Robert Wood Johnson Foundation

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Filling Major Knowledge Gaps About Health Care

Development of national rapid-learning systems

SUMMARY

From 2005 to 2010, researchers working on George Washington University's Health Insurance Reform Project, a nonprofit, nonpartisan project, promoted the concept of a rapid-learning health system and advanced its development. A rapid-learning health system involves using millions of electronic health records (with identifying information deleted) in searchable national databases to fill major knowledge gaps about health care and to develop better health care policies.

Rapid learning is especially important in learning about the value of existing and new technologies, since these technologies drive rising health care costs.

Key Results

- Generated interest in the concept of a rapid-learning health system through journal articles and reports, meetings, presentations and blog entries, including:
  - A special issue of *Health Affairs*, "Rapid Learning: Getting Technology into Practice" (January 26, 2007) with 13 articles (available online; scroll down to 26 January 2007). Six articles are from a project meeting held March 16–17, 2006.
  - A conference (April 23–24, 2008) and a report, *Building a Medicaid Rapid-Learning Network: A Key Investment for Medicaid's Future* (January 2009), to present the case for creating rapid learning for Medicaid.
- Worked with health care executives and other researchers to show federal health policy staff how to apply rapid learning to federal programs such as Medicare and Medicaid. Several ideas made it into federal laws, including:
  - A $10 billion Center for Medicare & Medicaid Innovation to rapidly research, test and disseminate information on new models for health care delivery and financing, included in the health reform law passed in March 2010
  - Funding totaling $1.1 billion for comparative effectiveness research (comparison of the costs and benefits of different ways to diagnose, treat, prevent or monitor disease), included in the American Recovery and Reinvestment Act of 2009

- Influenced Robert Wood Johnson Foundation (RWJF) investments to support a rapid-learning health system, including:
  - A five-year, $15.6 million grant[1] in 2007 to Archimedes, San Francisco, to build a reasonably priced health care simulator for use in answering questions about the effects of clinical and administrative interventions on health and logistic and economic outcomes in specific groups of people.
  - A three-year, $8.5 million grant[2] in 2008 to the Kaiser Foundation Research Institute, Oakland, Calif. (part of Kaiser Permanente), to help fund creation of a biobank to determine which behavioral, environmental and genetics factors are linked to certain diseases. In 2009, the National Institutes of Health made a $24.8 million grant to this project.

Funding

RWJF supported this project with two grants (ID#s 053797 and 060413) totaling $897,754. *Health Affairs* received funding from the federal Agency for Healthcare Research and Quality, Rockville, Md., and Kaiser Permanente, Oakland, Calif., to help pay for printing, mailing and publicizing the special issue of *Health Affairs* about rapid learning.

CONTEXT

Every day in the United States, physicians prescribe medications, use medical technologies and perform procedures based on limited information about how effective these interventions are on real-world populations. The reason is simple: Most clinical research is conducted in tightly controlled experiments, often with healthy volunteers or people who have only the disease being studied.

But patients often are much more complex. They may have multiple chronic diseases, such as high blood pressure and diabetes, and disabilities, such as limited eyesight or hearing.

The evidence is weakest for the effects on the patients physicians typically see, such as senior citizens and people who are disabled. Many of the patients with the most complex diseases and conditions are enrolled in Medicare and/or Medicaid. In 2004, Medicaid covered 58.2 million people, and Medicare covered 40.8 million, according to the *Medicaid 2004 Analytic Extract Chartbook.* Of those, 8.6 million were known as "dual eligibles," mostly older, chronically ill and disabled patients who were enrolled in both programs.

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[1] Grant ID# 057707.

[2] Grant ID# 064362.

The approval of new drugs and medical and surgical procedures is based on their safety and effectiveness in carefully selected clinical-trial participants at market entry. But patient safety issues often show up only when the new drug or procedure becomes widely used in clinical practice. Over time, physicians often use these new drugs and procedures for more diverse patients than those studied in clinical trials.

Physicians, patients and payers need to know more about the appropriateness of new drugs and procedures for specific types of patients, that is, the risks and benefits of one drug or procedure versus another.

Health Insurance Reform Project

With funding from RWJF, George Washington University launched the nonprofit, nonpartisan Health Insurance Reform Project in 1995 to:

- Help policy-makers and others in the health care field understand changes and innovations occurring in health care and health insurance
- Formulate innovative solutions to pressing health policy issues, such as how to improve care for Medicare and Medicaid enrollees

"If you think about the Health Insurance Reform Project more broadly, we take orphan ideas and nurture them and then hand them off to become national policies," explains Lynn Etheredge, a long-time contractor to George Washington University who directs the project. Etheredge also is a former director of the health policy unit at the federal Office of Management and Budget.

Previous RWJF grants to the Health Insurance Reform Project include:

- Three grants totaling $1,784,457 from 1995 to 2001[3] for identification and analysis of trends and critical areas in health policy, such as Medicare reform and options for helping uninsured workers and their families get health coverage. Project staff convened experts to discuss these trends and issues and then published journal articles and reports. See Program Results.
- Three grants totaling $1,007,042 from 2001 to 2003[4] to help officials from the Centers for Medicare & Medicaid Services (CMS) begin to design a voluntary program, Medicare Health Support, to improve Medicare quality for patients with multiple chronic conditions and to bring the concept of using tax credits to expand health insurance coverage to the uninsured into the health policy debate. See Program Results.

[3] Grant ID#s 027243, 030390 and 035292.

[4] Grant ID#s 041223, 041828 and 048295.

- A $214,129 grant from 2003 to 2004[5] to continue to work with officials from CMS to design Medicare Health Support. In 2005, CMS launched Health Support with nine regional programs. See Program Results.

RWJF's Interest in the Area

The Pioneer Portfolio invests in ideas, technologies and trends that have the potential for exponential change in health and health care.

Through the Pioneer Portfolio, RWJF has funded numerous initiatives involving electronic medical records. The goal is to find creative ways to use digitized health information to help scientists find new cures, clinicians treat diseases and patients take charge of their own health. See the team's Home Page for links to its Strategy Statement and Ideas Blog.

For example, Pioneer financed the following projects:

- Connecting for Health, a project from 2004 to 2007[6] to figure out how to remove the technical obstacles to creating a national, interconnected system of electronic medical records. See Program Results.
- *Project HealthDesign*, an ongoing RWJF national program to find ways to allow patients to manage and apply data to their personal health records. The goal is to give patients an electronic tool to help them manage their own health. See the Progress Report.
- OpenNotes, a 12-month pilot project launched in June 2010 to evaluate the impact on both physicians and patients of the electronic sharing of the comments and observations that physicians record after each patient encounter. Report available online.

THE PROJECT

By tapping into the collective power of millions of electronic health records, researchers from the government and the private sector could rapidly advance the evidence base for clinical care and policy-making. Electronic health records make it possible to create searchable national databases containing the clinical experiences of millions of patients, with their personal information deleted. Researchers could use these national databases to fill major knowledge gaps about health care. Armed with new knowledge from these research projects, policy-makers could then create better health policies.

Lynn Etheredge and his team at George Washington University's Health Insurance Reform Project dubbed this idea a "rapid-learning health system." From 2005 to 2010,

[5] Grant ID# 048827.

[6] Grant ID# 056712.

they helped generate strong interest in this system and advanced its development during the two grants covered by this report (ID#s 053797 and 060413).

Subcontracted under the second grant, staff at the Center for Health Care Strategies in Hamilton, N.J., worked with Etheredge to organize a conference and white paper about how research databases populated with electronic health records could be used to improve medical care for Medicaid enrollees. The center is a nonprofit organization specializing in improving health care for low-income people.

Uses of a Rapid-Learning Health System

Rapid learning is especially important in learning about the value of existing and new technologies, since new technologies drive rising health care costs.

Researchers could use rapid learning to study many aspects of health care, including:

- Why health care costs are increasing
- The benefits and risks of prescription drugs for different groups of people
- How well medical and surgical procedures work
- Variations in health care spending and use in different states, regions, cities and even between hospitals and within health plans
- The role of environmental and genetic factors in causing diseases

Policy-makers could use rapid learning to advance many health policy goals, such as:

- Competition based on value
- A redesigned Medicare payment system
- A Medicaid plan that is a national leader in health care
- National collaborative research
- A national technology assessment system

Introducing and Advancing Rapid Learning

During this project, Etheredge and his team:

- Hosted, co-sponsored and helped plan meetings and conferences on rapid learning
- Published a special edition of *Health Affairs* and reports on rapid learning

Etheredge also met one-on-one with key health policy staff at various federal agencies within the U.S. Department of Health and Human Services and in Congress. Federal agencies included:

- Centers for Medicare & Medicaid Services (CMS)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- Food and Drug Administration (FDA)

Other Funding

Health Affairs received funding from AHRQ in Rockville, Md., and Kaiser Permanente in Oakland, Calif., to help pay for printing, mailing and publicizing the special issue of *Health Affairs.* Kaiser Permanente is a nonprofit health care insurance and delivery organization.

RESULTS

The project director reported the following results to RWJF:

- **The project generated interest in the concept of a rapid-learning health system through journal articles and reports, meetings, presentations and blog entries, including:**
  - A special issue of *Health Affairs,* "Rapid Learning: Getting Technology into Practice," composed of 13 articles. Staffers at *Health Affairs* posted the issue online on January 26, 2007, and then distributed it to the journal's regular subscription list as a special print supplement to the March/April 2007 issue of *Health Affairs.* The issue is available online (scroll down to 26 January 2007).

    Taken collectively, the articles discuss the research potential of rapid learning as well as the obstacles that must be overcome to fully implement a rapid-learning health system.

    Examples of the papers in the special issue are:

    - "A Rapid-Learning Health System," the lead article by Etheredge, discusses how rapid learning could bridge gaps in knowledge, ranging from the benefits and risks of medications to the reasons behind rising health care costs.
    - "The Gap Between Evidence and Practice," written by Louise Liang, M.D., senior vice president of quality and systems support at Kaiser Permanente. Liang discusses how the health care field can use electronic medical records to understand clinician and patient behavior and to convert clinical evidence into better outcomes, for example, by learning how to motivate physicians to adopt evidence-based practices and patients to partner with physicians and participate in their own care.

- "Advancing Evidence-Based Care for Diabetes: Lessons from the Veteran's Health Administration," by Joel Kupersmith et al. at the Veteran's Health Administration (VHA), discusses how the organization tapped into its electronic medical records system to figure out how to improve diabetes care for veterans. To do so, the VHA built a diabetes registry optimized for research.

Six articles are from a project meeting organized by Etheredge and *Health Affairs* to introduce the concept of rapid learning. Held March 16–17, 2006, in Washington, the meeting attracted about 18 attendees, primarily researchers and policy experts.

— A conference and a report to present the case for creating a rapid-learning network for Medicaid. The Center for Health Care Strategies, a nonprofit organization in Washington specializing in improving health care for low-income people, co-sponsored the work, which included:

- "Building a Medicaid Rapid-Learning Network," a conference on April 23–24, 2008, in Washington. Keynote speakers included Carolyn Clancy, director of the Agency for Healthcare Research and Quality, and Mark McClellan, director of the Engleberg Center for Health Care Reform at the Brookings Institution. A total of 27 researchers, federal health agency officials, executives from health insurance companies and hospitals/health systems and foundation staff attended the event.
- The report, *Building a Medicaid Rapid-Learning Network: A Key Investment for Medicaid's Future* (January 2009), outlines ways in which Medicaid could play a leading role in facilitating rapid learning nationally. One idea is to create a rapid-learning network involving data from five to seven leading states, health plans and stakeholders to serve as a learning laboratory for Medicaid nationally.

For a detailed list of publications, presentations and blog entries, see the Bibliography.

- **Worked with the Institute of Medicine (IOM) to plan a workshop on the learning health care system, the beginning of a larger project that included 12 meetings and a number of reports.**

  Etheredge helped plan "The Learning Healthcare System," held July 20–21, 2006, in Washington, made a presentation about rapid learning and wrote a paper for the workshop report: *The Learning Healthcare System: Workshop Summary.* He also worked with the IOM on several related workshops and contributed to its reports.

- **Worked with health care executives and other researchers to show federal health policy staff how to apply rapid learning to federal programs such as Medicare and Medicaid.** Several ideas made it into federal laws, including:

- A $10 billion Center for Medicare & Medicaid Innovation, which was included in the health reform law (the Patient Protection and Affordability Care Act or PPACA) that Congress passed in March 2010. The innovation center is charged with rapidly researching, testing and disseminating information on new models for health care delivery and financing.

  Etheredge worked with executives from integrated health systems, such as Geisinger Health System, to develop the proposal for the innovation center, which was submitted to Congress and the administration.

  "The idea is that this is a continuous process," he says. "You would get insights from these huge research databases. They would come up with best practices. Then you would apply the new best practices through pilot projects and measure the results."

- Funding totaling $1.1 billion for what is known as comparative effectiveness research in the American Recovery and Reinvestment Act of 2009. Comparative effectiveness research is a process to compare different ways to diagnose, treat, prevent or monitor disease. The idea is to give physicians, patients and decision-makers concrete information about which interventions work best for specific categories of patients under specific circumstances.

  The publication of the special supplement to *Health Affairs* in January 2007 put the idea of comparative effectiveness research on the national health policy radar because it focused on how researchers could tap into research databases populated with millions of electronic health records to do comparative effectiveness research, according to Etheredge.

  "We laid out that there were capabilities to do this. It wasn't just a theory," said Etheredge, who also was part of a group of outside experts who worked with senior congressional staff to help finalize the comparative effectiveness research proposal.

  Some of the funds for comparative effectiveness research are targeted to developing rapid-learning capabilities, such as Medicare's chronic disease warehouse, and new federal support for national research registries for rare diseases.

- **Influenced RWJF investments to support a rapid-learning health system, including:**

  - A five-year, $15.6 million grant[7] in 2007 to Archimedes, San Francisco, to build a reasonably priced health care simulator (ARCHimedes Health Care Simulator or ARCHeS) for use in answering questions about the effects of clinical and administrative interventions on health and logistic and economic outcomes in

[7] Grant ID# 057702.

specific groups of people. For example, researchers will be able to evaluate different protocols for heart attack (e.g., diet, exercise, aspirin, beta blockers and other common medications) and simulate their comparative effectiveness and cost.

Archimedes is an independent organization that began as part of Kaiser Permanente. ARCHeS will be a simpler, less expensive version of the Archimedes Model, a mathematical simulation model of human physiology, diseases and behaviors and health care systems, including tests and treatments.

Archimedes founder David Eddy, M.D., presented this work at one of the project's meetings, at which RWJF Special Advisor for Program Development Nancy Barrand heard about it. Barrand worked with Eddy to design this project to create a simpler, more affordable simulation model.

— A three-year, $8.5 million grant[8] in 2008 to the Kaiser Foundation Research Institute, Oakland, Calif. (part of Kaiser Permanente), to help fund creation of a biobank to determine which behavioral, environmental and genetics factors are linked to certain diseases. Kaiser researchers are linking electronic medical records, data on environmental and behavioral factors and genetic samples from 500,000 consenting health plan members.

RWJF's investment was followed by a $24.8 million NIH grant in 2009 for this work.

"The unequaled size and power of this biorepository will enable researchers to analyze genetic, environmental and other health data in ways that were never before possible," said RWJF President and CEO Risa Lavizzo-Mourey, M.D., M.B.A. "The findings they generate will help us target effective prevention and treatment strategies that dramatically improve people's health and the quality of their care."

RWJF's Barrand contacted Kaiser after Etheredge told her the organization was thinking about building a biobank.

LESSONS LEARNED

1. **Be flexible enough to revise a project in midstream to respond to changes in the national health policy environment.** After the election of President Barack Obama in November 2008, for example, the national debate on health reform presented an opportunity to get the concept of rapid learning cemented into federal laws. The project director went from promoting the idea of rapid learning networks to helping develop specific initiatives, such as the concept of a Medicare and Medicaid innovation center. (Project Director/Etheredge)

[8] Grant ID# 064362.

2. **Recognize that the progression from innovative idea to national health policy is lengthy and collaborative.** "People don't quite understand that having a brilliant idea and publishing it is the first step," says Etheredge. "It takes a process of five to 10 years of professional development and refinement, proof of concept and dialogue among a wide network of professionals who work on these issues."

3. **Improve national health care policies by working with the professional staff of federal agencies rather than politicians.** Etheredge focused on working with "career professional staff" in federal agencies, who he says can bring new technologies and new ways of thinking into the policy process.

4. **Consider ways to use electronic health records and databases composed of these records.** This project showed that these records and databases could be used in many ways to advance the theory and practice of medicine. (Project Director/Etheredge)

AFTERWARD

With a RWJF grant of $747,234,[9] Etheredge and his team of researchers at George Washington University are expanding and advancing rapid-learning initiatives and continuing to promote their inclusion in federal health policy. Their primary focus is on Medicare and Medicaid enrollees, for whom the largest evidence gaps exist.

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[9] Grant ID# 067397: May 2010 to May 2012.

BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Special Journal Issue

Health Affairs special issue, "A Rapid-Learning Health System," January 2007. Available online. Scroll down to 26 January 2007.

Articles

- "A Rapid-Learning Health System," Lynn M. Etheredge.
- "Linking Electronic Medical Records to Large-Scale Simulation Models: Can We Put Rapid Learning on Turbo?," David M. Eddy.
- "Federal Initiatives to Support Rapid Learning About New Technologies," by Sean R. Tunis, Tanisha V. Carino, Reginald D. Williams II and Peter B. Bach.
- "Advancing Evidence-Based Care For Diabetes: Lessons From The Veterans Health Administration," Joel Kupersmith, Joseph Francis, Eve Kerr, Sarah Krein, Leonard Pogach, Robert Kolodner, and Jonathan B. Perlin.
- "Reshaping Cancer Learning Through The Use Of Health Information Technology," Paul R. Wallace.
- "Bridging the Inferential Gap: The Electronic Health Record and Clinical Evidence," Walter F. Stewart, Nirav R. Shah, Mark J Selna, Ronald A. Paulus and James M. Walker.

Commentaries

- "The Gap Between Evidence and Practice," Louise Liang.
- "Moving Closer to a Rapid-Learning Health Care System," Jean R. Slutsky.
- "Archimedes: A Bold Step Into The Future," John R. Lumpkin.
- "Speed Bumps, Potholes, And Tollbooths On The Road To Panacea: Making Best Use Of Data," Richard Platt.
- "Challenges Ahead For Federal Technology Assessment," Peter J. Neumann
- "Health Information Technology: Does It Facilitate Or Hinder Rapid Learning?," L. Gregory Pawlson.
- "Information Technology And The Inferential Gap," Jonathan B. Perlman and Joel Kupersmith.

Articles

Etheredge L. "Medicare's Future: Cancer Care," *Health Affairs*, 28(1): 148-149, 2009. Available online.

Abernethy A, Etheredge L, Ganz P, Wallace P., German R, Chalapathy N, Bach P, Murphy S, "Rapid-Learning System for Cancer Care," *Journal of Clinical Oncology*, 28 (26): 1-7, 2010. Abstract available online.

Etheredge L. "Rapid Learning in the Health Sector." Submitted to the *Chronicle of Philanthropy*, unpublished.

Blogs

Etheredge L, "BIG Health and New Technologies." Big Health Blog of the Big Health Consortium. Appears online. Posted October 7, 2008.

Etheredge L, "BIG Health and a Rapid-Learning Network for Children's Health." Big Health Blog of the Big Health Consortium. Appears online. Posted October 14, 2008.

Robert Wood Johnson Foundation, "Pioneering Ideas." Appears online. Posted May 7, 2008.

Robert Wood Johnson Foundation, "Pioneering Ideas. Appears online. Posted May 8, 2008.

Presentations

Amy Abernethy and Lynn Etheredge, "A Rapid Learning Health System for Cancer Care. Two Perspectives: System-Centered & Patient Centered," at a Foundation for Evidence-Driven Practice: A Rapid-Learning System for Cancer, Institute of Medicine, October 5–6, 2009, Washington. Proceedings available online. (On right hand side of screen, click on "presentations," and click on first presentation in list)

Lynn Etheredge, "A Rapid Learning System for Cancer Care: An HHS-wide Challenge" at a Foundation for Evidence-Driven Practice: A Rapid-Learning System for Cancer, Institute of Medicine, October 5–6, 2009, Washington. Proceedings available online. (On right hand side of screen, click on "presentations" and click on sixth presentation on list)

Lynn Etheredge, "A Rapid Learning Health System," The Learning Health Care System, Institute of Medicine, July 20–21, 2006, Washington. Proceedings available online.

Reports

Bella M, Shearer C, Somers S, Etheredge L, Moore J. *Building A Medicaid Rapid-Learning Network: A Key Investment for Medicaid's Future Center for Health Care Strategies and Health Insurance Reform Project.* Washington: George Washington University, 2009. Also available online.