



AcademyHealth REPORTS

Summit Examines Data and Methods Needs, Recommends Steps to Meet the Demand

With health care reform a top priority for the Obama administration, there is increased awareness of the importance of health services research (HSR) as a means to better understand the complex issues behind rising costs, limited coverage and poor quality. The demand for HSR is greater than ever before due in no small part to the 2009 American Recovery and Reinvestment Act (ARRA) which provides for substantial investments in comparative effective research (CER) and health information technology (HIT).

These new opportunities are not without some challenges. The increased data generated as a result of the widespread use of HIT may provide a wealth of new data for researchers, but governance, privacy and data quality issues must be addressed. The multidisciplinary nature of CER also raises questions about appropriate methods and the difficulties of communication among disciplines.

With support from the Robert Wood Johnson Foundation and The Commonwealth Fund, in June, 2009 AcademyHealth convened a high level invitational summit that brought together fifty key leaders from the field to generate a set of recommendations to strengthen the quality and accessibility of the data and the methods needed to produce HSR in the United States. This summit is the second in AcademyHealth's *Health Services Research of 2020 Summit* series. The first took place in 2007 and focused on the status of the field's workforce and its needs going forward.

Summit participants reviewed fourteen commissioned papers with three distinct themes: 1) general data challenges, 2) general methods challenges and 3) data and methods challenges

related to specific health policy topics. The data papers addressed issues of governance, privacy and confidentiality, and data linkages and quality. Methods papers examined causality in observational research, methods for modeling policy options and methods for modeling public health outcomes. The policy papers covered delivery system reform, healthcare workforce, patient safety, the under and uninsured, disparities, multiple chronic illnesses, health care costs, and value-based purchasing. There was a concerted effort by the authors to cross-reference these different perspectives and to produce a shared set of proposals to address them.

Challenges

While there is likely to be a surge in available data at the national, state, and regional level, health services researchers should not assume that this will immediately increase our research capacity. Challenges exist in the collection, storage and analysis of large datasets when contributed by multiple sources (e.g., patients, providers and payers). Furthermore, concerns about duplicate and missing data, as well as problems with access to and cost of obtaining health data, especially proprietary data, highlight existing barriers. On the public side, the hurdles include lengthy bureaucratic processes to obtain permission to use data and that access to many data sets is still contingent upon being present at the agency's physical location.

In addition, the increased visibility of HSR will likely intensify the debate over the application of different analytic techniques used in research, resulting in a

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Letter from Leadership



A decade ago, most politicians would boast that the United States has the “best health care system in the world.” Today, policymakers across the political

spectrum recognize our system’s failures and support comprehensive reforms to improve health care quality, expand access, and reduce costs. Health services research played a significant role in changing policymakers perceptions about health care. Facts, statistics, and other evidence about the health of our health system are frequently cited by policymakers who are working to deliver comprehensive change. And all the health care reform proposals to date include provisions that would greatly expand funding for infrastructure development, coordination, and research (see Coalition Corner page 5).

Our success in educating policymakers about what health services research is and what it has to offer is reflected not only in health care reform legislation, but also in policymakers’ willingness to invest in the research, its infrastructure, and its human capital. Part of this success is due to the efforts of AcademyHealth members, organizational affiliates, and other partners in the health community working through our “Friends” alliances, to lobby for increased funding for the Agency for Healthcare Research and Quality (AHRQ) and the National Center for Health Statistics (NCHS). In FY 2009, we secured funding increases for comparative effectiveness research, investigator initiated research, and health data through the regular budget cycle and the historic American Recovery and Reinvestment Act. FY 2010 appropriations show continued progress, with additional investments in research and data, as well as continued congressional

interest in increasing investigator initiated research and training grants, as well as more research funding to study the financing and organization of health care (see Coalition Corner page 5).

In addition to seeking funding for health services research, AcademyHealth and the Coalition have been lobbying the administration and the Congress to support the publication rights of researchers. As reported by AcademyHealth members, and documented in a 2007 study chaired by Sara Rosenbaum and Arnold Epstein, since 2000, contracts have become more restrictive, placing restraints on the publication of federally-funded public health and health services research. As President Obama has encouraged the highest level of integrity and transparency in the use of scientific information for policymaking, it is especially critical that research results are made public to advance the general knowledge regarding the effects of changes in public policy on health and health care.

We are on the precipice of change in the health care system in this country, with health services research providing the capacity to help make it more effective and efficient. On behalf of the Coalition Board of Directors, I thank you for your support in advancing our field and communicating its importance to policymakers. I encourage you to stay abreast on the status of federal appropriations, legislation, and regulations relative to the field by visiting our Web site, www.chsr.org.

Sincerely,

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The Latest

AcademyHealth Membership Benefits Expanded, New Rates Announced

At its June 2009 meeting the AcademyHealth Board approved several items which expand benefits for AcademyHealth members.

New “Speaker” Rate Available for the ARM

A new pricing structure for speakers at the Annual Research Meeting (ARM) has been approved by the Board. Speakers at the ARM who are AcademyHealth individual members can now register for the conference at a lower registration rate than non-members. Organizational affiliate members can also use their discounted rates to register speakers.

Interest Group Changes

Since the inception of AcademyHealth Interest Groups (IGs) in 2004, IG membership has been offered for free to members and non-members alike in an effort to add value to and grow AcademyHealth membership. After reevaluating the annual management cost of providing staff support to IGs, the Board approved requiring AcademyHealth membership for participation in all 12 *non-funded* IG activities. There will now be a fifty percent price differential between member and non-member prices to attend all IG meetings. Non-members may sign up for IG mailing lists whereby they will be kept informed about IG activities and programs.

Members and non-members alike may continue to participate in all *funded* IGs. External funding supports the programs offered by the Long-Term Care, Public Health Systems Research, and State Health Research and Policy IGs.

The leadership of the Interest Groups will work with AcademyHealth staff in the coming months to develop additional benefits for all IGs.

New Benefits

AcademyHealth leadership and staff have worked together over the past year to provide more and better benefits to members. An impressive array of online professional development courses have been developed with some available for free to members and others available at discounted member rates. The funding opportunities Web page has been expanded to provide members with a better resource, and an enhanced online directory of universities which offer health services research training programs has recently been added to the AcademyHealth Web site. A new collection of publications, online training programs, presentations, and suggested readings on comparative effectiveness research has also been added to our Web site to help you become more knowledgeable on this subject. Finally, two new scholarships for students to attend AcademyHealth conferences have been

initiated through the generous support of the Alice S. Hersh memorial fund.

New Dues Rates

Comprising over twenty percent of AcademyHealth membership, students represent an important and growing membership segment. To provide some financial assistance to graduating student members, starting in October 2009, AcademyHealth will start offering a one-year reduced membership dues rate of \$100, a savings of \$75 over regular dues rates for these students.

AcademyHealth has been able to maintain dues without an increase for more than six years. However, with the increase of benefits being offered to members, and plans to develop additional benefits to make AcademyHealth membership even more valuable, the Board has approved a modest increase in individual membership dues. Beginning October 1, 2009, regular, international, and fellows dues will increase by \$25 and student dues will increase by \$15.

If you have comments or suggestions on new or existing AcademyHealth membership benefits, please contact Jane Brookstein, Membership Director, at jane.brookstein@academyhealth.org or 202.292.6754.

For more information, please visit our Web site at www.academyhealth.org.

→ **Summit** Continued from page 1

concentrated focus on the limitations of current methods. This requires health services researchers to understand the wide range of disciplinary perspectives on the suitability of different analytic techniques and to generate new methods to address emerging questions. This is particularly true in the area of comparative effectiveness research, which engages both clinical researchers that are specifically trained to conduct and view randomized clinical trials, as well as econometricians and other types of health services researchers accustomed to using observational research.

Recommendations

The Summit recommendations focused on the need for statutory, regulatory, and federal and regional incentives that seek to make data accessible and high quality. They also emphasized the need to generate new research methods as a vital step in the growth of the field. Recommendations fell into three broad categories: changes in research policy, changes in data governance and changes in methods and training. A summary of each follows.

Changes in General Research Policy:

- The field of HSR, along with funders and journals, should emphasize the importance of using health system data to generate actionable knowledge.
- Funding mechanisms should include more small grants for quick turn around studies that have immediate application to improvements in care delivery.
- There is a need for new incentives to encourage innovative partnerships like those between researchers and health care organizations. New incentives are also needed to encourage researchers to translate their work into policy and practice.

- Journals should be encouraged to include articles on methods development, implementation research and research that documents negative findings.
- The national government should incentivize open and collaborative environments for research.
- Internal Review Boards (IRBs) need increased federal standardization to encourage consistency and discourage unnecessary hurdles in the research process, especially for multi-site design that require multiple IRB approvals.
- There is a need for mechanisms that gather user input into the research prioritization process.
- Similar incentives are needed to link modelers and other researchers to users who ask “what if” questions and need to generate quick answers.

Changes in Data Governance:

- Greater federal coordination with appropriate user input is needed to identify gaps and un-useful duplication of surveys.
- Federal surveys need to be standardized to facilitate greater linkages.
- A single on-line portal that protects privacy and streamlines approval processes needs to be established. It should be similar to ones used by the physical and biological fields.
- Different views were expressed on whether to obligate private providers to submit public use data files. Many participants prefer a “federated model” in which private providers and plans can keep their data as long as they participate in national and local research efforts.

- Legislative changes to identify researchers, rather than providers that submitted the data, as accountable for any breach in data privacy.
- A national provider ID system needs to be created.
- There is a need for data that permits new units of analysis including:
 - Following individuals over time and across sites of care;
 - Better data on teams of practice rather than single professions;
 - Data on a broader array of provider organizations not just hospitals;
 - A data base on health plans; and
 - A special need to focus on groups with multiple chronic conditions, children, young adults and minorities.

Changes in Methods and Training Policies

- There is a need to encourage a collaborative “sand box” for new researchers (expanded tent) to learn how to use data (training).
- Training should be provided on how to link data sets.
- Standards in research methods should be explored.
- A well funded and collaborative environment should be developed for experimentation in methods.

Presentations from the Summit may be found at www.academyhealth.org/summit09. The papers and recommendations will be published in the journal *Health Services Research*.

Webinar Provides Overview of Internet Surveys

Internet surveys have emerged as a potentially inexpensive and quick approach to collecting information. “Best Practices in Designing and Analyzing Internet Surveys in HSR,” an introductory level methods seminar, provided an overview of the strengths and limitations of internet surveys for health services research. John Bremer, Senior Vice President of Harris Interactive, Inc., presented this live Webinar on July 21, 2009 to approximately 50 registrants representing a variety of disciplines within health services research. The seminar provided a discussion on the basic concepts of online health care research and some rules of thumb for sampling and surveying populations of interest via the internet; as well as some discussion of mixed mode approaches. Mr. Bremer gave further insight on common sampling issues during a question and answer session at the end of the presentation. An archived recording of this event will soon be available for purchase.

Coalition Corner

Legislative Update

As Congress works through the details of health reform, the emerging legislation contains provisions that would directly impact the field of health services research.

The Senate Health, Education, Labor and Pensions Committee's **Affordable Health Choices Act of 2009**, which passed the committee on July 15, includes provisions that would establish:

- A Center for Health Outcomes Research and Evaluation within the Agency for Healthcare Research and Quality (AHRQ) to collect, conduct, support, and synthesize research comparing health outcomes, effectiveness, and appropriateness of health care services and procedures;
- A Patient Safety Research Center with a budget of \$20 million in AHRQ to support research on delivery system improvements;
- A Prevention and Public Health Investment Fund of \$10 billion to provide an expanded and sustained national investment in prevention and public health programs, including prevention research.

The House Ways & Means, Energy & Commerce, and Education & Labor Committees released their proposal on July 14: **America's Affordable Health Choices Act of 2009**. This bill would establish a Center for Comparative Effectiveness Research within AHRQ. It would also **establish a new Assistant Secretary of Health Information** to coordinate health data across the federal government, establish key health indicators, and support state health surveys.

It is anticipated that the Senate Finance Committee's health reform package once released will include a comparative effectiveness research (CER) provision: the Patient-Centered Outcomes Research Act of 2009, introduced by Senator Max Baucus (D-MT) and Senator Kent Conrad (D-ND) on June 9. This provision would establish a nonprofit, non-governmental corporation to support comparative effectiveness research through contracts with federal agencies, as well as academic and nonacademic research institutions.

The Coalition is working with congressional staff to ensure that any new CER entity will support both investigator initiated research grants as well as contracts, and is precluded from imposing any prior restraint on contracted research.

Talk the Talk...

The Coalition's legislative term of the quarter is, "CBO Score."

The Congressional Budget Act of 1974 established the Congressional Budget Office (CBO) to provide Congress with budget data and analyses of fiscal, budgetary, and programmatic policy issues. The Act requires that CBO "score" legislation, i.e., develop five-year cost estimates associated with any proposed legislation or resolution. A CBO score can make or break a bill. CBO's unfavorable scoring of President Bill Clinton's health reform plan is often cited as one of the major reasons for the bill's demise. True to form, CBO's recent scoring of proposed health reform legislation is credited with slowing down congressional action on these bills. CBO needs clear evidence from research or program evaluations to grant a positive score for savings from mechanisms being proposed to limit health costs.

For more information on current health reform bills moving through Congress and to keep abreast of how this legislation may impact the field of HSR, check out the Coalition's newest Web-based resource: "Health Reform: Legislative Tracking," www.chsr.org/healthreform.

Increased Funding; Shifting Congressional Priorities for HSR Agencies

The FY 2010 appropriations process is well underway in Congress, with health services research and health data seeing moderate gains. The House and Senate have each provided \$83 million for the Veteran's Health Administration's health services research—up from \$75 million in FY 2009.

The House and Senate provide flat funding for AHRQ in FY 2010 due largely to the \$300 million AHRQ received for CER through the American Recovery and Reinvestment Act earlier this year. Within the proposed \$372 million budget, the House and Senate give clear direction to AHRQ in obligating funding based on the Coalition's recommendations—making greater investments in investigator initiated research,

training grants, research on health care financing, organization, and delivery, and research dissemination and translation. Most notably, the Senate explicitly targets \$23.6 million for investigator initiated research grants, nearly doubling AHRQ's Innovations Research Portfolio budget.

Under the House and Senate bills, the National Center for Health Statistics (NCHS) would receive a \$14 million increase in FY 2010, bringing the agency's total budget to nearly \$139 million. In keeping with the Coalition's recommendations, the Committee on Appropriations urges NCHS to use this funding to avoid further cuts to seminal surveys such as the National Health Interview Survey and the

National Health and Nutrition Examination Survey, as well as cuts to vital statistics that provide critical public health data on American births and deaths.

Although Congress hopes to clear all 12 appropriations bills under "regular order" before the September 30 close of the fiscal year, Congress may again need to enact a continuing resolution to sustain federal funding at FY 2009 levels through the end of the calendar year while valuable floor time is used to consider health reform and other pressing legislation.

For more information about health services research funding, please visit www.chsr.org/appropriations.

Members Matter

Student Members – Get Involved



As the membership organization for health services research and health policy, AcademyHealth student membership offers a wide array of benefits in order to enhance the learning and professional development experience for students in health services research and health policy.

Student members can apply for **scholarships** to attend the Annual Research Meeting and National Health Policy Conference or register at greatly reduced rates. In addition to learning about the latest research studies and current health policy issues at these meetings, they'll have a chance to meet informally with nationally known experts in the field of health services research at special events planned exclusively for students. Student poster sessions give students the opportunity to present their research and discuss it with leading experts in the field.

Visit our **Career Center** to search for professional training and job opportunities, fellowships, funding resources, and a directory of HSR training programs. Submit a resume to be reviewed by an AcademyHealth member experienced in your professional focus area.

Take advantage of **online resources for professional development**. Our professional skills webinars, such as an "Overview of Preparing and Presenting Research Posters," by Dr. Jane Miller from Rutgers University, are offered free to members. We also offer a growing list of online methods seminars, such as "Comparative Effectiveness and HSR," and "Best Practices for Designing and Analyzing Internet Surveys for HSR" which are available to students for only \$25.

Students can enhance their learning and professional development experience through **student chapter** participation. Starting one is easy and free – go to www.academyhealth.org/students to download a chapter toolkit which provides step-by-step instructions, chapter requirements and guidelines, and model chapter bylaws. Review the list of suggested student chapter activities to get a chapter started and energized.

Students can join one or more of AcademyHealth's 15 **Interest Groups** to learn about a specific topic area relating to health services research and

health policy. Interest Group members have an opportunity to exchange knowledge, disseminate research findings, inform policy and clinical decision-making, build research skills, and network with those sharing common goals.

Join an online community of researchers interested in **HSR methods** at www.hsrmethods.org. By joining students will receive the *Methods Minute*, a bi-monthly e-newsletter which provides current methodological discussions in the field, training opportunities and events, and new content and resources on HSRMethods.org.

Become an advocate for the field of health services research and health policy – join the email list of the Coalition for Health Services Research, the **advocacy** arm of AcademyHealth. Get regular updates about appropriations, legislation, and ways to advance the field. Find out more at www.chsr.org

AcademyHealth values its more than 800 student members, and is ready to provide them with the tools, resources, and networking opportunities to make them successful in their career now and in the future. Get involved in AcademyHealth!

Members to Determine Three New Directors for Board

The member election for AcademyHealth's Board of Directors is open from Tuesday, September 8 to Wednesday, September 30. This is your opportunity to have input on AcademyHealth's leadership and your vote does matter. Members active on August 1 may vote online for three of the following six candidates:

→ Timothy S. Carey, professor, University of North Carolina at Chapel Hill

→ Debbie I. Chang, vice president, Nemours

→ Darrell J. Gaskin, associate professor, University of Maryland at College Park

→ Glen P. Mays, professor and chair, Department of Health Policy and Management, University of Arkansas for Medical Sciences

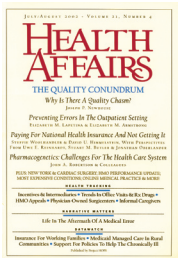
→ Vincent Mor, professor and chair, Department of Community Health, Brown University

→ Deborah Klein Walker, vice president, Public Health and Epidemiology Health Division, Abt Associates, Inc.

Voting instructions and bios were sent by e-mail and postal mail on September 8. Questions about the election process may be directed to Bonnie Austin, director, at 202.292.6700.

News from the Journals

AcademyHealth's official journals, *Health Affairs* and *Health Services Research*, provide updates on recent issues in health services research and policy. AcademyHealth members may subscribe to the two journals at a discounted rate. For more information, visit the AcademyHealth Web site at www.academyhealth.org/membership.



Health Affairs' July/August 2009 Issue – Delivering on Global Health

Eliminating polio everywhere will require global cooperation on several fronts, including lowering the cost for poor

countries to vaccinate with inactivated polio vaccine (IPV), says a leading global health researcher in the July/August 2009 Health Affairs thematic issue on global health. The issue explores common health challenges, solutions to eradicating polio, combating malaria, and providing care in developing countries.

Highlighted findings from the issue include:

- The global fight against malaria faces the ongoing challenge of making effective medicine affordable in developing countries. Growing resistance to traditional antimalarial drugs has made treatment more difficult, and newer, artemisinin-based medications are at least 10 times more costly.
- Health care costs burden families all over the world, but a new study shows that people in low- and middle-income countries are hit

especially hard. One in four families in those countries borrows money or sells assets to pay for health services.

For more details on this thematic issue, visit www.healthaffairs.org.



Deadline Extended for HSR Theme Issue on Payment Reform - September 30, 2009

As the country struggles to find a way out of the perfect storm of rising costs, falling access, and uncertain quality, there is

widespread agreement that changes in the payment system must be part of the solution. Public and private payers have been experimenting for several years by tweaking the way they pay for care, but so far there has been little comparable evidence about the intended and unintended consequences of different approaches.

HSR and the Agency for Healthcare Research and Quality seek to collect and present solid evidence about this experimentation to inform future

payment initiatives in a themed issue on payment reform. Additionally, the themed issue will provide a strong basis in evidence to ground the thinking of those in the public and private sectors considering more comprehensive changes in payment that go beyond the current experiments.

Types of submissions:

- Research studies, evaluations, policy analyses, and simulations using rigorous methods to assess the impact of efforts to improve care by changing the way we pay for it (e.g., pay-for-performance, non-coverage of health care-acquired conditions, bundled payments, shared savings, new prospective payment systems, new contracting models) or by encouraging consumers to use evidence-based care (e.g., value-based benefit design or provider tiering). Research can include experiences outside the United States, provided the applicability to the United States is clear.
- Comparative evidence, e.g., comparing patient-oriented reform to provider-oriented schemes, and evidence about intended and unintended consequences or short- and long-term impact.

For more information, visit www.hsr.org/hsr/abouthsr/call-for-papers-payment-reform.jsp.

Student Scholarships Available for 2010 National Health Policy Conference

Applications for the Alice S. Hersh Student Scholarship, which provides two complimentary registrations for the National Health Policy Conference, are now being accepted. The conference will be held on February 8-9, 2010, in Washington, D.C. Applicants must be current student members of AcademyHealth enrolled in a masters or doctoral program at the time of application. The application deadline is November 15, 2009. For more information, go to www.academyhealth.org/scholarships or contact Regina Onyango at 202.292.6755.

2010 National Health Policy Conference Brings Health Care Reform into Focus

National Health Policy Conference to clarify key priorities of national health care reform and explain implications for stakeholders



Health care reform efforts in Washington have left researchers, policy professionals, and analysts questioning the future. With so much yet to be decided, the

National Health Policy Conference (NHPC) offers an opportunity for participants to hear directly from policymakers about their focus for health care in 2010.

The NHPC, co-sponsored by AcademyHealth and *Health Affairs*, is the first opportunity to get a clear picture of national health policy priorities for 2010. Leading experts, including government officials, academics, policy analysts, and researchers, will

recap the progress of reform at the federal and state levels and provide their perspectives on upcoming implementation challenges.

Ask the Experts

As a new feature, attendees are encouraged to help shape the conference discussion by submitting their own questions to AcademyHealth via www.academyhealth.org/nhpc. Select questions will be addressed by panelists during the conference.

The NHPC will take place February 8-9, 2010 at the J.W. Marriott Hotel in Washington, D.C. Registration for the conference opens October 1. For more information on the agenda and full registration details, visit the NHPC Web site at www.academyhealth.org/nhpc.

Dates to Watch

September

8-30 Board of Directors Member Election

October

1 National Health Policy Conference Registration Opens
26-29 Health Policy Orientation

November

2 Annual Research Meeting Call for Abstracts Opens
15 Application Deadline for Alice S. Hersh Student Scholarship to Attend NHPC 2010

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