropriate and high quality of care. AHCPR's roles in conducting health services research, disseminating research findings, and evaluating the use of this research in influencing practice behavior has a significant impact on improving the quality of patient care.

For example, the 12 Evidence-based Practice Centers that AHCPR supports provides an appropriate role for the federal government in outcomes research. This research creates the information base necessary to develop practice guidelines and quality improvement protocols. AHCPR looks to those who are interested in developing guidelines and assists their efforts with objective, scientific evaluation of the studies that have been conducted in terms of their design and validity.

As a result, the patients of the future are ensured that good science has been used in the development of practice guidelines. Good guidelines ultimately lead to good care for more patients. The National Guideline Clearinghouse is a logical and much

needed approach to making clinical practice guidelines available to all those health care providers, clinicians, and consumers that could benefit from their use.

AHCPR is not in the business of duplicating the work that the private sector has the ability and resources to do. In fact, AHCPR looks to find opportunities to supplement, build upon, and fill gaps with their research, often providing the only available resources for a particular study.

The Consumer Coalition is particularly interested in and supports the role of AHCPR in researching the impact of managed care on quality. The Coalition was created in 1993 in response to the health reform efforts that could have moved millions of Americans into managed care delivery systems. That potential led us to develop views on what kinds of information consumers need in such systems and how health care delivery should be evaluated. We did not and do not oppose managed care. We believe that AHCPR is in an ideal position to improve the public debate about health care delivery systems and their advantages and disadvantages by researching the areas of practice that are most likely to produce risks and benefits to consumers. This research must be broadly based and lead to a better understanding of how delivery systems could be modified to best serve the consumer.

#### *AHCPR's Fiscal Year 2000 Proposals*

I would like to make a few brief comments on the ambitious and admirable plans that AHCPR has for the next fiscal year. To begin, I commend AHCPR for its focus on new research priorities. AHCPR has proposed to fund research in several areas about which the Coalition cares deeply. We believe that one of the critical measures of any health care system is how well it serves the chronically ill and the elderly. AHCPR will study how various system characteristics affect the health outcomes, access, and quality of care provided to these vulnerable populations.

Children are also a focal point of AHCPR's research effort in the future, including a study of the effectiveness of certain diagnostic and preventive interventions for children with chronic illnesses and disabilities. Research on women health, domestic violence, and improving outcomes for minorities are also priorities for 2000 and we commend these choices.

Another identified priority for AHCPR is the creation and improvement of databases and tools to be used in monitoring health care systems and decision-making. For example, the Coalition supports the development of an early warning system to measure and track changes in quality, access, and cost. This will enable AHCPR to develop reports on the quality of care that consumers receive in terms of clinical quality, access, and patient satisfaction.

Emergency care has been a hotly debated issue of late, and AHCPR will be able to track the impact of managed care policies on access to emergency care services. More objective information will influence the public policy discussions and inform consumers and providers of the practice patterns that exist. AHCPR will also track Medicaid beneficiaries' use of primary care services and their relationship to hospital stays. Research findings may indicate that increased use of primary care improves quality and saves dollars. We also support the use of research grants to develop and test quality measures and CAHPS in nursing homes and other facilities.

#### *Conclusion*

In conclusion, I want to address the issue of funding AHCPR. I understand that AHCPR has a budget that is approximately one percent of the budget of the National Institutes of Health (NIH). NIH does important work and I would not argue to reduce their funding. However, I believe that we need to pay closer attention to the direct and often immediate return on the investment that is made with funds provided to AHCPR. Their budget is simply not large enough to do all that could and should be done to improve the practice of medicine, improve the outcomes of treatment for patients, and inform practitioners and patients of the effectiveness of their care options.

Again, I want to thank you for the opportunity to testify before this distinguished Committee. The Consumer Coalition believes that AHCPR plays an integral role in the health care system that would not otherwise be fulfilled. Their independent, objective, and scientific approach to quality research has served both consumers and clinicians well. AHCPR's commitment to partnerships with stakeholders in the health care system and the fact that their products serve such a broad range of practitioners and health care organizations makes them an invaluable player in this field.

Thank you and I would be pleased to answer any questions that you may have.

Mr. BILIRAKIS. Thank you very much, Mr. Lindberg.

Let me go to Dr. Mahan. The advancements that Florida has made that you referred to in providing access to prenatal care for mothers is impressive, and I was very interested to hear your comment about "build them right and they will come."

I know back in the days when our late Governor Chiles was up here in the Senate, I worked with him very closely on infant mortality because the statistics were just horrible, not just for Florida but for the entire United States. We came to the conclusion at that time that the resources were there, but we just had to find a way to get the mothers to the resources. We even talked about mobile facilities to go into the neighborhoods. So I am very pleased to hear you make that comment. But how would reauthorization of AHCPH help the University of South Florida?

Mr. MAHAN. Well, I think it would help us focus on the—obviously we are pretty far along in our partnership with the Disney folks, and this is after 20 years of experimenting on my part in Minneapolis and North Florida and finding that it works very well to do it. But as health care providers, we are all pretty sure that we are doing the right thing, and it takes modern methods of prevention, marketing, focus groups, to go out into the community and talk to people that are not receiving care, and those are middle income and lower income people, to go back and convince practitioners in that community that we need to do a lot more to reach out to them.

Mr. BILIRAKIS. Doctor, I believe we are going to reauthorize the agency, but if it were not reauthorized, would that hurt your efforts?

Mr. MAHAN. I think so. We have worked with Dr. Simpson from the agency for years. She has been down to the college. We have talked about improvements in access issues, and it certainly would—we would hope that they would be our partners in this effort nationally, which we consider to be a 10- to 20-year national program, finding what works and getting people to use the health insurance that we are offering.

Mr. BILIRAKIS. So you consider them an integral part of what you are trying to do?

Mr. MAHAN. Absolutely.

Mr. BILIRAKIS. Let me throw this out without requiring an answer at this point. We are governed up here by CBO. A piece of legislation like this, they score it. And of course they always take into consideration the money going out and never really take into consideration the money that might come in.

So I would ask you to furnish in writing to us how you determine the savings. We know that there are going to be savings over the long haul, but how do you determine the savings achieved from services that your center provides, the pregnancy counseling, et cetera? If you can do that, that can be an awful lot of help to us in scoring, which is tough to try to overcome.

Mr. MAHAN. Absolutely. With mothers and children, it is easy to measure those savings.

Mr. BILIRAKIS. It would be great to get that information.

Mr. Kahn, you expressed in your testimony the difficulty an agency like this can run into if it delves into health policy and gets into the business of standard setting. Is there anything more that

we as a Congress should do to help to shield the agency from such criticism in the future? We are talking about reauthorizing legislation.

Mr. KAHN. I think the agency has done yeoman's work in terms of fine-tuning its mission, and I think the reauthorization language on the Senate side or comparable reauthorization language is—would set it on the right path for the future.

I guess I would like to stress two points: one, the work in health policy up here can really not be done without the medical expenditure survey work that is done by AHCPR. No one else has that data.

Mr. BILIRAKIS. No one else private or public?

Mr. KAHN. That is correct. And the budget office could not do some of the estimates without that data. So that is a critical role.

Second, I believe that—and it is easy for me to say, but I believe the agency ought to get the higher authorization level, and as high an authorization level as you can see your way clear to because basically they now have a queue, and that queue has in it possible benefits to patients and conditions that can be reviewed and studied and health systems questions regarding the uninsured and others, and that queue is pretty full and it almost is down to—and I think they do a careful job of triaging that queue—it comes down to dollars. And the more dollars they have, the more conditions they can look at and the more critical questions they can ask in terms of health systems delivery.

So I guess what I would ask you to do is to search through your set of priorities and see how far you can go. But I think a healthy reauthorization level for a number of years is very important.

Mr. BILIRAKIS. Thank you so much. Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman. Mr. Lindberg, I had asked Mr. Eisenberg about endocrine disrupters and estrogenic substances. Sort of playing off the question and his very good answer, how do we encourage and stimulate more research and physician education and patient knowledge about the whole issue of synthetic chemicals and mimicking hormones and what that does to the next generation or two?

When you look back at our society 50 years when we looked at toxic chemicals, we figured if they did not kill somebody or cause illness right away that they were more or less safe, and then we studied chemicals for cancer; and that is what we have done over the last 2 or 3 or 4 decades. And only now people are beginning to understand more both in laboratory studies and in animal studies, and with human beings, what they might do in the future.

Where does that fit in for government research? He mentioned NIH, and we both mentioned NIH and also AHCPR. How does that fit in for you in your mind?

Mr. LINDBERG. First let me comment on the funding issue. We did some quick numbers, and it appears that AHCPR's budget is like about 1 percent of what NIH's budget is. From the consumer viewpoint, we just do not think that is enough.

The kinds of information that consumers are beginning to demand are exactly the kinds of information that AHCPR is developing and providing both to practitioners and to consumers. We have a major—to try and address your specific question a little

more precisely—we have a very difficult role ahead of us in getting consumers ready to understand the information that is being developed.

I would argue practitioners are not even in tune with a lot of the most recent up-to-date outcomes research that is being done. There is certainly a role in the different health care systems to bring practitioners up to snuff. The Consumer Coalition has been working to develop ways to train consumer advocates and consumers about report cards and the options that they will have, but we have a long way to go. If we don't keep funding this kind of information development and synthesis and dissemination, both among consumers and practitioners, we will reach a point down the road where we will actually have consumers who are demanding a lot more than is available. And that is why I think, even though a lot of consumers may not be able to pull some of the reports off the shelf from the 12 centers and understand where they are in terms of their health care decisionmaking, we will reach a point where the work done will be widely used by millions of consumers in their decisionmaking and, of course, in the give and take that they have with their physicians and health plans about their treatment regimen.

Mr. BROWN. I yield back.

Mr. BILIRAKIS. I thank the gentleman. Mr. Deal.

Mr. DEAL. Thank you, Mr. Chairman. I have listened and read the summaries of what the agency does, and I want to play the devil's advocate. As I have listened to what you say the functions really are and read those, by and large it is a public dissemination agency. I want to ask you if we could not better spend the \$200 million annually to educate physicians or to put it into pure research through NIH. All of this public information dissemination is in a context that presumes that the private market and the free enterprise system won't work. We have underwriting laboratories that do the same kind of testing in some degree with products. We have the so-called Good Housekeeping Seal of Approval that everyone wants for their product in order to sell it. We have consumer reports that do an analysis of things that are available.

Why should the government in this one area have the responsibility of being that public information filter. Why is the private sector not able to do it?

Second, in your written testimony, Mr. Lindberg, you said part of the function here is to reveal medicine's hidden secrets, medical uncertainty, practice variations and the limitations of medicine. That does not make a hill of beans difference if there is nothing available to you. The information of dissemination presumes that the consumer has a choice.

In parts of my district, the consumer has no choice. There are few doctors in rural areas. If there are doctors, it is very difficult to get an appointment with them. So my real question is what difference does it make that you are well informed about various options that are out there if you don't have a doctor who can provide the service? As I said, it is a question posed as the devil's advocate, but I think it is one worth asking. We are a Nation of limited resources. We are a government of limited resources. Why couldn't we simply train physicians with \$200 million a year?

Mr. KAHN. First, I think it is important to point out that the agency develops the means of analyzing various types of treatments for conditions, and that is a different function than what NIH generally does, which is to deal with the hard science, sort of the underlying factors that lead to various kinds of physical ailments and occurrences. And I guess I would argue that the culture at NIH is different than what we need in this kind of agency. So this agency is justified, in a sense, to be separate from NIH.

Mr. DEAL. Why could that function not be fulfilled by the medical schools and by the specialties within the medical community that has as part of their purpose to disseminate that kind of information?

Mr. KAHN. It is actually the collection of data and doing research on whether it is various kinds of treatments for heart ailments or other treatments, so it is more than just dissemination. An example, many years ago I worked for Senator Quayle in the Senate and he developed legislation. And at that point—this was in the early eighties, the buzz word was technology assessment; it wasn't outcomes research. But in those days he developed legislation, and it was passed that set up or tried to set up in the National Academy of Sciences a clearinghouse for information about technology assessment. In a sense, that was just going to be dissemination.

The legislation was designed to bring together the medical community and the various user communities, whether insurance or others, and it didn't work. It really was an attempt to have a little Federal seed money, but basically to have a private sector clearinghouse on technology assessment. And it didn't work, I think, because there wasn't strong leadership. There wasn't—and there also wasn't the one thing that you have in an agency like this, which is a clear mission and sort of the assurance of an ongoing activity, an ongoing line of funding at a sufficient level to do things like drawing the right people together and setting an agenda on which conditions ought to be looked at first.

And so I guess my argument would be that in some small ways some of the things that you are describing have been tried and have failed.

Second, on any given day I am not going to argue that a foundation, Johnson Foundation or others, will not come in and fund X activity, but it is very difficult to get that ongoing year in year out that you are going to get from this kind of agency. I guess that would be my answer to you.

Mr. LINDBERG. Mr. Chairman, may I comment on it as well?

Mr. BILIRAKIS. If you do it briefly.

Mr. LINDBERG. First I would like to argue that there is a public health responsibility that the Federal Government has here.

I believe we need to assure that the best care is being provided, that the research that directs that care has been validated. So we can't just assume in this case, I don't believe, that the private sector will do that.

With regard to the rural setting, I think most of us are very sympathetic to that, the issue of getting more physicians and other health care providers into those settings, and that that should be done and there should be efforts to do that. But even the physician in the rural area that you have a hard time getting into see, I

would argue he may or she may be even more likely not to have all of the cutting edge tools at his or her disposal. And, therefore, the work of an AHCPR which would help provide the research that would lead to guideline development by a professional society, for example, that that physician uses is still benefiting that community because if an individual patient goes in there and gets the wrong treatment, it may be just as bad or worse than not getting any treatment at all.

Mr. DEAL. I would rather see a doctor who may not have the latest technology than not to be able to see a doctor at all, and sometimes that is the choice.

Mr. BILIRAKIS. Ms. Eshoo to inquire.

Ms. ESHOO. Thank you for having this hearing in anticipation of the bill you introduced with Sherrod Brown to reauthorize the AHCPR. And thank you to the panelists. I was up at the rules committee and I missed the first panel.

Is there anything that you think needs to be dropped from the mission in the drafting of the bill or added to the mission of the AHCPR to improve upon these extraordinary things that each one of you have touched on here? So that is just my first question to each one of you.

My second question I want to direct to Dr. Mahan.

Mr. LINDBERG. I will take a quick shot at it. We concur with the mission—and I can't recall the specific language in the mission that relates to outside input, but I would always promote a defined external role for consumer and consumer advocate input into the process.

Dr. Eisenberg talked about bringing people in and talking about what their needs are, and he has done that with consumers, and I promote to the extent necessary making that a statutory requirement because I think it is critically important, and he agrees.

Mr. KAHN. I think over the 10 years the mission has been honed. And the agency is basically now a facilitator as well as an agency that funds and sponsors research and then disseminates results. So I think the agency is on target and it is just time to reaffirm what we have learned over the last 10 years.

Ms. WOOLLEY. It is consistent with the kind of public opinion polling and focus group testing that we conduct that the agency—that anywhere and everywhere it can be emphasized that the agency is interested in evidence-based delivery of health care. That research is driving it, that would fit very well into the public's expectations and their hopes for the future of health care.

Ms. ESHOO. Reliable information for reliable care, right?

Ms. WOOLLEY. Yes.

Ms. ESHOO. Doctor, you gave superb testimony, and I am moved by what you said. I always get excited to hear from the best successes. You offered a great deal to us. I don't know if there might be another setting at some point, Mr. Chairman, with our subcommittee, to explore some of the things that you experienced, about some of the things that you integrated when you went to Disney. I am very interested in what you said.

I want to pay tribute to our Chairman in the work that he did to erase those horrible numbers in terms of infant mortality. That



is really one of the great measures, yardsticks of how a society is measured. And I salute you for the work that you have done.

Can you give us an example of how the AHCPR—define the nexus between the work that you have done and the outcomes that are experienced and relate them back to what the agency has—how the agency has assisted you in that effort?

Mr. MAHAN. Yes. I think it falls in the category of the quality improvement that Dr. Eisenberg pointed out. I think it is very important, as I said, when you talk to any of us of any income level or education level about quality and health care, a lot of what we add on to that is how we were treated.

I think that the agency can certainly add that in as a measure of quality. It is tricky. I mean, asking people right after they have seen a doctor, Were you satisfied with your care? Well, they have already been there and most of the time they are satisfied. The trouble is that we are asking the people already going for care. What we need to do is get out to the folks that are using emergency rooms as their main source of care and say why are you doing this. Then we find out that there is a whole other shadowy part that we need to research as part of quality and access.

Ms. ESHOO. I appreciate what you've said, and I salute each one of you for your work. I for one am very glad that the agency was not eliminated in 1995, and I think each one of you have very unique perspectives, and there seems to be resounding applause for what the agency does and what its mission is.

Mr. Chairman, I look forward to your bill and our ranking member's bill for reauthorization because I think this is an agency that is serving the Nation very, very well.

Mr. BILIRAKIS. I thank the gentlelady. And obviously, the testimony that we have heard today is going to be a helpful factor in that regard.

I might add that we are going to be visiting the NIH in June and also the CDC in Atlanta. We may be able to go see the healthy mothers and babies operation in the Tampa, Florida area. We will work on something like that.

We have talked a lot about research. We have talked about biomedical research and of course this research that the agency does which ties in, obviously. I think that most of us, if not all of us, are committed to doubling, certainly increasing, the research funding over the next few years. The BRAVO Act is something that we hope will help supplement that funding.

So we would need you all to help us out in that regard in getting the cosponsors that it will take.

Chip, Ways and Means has been the problem insofar as the BRAVO Act is concerned.

Mr. KAHN. I don't work there any more.

Mr. BILIRAKIS. But you still have some influence there. Your face is red, and it should be.

Anything further, Mr. Brown?

Mr. BROWN. No.

Mr. BILIRAKIS. That being the case, you have been an awful lot of help, and we really appreciate your taking the time to be here.

[Whereupon, at 11:45 a.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows:]

## PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) strongly supports the reauthorization of the Agency for Health Care Policy and Research (AHCPR). The AAMC represents the nation's 125 accredited medical schools, some 400 major teaching hospitals and health systems, 86 professional and scientific societies representing 87,000 faculty members, and the nation's medical students and residents.

Complementing the medical research conducted at the National Institutes of Health, AHCPR sponsors health services research designed to improve the quality of health care, decrease health care costs and provide access to essential health care services in a rapidly changing market. In addition, the agency has made a major commitment to the advancement of evidence-based medicine.

As the lead federal agency to improve health care quality, AHCPR's overall mission is to support research and disseminate information that improves the delivery of health care by identifying evidence-based medical practices and procedures. AHCPR supports a number of research initiatives designed to enhance consumer and clinical decision making, provide improved health care services, and promote efficiency in the organization of public and private systems of health care delivery. To build an evidence base for clinical practice, AHCPR funds twelve Evidence-based Practice Centers to review relevant literature about selected topics and publish evidence reports summarizing such information. In an effort to improve medical outcomes, AHCPR supports studies to evaluate the effectiveness of treatment strategies for many of the country's most prevalent and costly diseases.

The AAMC firmly believes in the value of health services research as this nation continues to strive to provide high-quality, efficient, and cost-effective health care to all of its citizens. Consequently, we believe that the agency's budget should be increased substantially to accomplish this critical mission.

In conclusion, the AAMC emphasizes the essential linkage between robust support of health services research and support for medical research to ensure that the benefits of basic and clinical medical research will flow to all Americans. We appreciate the attention the Subcommittee on Health has given to the agency at the April 29 reauthorization hearing and look forward to working with the Subcommittee as the reauthorization legislation moves through Congress.

## PREPARED STATEMENT OF AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 88,000 member American Academy of Family Physicians would like to submit this statement for the record on an issue of critical importance to our organization: the need for strong support for primary care research at the Agency for Health Care Policy and Research (AHCPR). We look forward to working with you as the Committee reauthorizes this agency.

*Support for the Agency for Health Care Policy and Research*

The Academy is a long-time advocate of the Agency for Health Care Policy and Research. The AAFP supported AHCPR's establishment and, in particular, the agency's statutory authority to support clinical practice research, including primary care and practice-oriented research. In fact, the 1992 Senate Report 102-426 accompanying P.L. 102-410, which reauthorized AHCPR, states that the Agency should strengthen its commitment to family practice and primary care research. The report asserts that,

"The committee believes that inadequate attention has been given to conditions that affect the vast majority of Americans—that is, the undifferentiated problems individuals present to their generalist physicians. A focus on family practice/primary care research is essential if we are to redirect the US health care system that is currently skewed toward high technology medicine for catastrophic diseases.

The Center for Primary Care Research at AHCPR, whose mandate is to support research in primary care, is the centerpiece of the agency's work in this area. It is the *only* federal agency with this charge.

*Need for Primary Care Research*

American medicine is praised worldwide for its excellence in biomedical research. While in the past we have invested heavily in new technologies, drugs and procedures, they are increasingly being viewed as very costly advances for increasingly modest gains. We have also seen overutilization of expensive interventions and learned that all new developments have both benefits and harms. Part of primary care research is determining the appropriate way to use the knowledge that has been developed in a manner that helps improve quality and meets patient needs.

It is not enough to develop new treatments; we must also ensure that they can be implemented and actually result in improved patient outcomes.

In addition, the medical community has often been unable to translate breakthroughs in new technologies, drugs and procedures to practical treatments that became readily available to the population at large. This is in part because what may appear to be promising in the laboratory or in highly controlled clinical trials undertaken in university centers may not be practical when attempted in the real world, or may work differently in different settings or with different population groups.

While most medical care is provided in the outpatient setting, ambulatory medicine is the least researched mode of patient care. Over 95 percent of all medical conditions have been evaluated and treated outside of hospitals over the last 30 years. Nevertheless, physicians today are educated and trained using research information that has largely been derived from hospitalized patients, or patients with conditions in an advanced state.

Consequently, the formal knowledge base used by physicians is derived principally from the inpatient treatment of those who have selected serious health conditions. Primary care physicians whose principal responsibility is to diagnose and treat such conditions before they require inpatient care all too often must proceed without anywhere near the level of research-based assurance that their subspecialist colleagues can utilize. Indeed, American health care is increasingly biased toward institutions and systems that use highly technological methods to treat catastrophic and end-stage disease.

This bias is evident in the dramatic difference in funding for FY 1999 for the National Institutes of Health (NIH). The NIH currently receives \$15.6 *billion* and, by contrast, funding for the AHCPR is \$171 *million*, slightly over one percent of the nation's biomedical research budget.

According to the 1996 Institute of Medicine (IOM) report on primary care, *Primary Care: America's Health in a New Era*, federal investments in primary care research today total between \$15 and \$20 million annually. The IOM report recommended an immediate fourfold increase in primary care research. We believe that U.S. research facilities must complement their understanding of high-tech research with a similar dedication to applying state of the art medicine to understanding primary care. We need to rebalance the research investment to meet today's health care needs.

#### *Primary Care Research Agenda*

It is essential that increased funding for primary care research needs to be guided by a clear agenda. This agenda should include a number of components, including research to determine the origin of disease and the loss of health, and research to improve diagnostic accuracy, appropriate treatment, the physician-patient relationship, health care delivery, and patient satisfaction. It must also include investments in the necessary infrastructure for primary care research, such as training programs. This agenda is described further in the widely distributed AHCPR report, *Putting Research into Practice: Report of the Task Force on Building Capacity in Primary Care, 1993*

Regarding improved diagnostic accuracy, we know that most individuals present their physicians with a cluster of ill-defined symptoms. It is the responsibility of the family physician to make sense out of these symptoms and determine whether they constitute a short-term problem or one requiring ongoing or intensive treatment. Primary care research would assist physicians in streamlining the diagnostic process and increasing accuracy of diagnoses.

A primary care research agenda would include a significant emphasis on treatment plans, especially for problems with the poorest prognoses. As family practice and the new health system seek to adopt evidence-based approaches to clinical care, we frequently find that the research has not been completed that answers these key questions. The development of outcomes-based clinical policies and of evidence-based quality measures has been thwarted by the lack of appropriate research. In the absence of such studies, "expert" opinion and experiential decision-making has been used to develop treatment plans. Primary care research can clarify appropriate treatment plans, as well as reduce the potential for use of expensive, unnecessary or potentially dangerous medical tests.

Because of the paucity of research in this area, the Academy strongly supports the Evidence-based Practice Centers (EPCs) funded by the AHCPR. The purpose of the centers is to review the science around a number of specific topics and use this information to develop reports on effective treatment in the practice setting. These reports will be practical tools for practicing clinicians and health care systems. These analyses will also be extremely useful in helping specialty societies develop clinical guidelines and quality measures. According to John M. Eisenberg, MD,

AHCPR Administrator, "These state-of-the-science reports and technology assessments, once distributed, will help reduce inappropriate variations in medical care and improve the overall quality of the health care system."

#### *Quality Issues*

The growing interest in primary care research is integrally related to the recent attention to measuring the quality of health care. The changing shape of American health care, with its movement away from fee-for-service medicine to a variety of managed care systems, has both exacerbated concerns about quality and made primary care research more relevant. More generally, physicians, health plans and researchers are still seeking answers to the questions, "What defines health care quality? What are the best health care outcomes? How do we measure quality?"

In a May, 1997, article in the *Journal of Family Practice, Primary Care Research: Current Challenges, Future Needs*, the author states:<sup>1</sup> "This change has sparked increasing interest among managed care organizations in knowing how to provide primary care services in the most efficient and effective manner... At the same time, widespread efforts by managed care companies to reduce the cost of health care services have created public concern that quality of care is being jeopardized." The resulting desire by MCOs to provide quality, effective care to their members relies heavily on the answers provided by primary care research.

The Academy is strongly committed to health care quality improvement and believes that primary care research is an important basis of efforts to improve health care quality. In fact, the AAFP's Ad Hoc Committee on Quality Assessment and Improvement recommended recently that AAFP partner with other researchers, for example, at AHCPR, to study the efficacy of quality improvement programs. This project would include determining effective ways to change physician behavior or patient behavior, guideline compliance, effectiveness of quality measurement and improvement programs, and developing a plan to influence researchers to study the areas determined to be important.

#### *Examples of Primary Care Research Needs*

The following two examples illustrate the types of questions that could be answered by primary care research.

Family physicians see patients every day in their practices who suffer from multiple diseases. An example of this comorbidity is the patient with diabetes, hypertension, depression, low back pain and heart disease. However, traditional, disease-specific treatment is not useful in this situation; treatment for one disease may exacerbate the other conditions. Primary care research is needed to provide information to physicians on the most effective treatment plans for patients with numerous, serious conditions.

A second example of a question to be potentially explored by primary care research involves the 20 million Americans who suffer from headaches. While headaches afflict millions of individuals, the primary care physician has little information on how to identify the few who suffer from life-threatening illness. Research is needed on differentiating the common headache from one with serious implications.

#### *AAFP Research Initiative in Family Practice Research*

In September, 1997, the Academy announced a major, new initiative, committing nearly \$8 million to a multi-year program to stimulate the infrastructure to conduct family practice research. Not only was this a culmination of long-standing concern about the underfunding of research in primary care, but an indication to the field that this research was simply too important to wait. The size of the commitment underscores the Academy's real concern that primary care research is a critical piece of the nation's research agenda.

The AAFP initiative includes five components to address the need to enhance family practice research: partial support of research centers; funding to increase the pool of quality family practice research in the form of advanced research training opportunities; funding for support of practice-based research networks; development of partnerships with managed care organizations to jointly fund research and/or research related projects and advocacy. We would also like to work with AHCPR on a national research conference. It is our hope that this initiative will encourage much more significant efforts at the federal level to support primary care research and will complement these efforts, as well.

<sup>1</sup>Lanier, D. and Clancy, C. *Primary Care Research: Current Challenges, Future Needs*. *Journal of Family Practice* May 1997; Vol. 44; 434-43 8.

*Conclusion*

The need for an increased emphasis on primary care research is acute. Both individual physicians and the health care system will benefit greatly from science-based, quality information about what works in the clinical practice setting. We look forward to working with you and the Agency for Health Care Policy and Research to enhance and stimulate work in this area.

