

On a day-to-day basis, you track any number of health policy topics. You have a good working knowledge about a plethora of these issues, but rarely have an opportunity to dig into any specific topic in depth. When asked to organize a hearing on an issue, how can you quickly track down the best evidence and expert witnesses to present testimony? What is your boss's position on the issues being debated, and what evidence exists to support this position in her papers and speeches? How can you support your policy recommendations to senior staff in your agency? You might look to HSRProj (Health Services Research Projects in Progress), a free database coordinated by the National Information Center on Health Services Research and Health Care Technology (NICHSR) for the National Library of Medicine.

Background

HSRProj is a database of information about grants and contracts in health services research that have been funded and are still in progress. The database is a joint effort of AcademyHealth and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina, Chapel Hill and is funded by the National Library of Medicine. Records in HSRProj include grants and contracts awarded by major public and private funding agencies and foundations. Individuals can retrieve:

- ◆ Names of the organizations conducting and sponsoring the research;
- ◆ Principal investigator contact information;
- ◆ Beginning and ending dates of the project; and
- ◆ Information about the study design and methodology, including demographic characteristics of the study group, number of subjects in the study population, population base of the study sample, and the source of the project data.

HSRProj records are indexed with the NLM Medical Subject Headings (MeSH). Project abstracts are included whenever possible.

How HSRProj Can Help You?

HSRProj provides access to ongoing research projects before the results are published. Findings from recently completed, but not yet published, health services research projects can be valuable to policymakers, researchers, funders, and conference organizers. This listing of ongoing and recently completed research projects provides policymakers and researchers with a vital link to information not readily available from other sources.

HSRProj can be used to identify:

- ◆ The most up-to-date evidence on policy issues important to you, including unpublished preliminary findings;
- ◆ Experts with current knowledge about your policy topic to serve as sources of new evidence; witnesses for legislative hearings; participants in a consensus development process convened by a policymaking body; or reviewers of proposed regulations; and
- ◆ Researchers and/or funders interested in studying or funding examination of important policy relevant questions about which little information exists.



Scenarios Where HSRProj Can Be Helpful



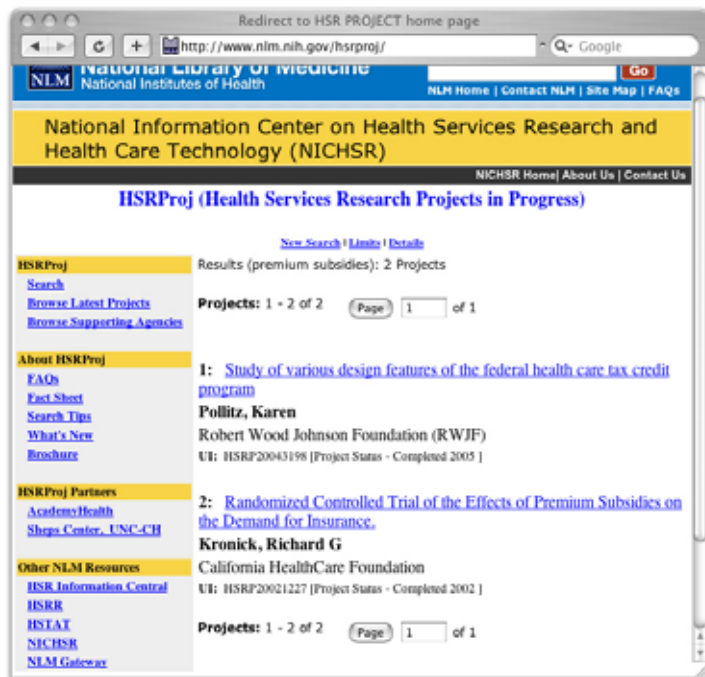
1. Preparing for a Committee Hearing

For the last several months representatives of small businesses, many of which are located in your Senator's state, have been sending you letters requesting that the federal government establish a health benefits plan for them with benefits similar to the Federal Employees Health Benefit plan. Recently, the other senator from your state introduced legislation that would establish such a health plan, requiring small employers to offer health insurance coverage to all full time employees with federal premium subsidies for low income employees. A hearing to discuss this proposal is scheduled for next week.

It is widely acknowledged that many small employers find it impossible to bear the financial burden of offering health insurance coverage to their employees. As a result, they and their employees and their employees' families often have no health insurance coverage, relying on public programs such as Medicaid or the State Children's Health Insurance Program (SCHIP) for their children and only seeking care for themselves in medical emergencies. Clearly, something needs to be done, but you are not sure what the potential impacts of the proposed plan might be.

Within the next week, you must prepare to brief your Senator for a hearing on this topic, as well as identify several expert witnesses to testify at the hearing. The concept of a federally-subsidized small employees benefit plan is relatively new, so you know no one is likely to be examining such a plan specifically. However, it involves aspects of policies that have been proposed in the past, including premium subsidies and employer mandates.

Turning to HSRProj, www.nlm.nih.gov/hsrpoj, you search first on "premium subsidies," and two records are identified. One is a study of premium subsidies to small employers in one locality. The work explores the impact of various levels of premium subsidy on employers' decisions to offer insurance and employees' decisions to accept coverage. While there are not yet any published findings, the project is nearing completion. The issues addressed are exactly the ones about which you would like to learn more. You are familiar with the name of the principal investigator, but do not know him personally. You do a Google search on his name and find that he has testified before Congress several times in the past and, in fact, he recently participated in a roundtable discussion about how to translate insurance studies into policy proposals. You immediately call him and confirm that he is available to testify at next week's hearing.



You would also like to have a witness familiar with evidence about mandating employers to provide insurance, since this is a very controversial aspect of the proposal currently being debated. An HSRProj search on "employer mandates" reveals no ongoing work, and the published literature is nearly ten years old. But, performing an author search in HSRProj, you find that the author of one of the seminal articles on the impact of insurance mandates on small employers, published ten years ago, is currently doing a series of research projects on covering the uninsured. You speak to him and confirm that his more recent work can inform his prior findings, and based on that he is willing to testify about the likely impacts of mandating small employers to offer insurance coverage. You confirm him as the second witness for the hearing. You now begin work on your briefing paper, basing it in part on your detailed phone conversations with the two experts, as well as the draft papers summarizing their findings that they have given you permission to cite.

2. Developing a Position Paper for a Candidate

You have taken six months off to work on your local candidate's campaign for the House of Representatives. He is a corporate lawyer who has always had an interest in local politics and recently decided to run for office. He is running as an independent candidate, preferring to take positions that he views as "right," rather than relying on a party platform. The candidate has made it quite clear that one of his priorities is addressing the problem of the uninsured in the United States,

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and the press is now asking him daily what specific proposals he supports. The campaign manager has asked you to draft a position paper on state high risk pools for health insurance and to support that position with available evidence.



A search of “high risk pools” in HSRProj, www.nlm.nih.gov/hsrproj, yields three records. It turns out that someone at the university across town has been tracking state efforts to expand coverage through the use of high risk pools. You give her a call and set up a meeting for tomorrow afternoon. She shows you how to access the database she maintains, shares information with you about which of the risk pools have been successful and which have not, as well as her sense of the factors affecting their success. After returning to your office, you contact several risk pool administrators to ascertain their sense of the merits of the pools. In addition, the administrators contact several pool enrollees, who voluntarily agree to speak with you about their experiences. You need to process the information you have gathered overnight, but by tomorrow morning you will be able to outline the position paper and discuss it with the campaign manager. A draft will be completed by the end of the week.

3. Developing and Making a Policy Recommendation

It is a priority of Congress and the Administration to provide incentives for research and development of new medications, particularly countermeasures to chemical, biological, or radiological attack or infectious disease outbreak. Several attempts to legislate such incentives have been introduced in the House and Senate. One common component of each bill is a limit on exclusivity in marketing, which seems to apply to all pharma-

logical research and development. There is concern in the industry and among associations representing those suffering from rare diseases that this provision would erode protections put in place under the Orphan Drug Act (ODA) of 1983. The market exclusivity provisions of the ODA were one component of a multifaceted approach to stimulate the development of drugs for rare diseases. Exclusive marketing rights limited competition by preventing other companies from marketing the drug for seven years. A May 2001 evaluation by the Office of the Inspector General (OIG) concluded that there was general satisfaction with the ODA’s provisions, and “no regulatory or legislative changes are needed at this time.”

However, current discussions of the pharmacological industry incentives are taking place in a politically charged, post-September 11th environment. Next week, you must make a recommendation to the Secretary as to whether the agency should support limits on market exclusivity of pharmacological development that might threaten advances made under the ODA. Aside from the OIG report that assessed industry and patient satisfaction with the ODA, you need to know if there is evidence about the actual impact of the market exclusivity provisions of the ODA.



An initial search of HSRProj, www.nlm.nih.gov/hsrproj, identifies one project currently examining the ODA. You contact the principal investigator, who fully understands what you need to know, but has not been examining the market exclusivity provisions specifically. However, he refers you to colleagues of his that explored the impacts of ODA in the early 1990’s. In addition, he suggests that you contact a colleague of his in the business school who has worked closely with a number of airlines as they negotiated market exclusivity provisions they held with travel agents after challenges to the business

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relationships were brought by the Department of Justice (DOJ). In hopes of better understanding both the specific impacts of market exclusivity in the pharmacological industry and the underlying economic theory, you set up conference calls with the health services researchers who examined the impact of the ODA in its early years, your colleague in the OIG who authored

the agency's report, a contact you have at the National Organization of Rare Disorders, your contact's colleague at the business school, and an acquaintance of at the DOJ. You are now confident that you will be able to brief the Secretary and make a recommendation by next week.

HSRProj Can Help. How Do You Search?



- ◀ Enter search terms in the query box. Use double quotes ("") around the terms to search for a multi-word phrase, Boolean operators (AND, OR, NOT), and field tags enclosed in square brackets to search within a field (e.g., [ir] to search for investigator).
- ◀ Select the type of search (e.g., investigator/researcher or supporting/funding agency).
- ◀ To conduct a more-tailored search, (e.g., if you are seeking projects recently added to HSRProj, projects funded in a particular year or in a certain state, or completed projects), click on the limits option above the query box and enter the appropriate parameters.
- ◀ Click the search button. A results screen is displayed.



- ◀ HSRProj records are displayed in a brief format, displaying the project title, full name of investigator, sponsoring agency, unique identifier number, and project status. Note that HSRProj displays records in reverse chronological order of the project's status. (For example, a project that has an end date of 2009 will appear before a project that has an end date of 2005.)
- ◀ View the full record by clicking on the hyperlink of the project title, (this opens a new browser window).
- ◀ Use the print function of your browser to print all the information displayed on the Web page.

How Can You Be Sure Your Project Is in HSRProj?

Researchers are invited to submit a description of their current health services research projects. Send an email to hsrproj@academyhealth.org or complete an online submission form at www.academyhealth.org/hsrproj/input.cfm

Questions?

Call AcademyHealth HSRProj staff at 202-292-6700, email hsrproj@academyhealth.org, or visit www.academyhealth.org/hsrproj. For technical assistance, click on Contact Us on the top of the screen at www.nlm.nih.gov/hsrproj.