



AcademyHealth REPORTS

How HIPAA Impacts HSR: Findings From a Recent AcademyHealth Survey

The Health Services Research (HSR) 2020 Summit noted that the field has grown significantly in size since 1995, but faces new challenges. Of particular concern are an overall drop in public dollars and a decline in extra-mural grants funding HSR, as well as declines in funding for some data sources and limited access to HSR data. At a time when developments of new methods and the availability of new types of data—including genomic information—offer much promise, it is particularly important to address the challenges of conducting research based on personal health information. Realizing the promise of data that can be collected in electronic information systems while maintaining individual privacy is a key issue for the future of HSR.

Central to these issues is the need to understand ways in which the Health Insurance Portability and Accountability Act (HIPAA) affects HSR. The promise of new data sources and methods to evaluate clinical and health delivery systems relies on timely access to high-quality data. The extent to which HIPAA helps or hinders HSR is central to understanding whether researchers feel they can make meaningful contributions to health policy and practice.

HIPAA was developed to set national standards for the protection of health information. A goal of the regulation is to protect the use of individuals' health information while maintaining the flow of information needed to deliver high-quality care. This flow of information includes data needed for research, care delivery, and payment.¹ However, since the HIPAA Privacy Rule was enacted in 2002, many health services researchers have expressed concern

that HIPAA has hindered their ability to conduct research on health care.

As part of AcademyHealth's efforts to address the needs of the field, in the fall of 2007 AcademyHealth conducted a survey of members' experiences with HIPAA. This study was conducted for the Institute of Medicine's Committee on Health Research and the Privacy of Health Information. Seven hundred AcademyHealth members responded to the HIPAA Privacy survey. (See box on Methods page 5.) Overall, responding health services researchers report that they believe the HIPAA Privacy Rule:

- Protects individual privacy at the expense of data access for researchers;
- Increases the time and cost of conducting research studies; and
- Impacts access to existing data sets.

While many researchers say they feel the HIPAA Privacy Rule is necessary and important, the majority express frustration with HIPAA as it is currently applied.

Other studies have found a similar result. One such study that focused on epidemiologists indicates that nearly 70 percent of respondents think it has been more difficult to conduct research since HIPAA was enacted.²

Members report that other effects of HIPAA include a decreased rate of recruitment among study participants and greater difficulty gaining approval from their organization's institutional review board (IRB). Researchers also report difficulty getting

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Letter from Leadership



This June marks the 25th Annual Research Meeting, and we've come a long way. Nearly 300 participants attended the first meeting in June 1984.

Since then, the meeting has grown to include more than 2,000 attendees, 150 sessions, and 850 poster presentations.

As we celebrate the 25th anniversary of our Annual Research Meeting, we recognize the special contributions of the visionary leaders of the original Association for Health Services Research (AHSR) who laid the foundation for our field to grow and prosper.

This 25th anniversary encourages us to reflect on our progress and look forward to the new challenges and opportunities for our ever-expanding field. In 1995, the Institute of Medicine estimated the size of the field to be just short of 5,000. A 2007 AcademyHealth study showed that our field numbers at least 11,000 researchers, more than doubling in size in just over a decade.

Unfortunately, further expansion of our field is dependent on corresponding growth in the funding base. Yet, federal funding for health services research has remained relatively flat and has actually declined in real dollars. Regrettably, this trend has led to a decline in public funding for investigator-initiated research and training grants for new researchers. While your Coalition for Health Services Research

continues to educate policymakers on Capitol Hill about the value of health services research and the need to bolster its infrastructure, we face the challenge of advocating for increased funding in a tight fiscal climate.

Under your AcademyHealth Board's leadership, we have embarked on a number of exciting new initiatives focused on reinvigorating our field by strengthening education programs for researchers, advancing innovative methods, promoting the development and use of improved data sets, eliminating barriers to data, and addressing privacy concerns. To guide the development of the field, AcademyHealth has convened a Council of Sponsors comprised of the major public- and private-sector funders of health services research. This Council, chaired by Dr. Mark McClellan and Dr. Risa Lavizzo-Mourey, is charged with identifying emerging research needs and assessing the key infrastructure needs of the field. Taken together, these efforts will enable us to meet the increasing demands for better information and analysis to improve our nation's health care.

The field of health services research continues to evolve and AcademyHealth strives to meet these emerging challenges and opportunities. I look forward to reflecting and celebrating with you at our 25th Annual Research Meeting.

W. David Helms, Ph.D.

Dates to Watch

July

30 Deadline to submit nominations for HSR Impact Award

September

2-19 Member Election of AcademyHealth Board of Directors

21-26 The Netherlands International Health Study Tour

October

20-23 Health Policy Orientation

NCHS and AcademyHealth Name 2008 Health Policy Fellows

The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS) and AcademyHealth are pleased to announce the recipients of the 2008 NCHS/AcademyHealth Health Policy Fellowships. In its seventh year, the fellowship program brings visiting scholars in health services research-related disciplines to NCHS in Hyattsville, Md., to conduct studies of interest to policymakers and the health services research community. Fellows have access to NCHS data resources and work on collaborative projects with NCHS staff. ■

2008 Fellows

Ashley Schempf, Ph.D.

Post-doctoral Fellow
Population, Family and Reproductive Health
School of Public Health
Johns Hopkins University
Project Title: "An Examination of Policy-Relevant Geographic Variation in Low Birth Weight and Infant Mortality"

Manfred Stommel, Ph.D.

Associate Professor
College of Nursing
Michigan State University
Project Title: "BMI and Morbidity and Mortality Risks in Racially and Ethnically Diverse Populations"

The Latest

Project Leads to Code of Practice for the Recruitment of Foreign-Educated Nurses to the United States



The international nurse recruitment industry is burgeoning in response to a rising demand for nurses in the United States. The number of firms specializing in the recruitment of foreign-educated nurses and allied health professionals has grown from approximately 40 to almost 300 in the past 10 years. Dependence on international nurse recruitment presents many public policy challenges including protecting the rights of immigrant nurses, ensuring high-quality care for U.S. patients, and reducing the harm to source countries with already weak and understaffed health systems. Addressing these challenges requires a careful balancing of the interests of all those involved.

This summer, AcademyHealth will complete a two-year initiative resulting in the development of a *Voluntary Corporate Code of Ethical Conduct for the Recruitment of International Health Professionals to the United States*. The goal of the project is to examine current international nurse recruitment practices and facilitate consensus among stakeholders on how to reduce the harm and increase the benefit of recruitment for source countries and migrant nurses themselves. The initiative is funded by the MacArthur Foundation and guided by an advisory committee comprising representatives from recruitment companies, hospitals, nurse associations, and foreign-educated nurses. AcademyHealth serves as the convener.

The Code of Conduct is the result of a year-long consensus-building process among diverse stakeholders. Organizations that recruit and employ foreign-educated nurses, including third-party recruiting firms, staffing agencies, hospitals, long-term care facilities, and health systems, will have the opportunity to subscribe to the Code—voluntarily agreeing to comply with a set of minimum standards and striving to achieve certain best practices.

“The significance of this work cannot be overstated. Creating this framework for the ethical recruitment of foreign-educated nurses signals to the global community that the U.S. health care industry is committed to combating unethical recruitment practices, treating this valuable human resource with respect, while being mindful of the growing need to build a sustainable nursing workforce.”

— Cheryl Peterson,
American Nurses Association

In September AcademyHealth will officially roll out the Code and launch a second phase of the project, which will focus on designing and implementing a mechanism for monitoring compliance with the Code.

For more information on this project, visit www.academyhealth.org/international/nurses.htm. ■

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

Coalition Corner

Thorpe Testifies on Importance of HSR Investment

This year, the Coalition for Health Services Research was selected to offer testimony at a public witness hearing of the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations. On March 13, Coalition Board of Directors Member Ken Thorpe, Ph.D., of the Rollins School of Public Health at Emory University, testified before Chairman David Obey (D-Wisc.) and subcommittee members regarding the need to invest in health services research and health data.

“Health services research provides the data and evidence needed to make better decisions and develop effective policies to optimize health care financing, facilitate access to the delivery system, and improve health care outcomes,” said Thorpe. “Unfortunately, despite what we know and what we can learn from health services research, there has been an erosion of federal funding for this important field....We ask that the subcommittee

strengthen the capacity of the field to address the challenges America faces in providing access to high-quality, cost-effective care for all its citizens by investing in several federal agencies that support this research.”

In his statement, Thorpe summarized the field’s challenges, specifically building for investigator-initiated research and training the next generation of researchers. Showcasing the steady decline in the number of, and funding for, new, competing, and training grants at the Agency for Healthcare Research and Quality (AHRQ), Thorpe stressed that, “AHRQ needs funding for new and competing grants to rejuvenate the free marketplace of ideas, and to support the next generation of researchers to ensure the field’s capacity to respond to the growing public- and private-sector demand for research.”

At the conclusion of Thorpe’s statement, Chairman Obey noted that policymakers “need to know what works in health care,” and

Talk the Talk...

The Coalition’s legislative terms of the quarter are: Budget Resolution and Reconciliation

A type of concurrent resolution, the budget resolution is an agreement by the House and Senate on an overall budget plan. It does not require presidential approval to become law, but requires passage in identical form by both the House and Senate. A budget resolution may contain reconciliation instructions, i.e., the process by which Congress changes existing laws to conform revenue and spending levels to the limits set in the budget resolution.

that divesting in health services research while entitlement spending increases is “penny-wise and pound-foolish.”

For a copy of Thorpe’s written statement for the record, visit www.chsr.org/testimony.htm. ■

FY 2009 Budget Resolutions Clear Chambers

The House and Senate have cleared their respective FY 2009 Budget Resolutions. In the Senate’s version, discretionary budget authority for Function 550 (public health broadly) is \$58.908 billion—a \$5.27 billion increase over FY 2008. In the House’s version, Function 550 would receive \$57.559 billion—a \$4.438 billion

increase. Function 550 sets the overall spending limit for public health programs.

Both the House and Senate versions provide for a deficit-neutral reserve fund to allow for legislation to establish a new federal or public-private initiative for comparative effectiveness

research. It is important to note that the Budget Resolution is not binding on appropriators; they have the discretion to spend the extra funds as they choose.

For more information, visit www.chsr.org/budgetupdate.htm. ■

Now Available: Advocacy Webconference Recording

In “Ten Steps to Becoming a More Effective Advocate,” advocacy experts share tips to help you engage in the policymaking process and review tools designed to facilitate your involvement. To purchase access to the audio and video recording of this session, visit www.chsr.org/event_040908.htm.

approval to collect personal health information from health plans, physicians, and research subjects.³ A small number report that an IRB or Privacy Board has prevented a study from being approved due to privacy concerns.

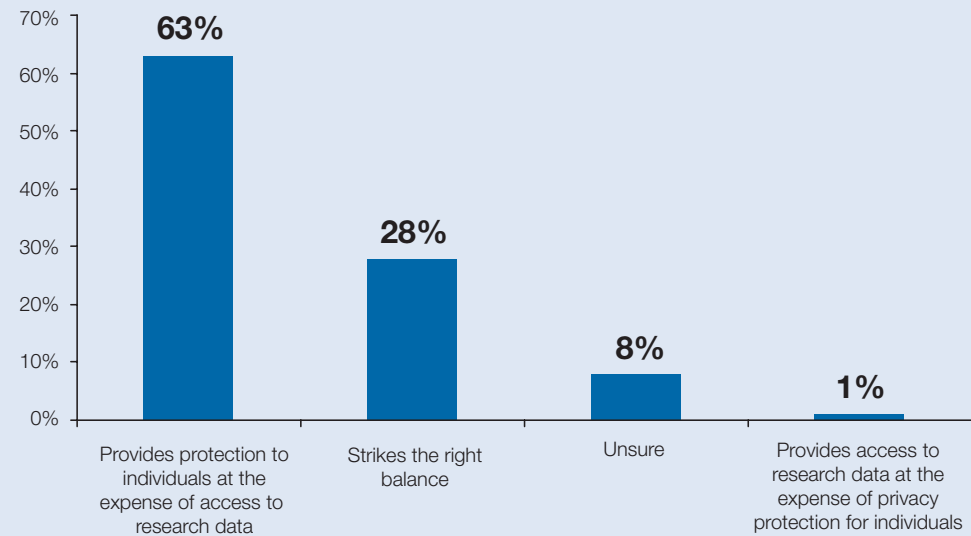
Most members say that their organizations have an IRB or has an IRB and a Privacy Board, but few have Privacy Boards only. Since IRBs have traditionally focused on ensuring ethical conduct of clinical or biomedical research, they may not have a clear understanding of the unique ethical issues and privacy considerations of HSR. Arguably, the potential harms that may result from conducting research with large claims databases are distinct from those that involve, for example, randomized invasive procedures or collection of tissue samples. Despite these differences, many IRBs have the same forms and procedures for clinical research as database research studies.

Nearly half of the members that responded to the survey report that they do not believe their IRB or Privacy Board correctly differentiates between clinical research and HSR, resulting in additional time and cost needed to conduct studies. Respondents who believe their organization's IRB or Privacy Board makes correct distinctions between clinical research and HSR are much less likely to say that research studies are more costly or time-consuming since HIPAA implementation.

The survey also demonstrates that HIPAA has significantly affected access for those who use existing datasets. Despite the fact that most say they were ultimately able to access the data, in many cases researchers said the data was accessible only after it had been stripped of personal identifiers. Unfortunately, the vast majority of researchers with this experience said that removal of identifiers interfered somewhat or significantly with their research, particularly in cases where geographic identifiers were needed to conduct analyses of variations in care or outcomes. For a small number of projects, removing identifiers has prevented research entirely.

Though there is recognition of the importance of collaboration across organizations, the survey findings demonstrate that HIPAA is a significant impediment to conducting multi-site research projects. Among the respondents who conduct multi-site research, half say they must receive HIPAA approval from *all* institutions participating

Perspective on the Balance of Individual Protections and Research Access



Methods

The AcademyHealth HIPAA Privacy Survey was open to all current AcademyHealth members. Members were sent an e-mail invitation and directed to an online survey portal to complete the survey confidentially. The survey was open to respondents for a five-week period. Halfway through the field period, an additional reminder e-mail was sent to encourage participation.

The overall response rate for the survey was 20 percent. Since nearly one-third of AcademyHealth's membership identify themselves as working primarily on health policy topics rather than health services research, it is possible that this group did not respond to the survey because they did not feel the topic applied to them. Overall, survey respondents are representative of AcademyHealth's membership.

Individuals were asked whether they had been a primary investigator on a study that required research recruitment, a data collection plan, or a study protocol to comply with the rule. Those who were not principal investigators on a study that had to comply with HIPAA were not asked questions about their experiences with the HIPAA Privacy Rule, but were given an opportunity to offer comments on the rule.

in a multi-site project before their research can progress, which can be time-consuming, costly, and frustrating.

In light of the findings from the HSR Summit and the HIPAA survey, it is important to consider implications for the field in terms of data use, as well as potential limitations to research progress that may result from the challenges that have been identified. In the coming year, AcademyHealth will undertake a second summit on HSR to address current data issues and challenges. Drawing on themes identified by researchers in the field, the papers for the second summit will address the

promise and potential pitfalls of new types of data and methods to conduct HSR. ■

Endnotes

- 1 Office of Civil Rights. *Summary of the HIPAA Privacy Rule*. May 2003. (See: www.hhs.gov/oct/hipaa)
- 2 Ness, R. "Influence of the HIPAA Privacy Rule on Health Research," *JAMA*, 298(18): 2164-2170.
- 3 These organizations are referred to as "business associates", individuals or organizations other than members of the health plans, providers, or health care clearinghouses covered by HIPAA that perform activities for these groups.

Members Matter

Interest Groups: Past, Present, and Future

First introduced in 2004, AcademyHealth interest groups were developed to enable health services researchers, policy professionals, and practitioners to interact around research and content areas of importance to the field. Ten interest groups were initially established, steered by volunteer advisory committees and sustained through AcademyHealth leadership and resources.

Today, 15 interest groups provide a forum for members to share information, network with their peers, and learn more about a topic. Nearly 5,000 individuals have registered for at least one; the largest interest group has more than 2,000 registered participants and the smallest nearly 200. Each interest group meets annually at the National Health Policy Conference and/or Annual Research Meeting (ARM), as well as during other AcademyHealth-sponsored meetings as space is available. In addition, each interest group facilitates ongoing communication throughout the year on its member-moderated online discussion board.

Most important, many of the interest groups have focused on fostering the professional development of students and early careerists through various programs such as awards, mentoring activities, and scholarships. During this year's Interdisciplinary

Research Group on Nursing Issues and Child Health Services Research Interest Group meetings at the ARM, a junior investigator from each will be presented with an annual award that highlights excellence in emerging scholars' work. Each year, the Health Economics Interest Group mentors students and early-career researchers by offering them advice in preparing oral and poster presentations that will be presented at the ARM. The Behavioral Health Interest Group includes a mentoring session during its meeting providing their student and early-career researcher attendees with one-on-one guidance from an expert in the field. For the first time, the Health Information Technology Interest Group is offering scholarships to students interested in attending its meeting; for a second year, the Public Health Systems Research Interest Group is awarding student scholarships and the opportunity to present a poster during its meeting.

As each interest group's leadership continues to develop programs like these, they welcome feedback and ideas about future activities from participants. Please contact Member Services at 202.292.6700 or visit an interest group's Web page at www.academyhealth.org/membership/interestgroups.htm for more information.

If you would like to join an interest group, simply contact the AcademyHealth membership department or complete the online registration at www.academyhealth.org/membership/interestgroupsform.cfm.

Current interest groups include:

- Behavioral Health Services Research
- Child Health Services Research
- Disability Research
- Disparities
- Gender and Health
- Health Economics
- Health Information Technology
- Health Policy Communications
- Health Workforce
- Interdisciplinary Research Group on Nursing Issues
- Long-Term Care
- Public Health Systems Research
- Quality
- Research Translation
- State Health Research and Policy

News from the Journals

Health Affairs May-June Issue Focuses On Health Reform

The fundamental dilemma of health policy is that the system is so interdependent that no one part can be fixed without fixing them all. But efforts to change the system as a whole, to finance insurance expansion by reducing waste, or to improve quality by restructuring delivery evoke fear that change is more likely to be for the worse than for the better.

In the journal's May-June issue, *Health Affairs* looks at health care reform in this constrained environment, with an emphasis on financing and

insurance. Health reform is again near the top of the political agenda, but politicians studiously try not to evoke the system-transforming, would-be solutions of years past. The mantra today is: Think big but promise no new taxes, no changes for the currently insured, no payment cuts to providers or suppliers, no 500-page policy documents, nothing that can be lampooned as regulation gone amok.

View more information online at www.healthaffairs.org.

Health Services Research Examines Medicare and the Elderly

The June issue of *Health Services Research (HSR)* takes a closer look at Medicare and the elderly by investigating the financial burdens on the U.S. health care system that are attributed to overweight and obesity among elderly Americans. The issue features articles on Medicaid and the uninsured that study whether poverty and lack of insurance are associated with perceived racial and ethnic bias in health care. In addition, articles on methods, nursing home performance and quality of care, and a look at the New York SCHIP market round out the issue. Members can access these articles online at www.academyhealth.org/membership/membersonly.htm.

2008 AcademyHealth Award Winners to be Recognized at the Annual Research Meeting

Each year, AcademyHealth honors health services research and health policy leaders with several prestigious awards that are presented during the Annual Research Meeting. We congratulate this year's winners.

The Distinguished Investigator Award recognizes investigators who have made significant and lasting contributions to the field of health services research through scholarship, teaching, advancement of science and methods, and leadership. **David Blumenthal, M.D., M.P.P.**, is the 2008 Distinguished Investigator awardee. Dr. Blumenthal is director of the Institute for Health Policy and a physician at the General Hospital/Partners HealthCare System in Boston. He is also the Samuel O. Thier Professor of Medicine and a professor of health care policy at Harvard Medical School. His research interests include the dissemination of health information technology, quality management in health care, the determinants of physician behavior, access to health services, and the extent and consequences of academic-industrial relationships in the health sciences.

The Article-of-the-Year Award recognizes the best scientific work that the fields of health services research and health policy have produced and published during the previous calendar year. The award-winning article provides new insights into the delivery of health care and advances the knowledge of the field. The 2008 Article-of-the-Year awardee is **Ming Tai-Seale, Ph.D.** Dr. Tai-Seale received this award for a body of work that includes lead authorship on "Time Allocation in Primary Care Office Visits," which appeared in the October 2007 issue of *Health Services Research* and was co-authored by Thomas G. McGuire and Weiman Zhang, and "Two-Minute Mental Health Care for Elderly Patients: Inside Primary Care Visits," which appeared in the December 2007 issue of *Journal of the American Geriatric Society* and was co-authored by McGuire, Christopher Colenda, David Rosen, and Mary Ann Cook. Dr. Tai-Seale is an associate professor of health economics in the Department of Health Policy and Management at Texas A&M Health Science Center.

The Alice S. Hersh New Investigator Award recognizes scholars early in their careers as health services researchers who show exceptional promise for future contributions to the field. This award commemorates the dedication of Alice Hersh, founding executive director of the Association for Health Services Research, to supporting the next generation of health services researchers. The 2008 Alice S. Hersh New Investigator awardee is **Ashish Jha, M.D., M.P.H.** Dr. Jha is an assistant professor of health policy at the Harvard School of Public Health, assistant professor of medicine at Harvard Medical School, and staff physician at Boston VA Healthcare System and Brigham and Women's Hospital.

J. Michael McWilliams, Jr., M.D., Ph.D., is the recipient of the 2008 Dissertation Award, which honors an outstanding scientific contribution from a doctoral thesis in health services research. Dr. McWilliams received this award for his dissertation, "Importance of Health Insurance for Adults with Chronic Conditions" for the doctoral program in health policy at Harvard University. Beginning in July 2008, he will be assistant professor of health care policy and medicine at Harvard Medical School.



International Health Study Tours the Netherlands September 21-26, 2008

Join AcademyHealth as we travel to the Netherlands for an unprecedented opportunity to learn first-hand about the Dutch health care system—a potential reform model for the United States. This unique health study tour will feature an exciting mix of site visits and briefing sessions, focusing on important issues like system reform, individual mandate, risk equalization, and quality of care. The tour is offered in partnership with the Royal Netherlands Embassy and the Ministry of Health, Welfare and Sport.

The registration deadline is Monday, June 30. To register, visit the tour Web site at www.academyhealth.org/studytours.

HSR Impact Award

Nomination Deadline: Wednesday, July 30, 2008

AcademyHealth requests nominations for its fourth annual HSR Impact Award, which recognizes outstanding research that has been successfully translated into health policy, management, or clinical practice and, as a result, had a positive impact on health and health care.

The author of the winning research receives:

- \$2,000 and complimentary registration and travel to the 2009 National Health Policy Conference, where the award will be presented; and
- Publication as part of the AcademyHealth "HSR Impact" series.

For more information about the award, including eligibility criteria and the application process, visit the award Web site at www.academyhealth.org/awards/hsrimpactsnominations.htm or contact Emily Bass at 202.292.6700.

Health Policy Orientation: October 20-23, 2008, in Washington, D.C.



The annual Health Policy Orientation continues to give participants an in-depth understanding of the formal and informal processes shaping the nation's health

policy agenda. With expert faculty members, group discussions, hands-on tutorials, and a congressional site visit, participants gain an understanding of the Washington health policy environment and master the fundamentals of policy development and implementation.

The orientation is ideal for health policy fellows and analysts, public officials, federal or state government employees, private-sector health care employees, consultants, and students.

The program features a review of the essentials of health policymaking, as well as diverse stakeholder perspectives on timely issues. Expert faculty members provide insight from their years of experience advising the president, staffing members of Congress, and administering federal health programs. The faculty also includes leading researchers, legal scholars, and public opinion experts.

The Orientation will be held at the Kaiser Family Foundation's Barbara Jordan Conference Center in Washington, D.C. Registration opens July 1.

For more information, visit the Orientation Web site at www.academyhealth.org/orientation or call 202.292.6700. This program is organized with support from the Centers for Disease Control and Prevention's National Center for Health Statistics. ■



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