

A Compendium of Health Services Research to Inform Health Reform

May 2009

Background

AcademyHealth developed this compendium of ongoing or recently-completed health services research that has been funded by federal agencies and national foundations as a resource to inform health reform activities over the next few years. The compendium identifies intramural and extramural research on the following three broad health reform topics:

- Costs and value;
- Systems quality; and
- Coverage and access.

This report identifies projects, and their researchers and institutions, that have been funded to work on these three health reform topics from August 2007 to August 2008.

In addition to providing important research information for the Obama Administration, Congress, and relevant state agencies, this compendium also provides a basis for the AcademyHealth Council of Sponsors to help set priorities for further research needs. The Council, comprised of federal government agencies and national foundations, works to coordinate and target the limited funds that support the health services research (HSR) field.

Methods

The research records included in this project are drawn from the National Library of Medicine's HSRProj, a database of HSR projects in progress. The largest database of its kind, HSRProj includes more than 18,000 current and historical HSR projects dating back to 1991, and currently includes information on more than 2,000 ongoing HSR studies. Projects are primarily drawn from more than 150 funding organizations based on structured queries of federal research databases and targeted outreach to private-sector funders of HSR.

In the first phase of this project AcademyHealth reviewed research records in HSRProj that were initiated between August 2007 and August 2008 and that are funded by the federal agencies and national foundations represented on the Council of Sponsors. Organizations included in the query were:

Federal Agencies

Agency for Healthcare Research and Quality (AHRQ)
Assistant Secretary for Planning and Evaluation (ASPE)
Centers for Disease Control & Prevention (CDC)
Centers for Medicare & Medicaid Services (CMS)
Department of Veterans Affairs (VA)
Food & Drug Administration (FDA)
National Center for Health Statistics (NCHC)
National Institutes of Health (NIH)

Foundations

Commonwealth Fund
GrantMakers in Health
Kaiser Family Foundation
Kansas Health Institute
Kellogg Foundation
Milbank Memorial Fund
Robert Wood Johnson Foundation (RWJF)

Projects were then individually reviewed to assure their relevance to three broad health reform categories: 1) cost and value; 2) coverage and access; and 3) system quality. See Appendix A for examples of projects in each category.

In the second phase of the project, AcademyHealth asked representatives from the funding entity to add any additional research that they believed should be included in this compendium or to remove projects that weren't relevant for this compilation. These changes and additions were then reviewed by AcademyHealth staff to ensure that all records matched the initial inclusion criteria.

AcademyHealth acknowledges the assistance of the funders in compiling this report. Given that this report is dependent on the voluntary reporting from funders, its accuracy is subject to the limitations inherent with self-reporting and selection of relevant projects.

Findings

In total, 488 recent projects on health reform were identified across the 18 organizations participating in the Council of Sponsors. The vast majority of health reform projects (74 percent) are funded by three sponsoring organizations: RWJF, AHRQ, and the VA. One-third of the health reform records (34 percent) came from RWJF (n=165). Approximately 21 percent of the studies are sponsored by AHRQ (n=104) and another 19 percent by the VA (n=94) (see Table 1).

Performing organizations

While funding for health reform related research is highly concentrated among a few funders, there is a broad base of research centers across the United States that conduct these studies. No single or set of research centers dominates the landscape, suggesting there is great diversity of "performing" organizations. The 488 reform projects were conducted at 284 different institutions. See Figure 1 for a distribution of the number of projects at individual institutions.

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Table 1: Total Records Submitted, by Funder August 2007-August 2008*

Agency/Foundation	Total # of Records in HSRProj	# of Records Added by Organization	# of Health Reform Records
Federal Agencies			
Agency for Healthcare Research and Quality (AHRQ)	250	NA	104
Centers for Medicare & Medicaid Services (CMS)	105	NA	15
Department of Veterans Affairs (VA)	126	271	94
Maternal and Child Health Bureau, Health Resources & Services Administration (MCHB/HRSA)	8	NA	2
National Institutes of Health			
National Cancer Institute (NCI)	102	NA	2
National Center for Research Resources (NCRR)	10	NA	1
National Center on Minority Health and Health Disparities (NCMHD)	42	NA	0
National Eye Institute (NEI)	5	NA	0
National Heart, Lung, and Blood Institute (NHLBI)	50	NA	1
National Institute of Child Health and Human Development (NICHD)	65	NA	6
National Institute of Dental and Craniofacial Research (NIDCR)	13	NA	0
National Institute of Mental Health (NIMH)	103	NA	7
National Institute of Neurological Disorders and Stroke (NINDS)	3	NA	1
National Institute of Nursing Research (NINR)	21	NA	7
National Institute on Aging (NIA)	13	NA	1
National Institute on Alcohol Abuse and Alcoholism (NIAAA)	42	NA	11
National Institute on Drug Abuse (NIDA)	119	NA	11
National Institute on Disability and Rehabilitation Research (NIDRR)	35	NA	5
National Center for Health Statistics	NA	2	2
Office of Rural Health Policy, Health Resources & Services Administration (ORHP/HRSA)	11	NA	9
Private Foundations			
Commonwealth Fund	109	NA	29
Kaiser Family Foundation	NA	16	16
Robert Wood Johnson Foundation	672	39	164
Total:	1,904	328	488

Source: HSRProj (Health Services Research Projects in Progress) Database: <http://www.nlm.gov/hsrproj>. Data shown are derived from records submitted to HSRProj by members of the Council of Sponsors or their funded researchers between August 2007 and August 2008. Data also include organizations' submissions of records to AcademyHealth per data requested for this project.

* Not all members of the Council of Sponsors submitted records to HSRProj between August 2007 and August 2008. Those organizations that did not submit records include: American Legacy Foundation; Grantmakers in Health; Kansas Health Institute; Milbank Memorial Fund; Substance Abuse and Mental Health Services Administration (SAMHSA); The Brookings Institution; the U.S. Food & Drug Administration; and the W.K. Kellogg Foundation.

Figure 1: Distribution of Projects Occurring at Performing Institutions

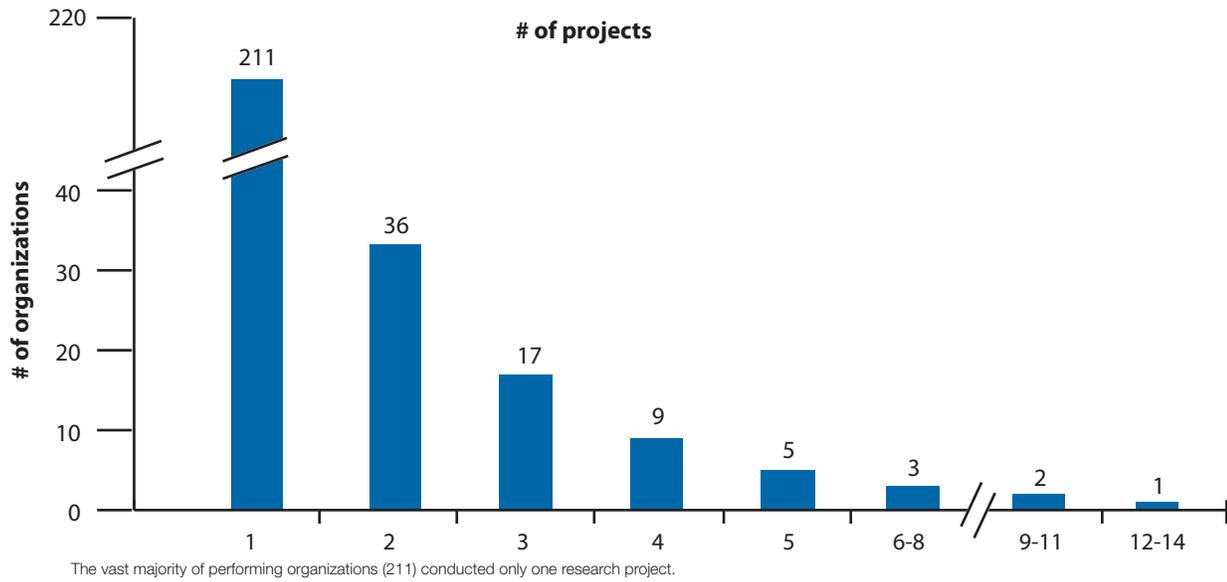


Figure 2: Distribution of Health Reform HSR Projects in the United States



Geographic Distribution

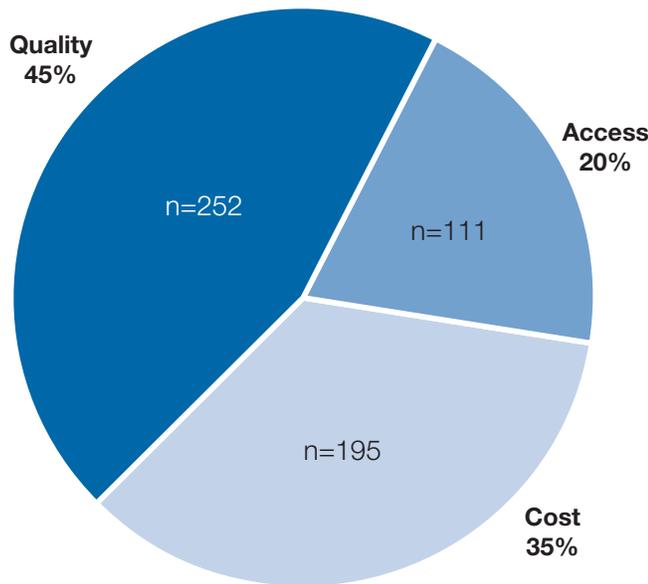
Not surprisingly, many of these research organizations and centers are affiliated with large research universities located in major metropolitan areas—many of which are located on the east and west coasts. As a consequence, though there is great diversity of reform research by institution, the geographic distribution of health reform projects is heavily weighted toward a subset of states, with approximately 10 percent of the total number of projects being performed in the following three states and the District of Columbia: Massachusetts (n=55), New York (n=50),

California (n=44) and the District of Columbia (n=50). With the exception of these few cases, there is a relatively uniform distribution of projects across the states (see Figure 2).

Health Reform Topics

Among the health reform projects identified, nearly half (45 percent) were focused on quality, 35 percent were focused on cost and 20 percent were focused on access or coverage. The distribution of projects according to the three major categories being assessed is shown in Figure 3.

Figure 3: Distribution of Health Reform HSR by Reform Category



Thirteen percent of the research projects focused on more than one of the three categories. The most common grouping was for projects focused on assessing both quality and cost.

Discussion

This project provides evidence of a significant volume of ongoing research¹ focused on health reform topics that can inform health reform and provide important lessons on topics ranging from population needs to best practices in program implementation.

We believe that taken in its entirety, this new wave of research should provide meaningful contributions to our understanding of key issues for health reform. The breadth and volume of work underway also makes evident the importance of coordinating research efforts.

AcademyHealth has advocated for a standard definition and uniform categories to better understand the current federal investment in health services research. This assessment of research in progress related to health reform was made difficult because funders do not use a standard definition and uniform categories to describe their research. It also unnecessarily complicates setting priorities for future research needs.

Improved research coordination and tracking would help ensure that future research priorities are clearly identified and that the research portfolio is appropriately balanced across major needs. It could also help researchers learn about related work of other researchers earlier in the research process.

Several limitations to this analysis bear noting. The first is that projects initiated before August 2007 were not included, though of course there may be important and relevant research on health reform that was initiated prior to this time. The review also did not include all funders since AcademyHealth was relying on the organizations that now participate in the Council of Sponsors to provide support for this data collection and analysis. Although HSRProj takes great strides to assure that all appropriate projects are identified and classified properly, we recognize that some relevant research was omitted due to definitional and classification issues.

Finally, as discussed, HSRProj relies on two approaches for obtaining projects—voluntary reporting from funders or researchers and a review of research databases with projects that are automatically coded as HSR, such as the NIH Computer Retrieval of Information on Scientific Projects (CRISP) database. Both approaches have their limitations, since the first relies on subjective categorization, and the latter relies on algorithms to assess whether projects are in fact HSR. Despite these limitations, HSRProj remains the most comprehensive resource for identifying ongoing research in the field.

AcademyHealth hopes users of HSRProj will find it helpful in identifying projects and researchers studying specific areas of interest, such as health reform in the case of this compendium. AcademyHealth believes this compendium validates the value of HSRProj as an effective search mechanism and will inform future efforts to coordinate federal and foundation sponsored research. Finally, this report is intended to help raise awareness among policymakers regarding the current and future contributions of field to important health and health policy topics.

Endnotes

¹ By December 2008, 135 projects (28 percent of all health reform projects identified) had passed their completion date. These projects are recently completed rather than active or ongoing.

Appendix A: Examples of Research Topics, by Category

Costs/Value

- Options for financing major health reform (tax breaks and subsidies; play-or-pay; value added tax, reforming tax exclusions)
- Private payer cost and quality strategies—promoting better value, including value based benefit design, pay for performance (P4P), bundled payment, partial capitation
- Medicare payment and delivery (bundled payments, chronic care management, P4P)
- Medicaid/SCHIP cost control and quality improvement strategies
- Options for the placement, governance, financing, prioritization, dissemination, and use of comparative effectiveness research
- Options for design and implementation (including provider incentives and financing adoption) of HIT and EHRs, including strategies to balance privacy protections with the need to access and analyze data.
- The potential of administrative simplification (including uniform claims, streamlined contracting and electronic claims submission) to reduce costs
- Impact of personalized medicine on health care delivery and health system.

Systems Quality

- Improving health care delivery (supply-side integration)
- Coordinating public health strategies with financing and delivery system health care reform
- Role of medical home and primary care to improve chronic care coordination and promote prevention
- Role of consumers – wellness; health literacy; compliance

Coverage and Access

- Individual mandates to increase level of coverage
- Employer mandates and other employer-targeted programs to increase the level of employer-sponsored coverage
- Subsidies (tax credits; reinsurance; premium assistance; etc)
- Workforce issues (especially primary care providers)
- Purchasing mechanisms (e.g., Connectors)
- Benefit design issues