Creating a Rapid-Learning Health System

Lynn Etheredge and a network of health policy experts find a way to improve health care quality, safety, and efficiency

**SUMMARY**

From 2005 through 2013, Lynn Etheredge, a consultant on health care and social policy issues, and Judith Moore at George Washington University, working with a network of collaborators, created, promoted, and spread the concept of a rapid-learning health system, which involves using electronic medical data to create large, searchable databases from many millions of patients with personal identifying information removed.

A rapid-learning health system gives researchers, physicians, patients, payers, and policymakers information to assess the overall value of myriad current and future medical technologies, medications, procedures, and patient care paradigms at individual organizations, across organizations, and nationally, such as through Medicare and Medicaid.

> “The objective of a rapid-learning health care system is simply to learn as fast as possible about what is the best treatment for each patient—and deliver it.”—Lynn Etheredge, Project Director

Through journal articles, white papers, reports, and blogs; planning meetings, conferences, and workshops and presenting at them; and collaborations with federal health policy staff and medical and health care experts, Etheredge and his partners generated interest and large national investments both in a rapid-learning health system in general and in developing rapid-learning projects in cancer, pediatrics, and Alzheimer’s disease. The national rapid-learning network now accesses more than 100 million patient records and continues to expand.

**Key Results**

Rapid learning is now part of the lexicon of researchers, health systems, government agencies, medical specialty societies, and other organizations, and rapid-learning ideas, investments, and initiatives are becoming part of—and starting to transform—mainstream health care.
• The federal government has begun to apply rapid learning in health care, including through:
  
  — The $10 billion Center for Medicare & Medicaid Innovation, included in the Patient Protection and Affordable Care Act (ACA) of 2010, which is charged with rapidly researching, testing, and disseminating information on new models for health care payment and service delivery to provide better care for patients, better health for communities, and lower health care costs.
  
  — $1.1 billion in funding from the 2009 stimulus bill (American Recovery and Reinvestment Act) and the establishment of the Patient-Centered Outcomes Research Institute (PCORI), with $650 million of funding per year. In 2013, the institute formed the National Patient-Centered Clinical Research Network, to provide real-time, standardized, clinical data for use in comparative effectiveness research from up to 100 million patients.
  
• The National Institutes of Health (NIH) has implemented several large-scale projects to incorporate rapid learning into clinical research. “NIH how has the leadership, vision, and commitment to create a new national clinical research system, has successfully enrolled key stakeholders, and has launched implementation,” Etheredge says.

The Big Data to Knowledge (BD2K) initiative supports the development of standardized policies, practices, software, and competencies to organize and integrate biomedical data so that researchers can easily access them. Established in 2013, BD2K focuses on four areas:

  — Enabling the use of data
  
  — Analysis methods and software
  
  — Enhancing training
  
  — Establishing centers of excellence in big data

• Rapid learning is being applied to specific diseases. The American Society of Clinical Oncology (ASCO) and the National Pediatrics Learning Network are developing rapid-learning projects on specific diseases and patient populations:

  — ASCO is developing CancerLinQ™ (Learning Intelligence Network for Quality), a rapid-learning network for cancer care.

  — The National Pediatrics Learning Network, part of the Patient-Centered Outcomes Research Institute, is developing a clinical data research infrastructure for research collaboration to improve pediatric health and health care delivery.

Rapid learning in the health system is a breakthrough idea that is transforming the health system, says Nancy Barrand, senior adviser for program development, Robert Wood Johnson Foundation (RWJF).
“This project has changed how we think about science and collaboration. By harnessing all of this vast data on disease and patient experiences in real time, rapid learning is giving us the tools and knowledge to develop optimal treatments for things like cancer and get them into the hands of doctors and patients in ways that will make a meaningful difference in outcomes.”—Lori Melichar, RWJF Senior Program Officer

Funding

RWJF supported the rapid-learning health system project through four grants to George Washington University totaling $2,044,988.1

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 takes place in tightly controlled experiments, often with healthy volunteers or people who have only the disease under study.

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.

New drugs and medical and surgical procedures are approved based on their safety and effectiveness in carefully selected clinical trial participants at market entry. But patient safety issues often show up only when a new drug or procedure becomes widely used in clinical practice, as over time, physicians often use these new drugs and procedures for more diverse patients than those studied in clinical trials.

And clinical trials are lengthy, expensive, and cumbersome, which means they are not a useful way to answer the “overwhelming majority” of questions in health care. “The rapid changes in technologies and medical practices makes answers (derived from these trials) obsolete almost as soon as they come in,” explains David Eddy, MD, PhD, founder and chief medical officer emeritus of Archimedes, Inc., which created the ARCHimedes Health Care Simulator or ARChES, an internet-based health care simulation model. (See the Program Results Report for more information on ARChES.)

1 ID# 53797 ($201,254, August 1, 2005 through January 31, 2007); ID# 60413 ($696,500, March 15, 2007 through March 14, 2010); ID# 67397 ($747,234, April 15, 2010 through May 31, 2012); and ID# 70018 ($400,000, June 1, 2012 through December 31, 2013).
Impact on Cost and Quality

The lack of a systematic approach to learning contributes to escalating costs as well as quality and safety problems in health care. One often-cited example is Vioxx—a nonsteroidal, anti-inflammatory medication to reduce pain, inflammation, and stiffness caused by osteoarthritis and rheumatoid arthritis—which was pulled from the market in 2004 after researchers found a link between the medication and a higher risk of heart attack and stroke. That connection could have been uncovered much earlier with a large, searchable database filled with data from real-world patients who had used the drug, Etheredge believes.

These databases also could help rein in health care expenditures.

“To control costs, you want to promote prevention and use of the most cost-effective treatments and strategies. Why don’t we use cost-effective treatments and strategies? We don’t have any way of producing evidence-based quality care that can diffuse rapidly through the health care system.”—Nancy Barrand, RWJF Senior Adviser for Program Development

Eddy says, “What can we do to make it better? The answer is better access to patient-specific data. Today’s mathematics is more than adequate to address the problems we face in medicine. Software and computing power are advancing rapidly on their own. What we in health care must do is provide the data.”

Health Insurance Reform Project

Etheredge began working on RWJF grants as a contractor on George Washington University’s nonprofit, nonpartisan Health Insurance Reform Project. Launched in 1995, this project was designed to:

- Help policymakers 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 Reform Research Project more broadly, we take orphan ideas and nurture them and then hand them off to become national policies,” explains Etheredge, who is also a former director of the health policy unit at the federal Office of Management and Budget.

For more information on Etheredge’s ideas and career, see a profile about him.

For more information on some of the projects supported by RWJF, see Appendix 1.

THE PROJECT

In 2005, Etheredge began working in a new area: rapid learning in the health system. Under four grants from RWJF, he and Moore at George Washington University, working with the journal Health Affairs and many collaborators, developed, promoted, and spread the concept of a rapid-learning health system from 2005 through 2013. A conference of potential authors took place in 2006, and Health Affairs published a special theme issue in 2007 on a rapid-learning health system.

Advancing Health Care Quality, Safety, and Efficiency

Rapid learning is about advancing the quality, safety, and efficiency of the health care system—and, thus, improving people’s health—by tapping into and analyzing aggregated electronic patient data contained in large, searchable databases. The data are culled from patient-specific electronic health records or clinical trials after identifying information has been removed.

A rapid-learning health system gives researchers, physicians, patients, payers, and policymakers information to assess the overall value—or the cost versus the benefit—of myriad current and future medical technologies, medications, and procedures at individual organizations, across organizations, and nationally through Medicare and Medicaid.

“The objective of a rapid-learning health care system is simply to learn as fast as possible about what is the best treatment for each patient—and deliver it.”—Lynn Etheredge

“We normally think of research as separate. People in academia do research and everyone else delivers care,” he adds. “This [project] is trying to integrate rapid learning into the whole health system—not only through registries of collective learning but also at
individual institutions that are learning as well about their performance and best practices.”

**How the Project Generated Interest in and Spread the Concept of Rapid Learning**

Etheredge and his network focused both on generating interest in and spreading the concept of a rapid-learning health system in general—now including more than 100 million patients—and on developing rapid-learning projects in cancer, pediatrics, and Alzheimer’s disease.

This involved a creative and wide-ranging process of information dissemination and discussion about this innovation, which included:

- Writing journal articles, white papers, reports, and blogs. *Health Affairs* published a special issue with articles written by project staff on rapid learning, Medicare and cancer care, and comparative effectiveness research (comparing different ways to diagnose, treat, prevent, or monitor disease).

- Helping to plan meetings, conferences, and workshops and making presentations at them, including conferences held by the National Science Foundation, the Institute of Medicine, and the Center for Health Care Strategies

- Collaborating with representatives of the Institute of Medicine (IOM) on projects related to the learning health care system and rapid learning in cancer care, including helping to plan several workshops on the learning health care system

- Collaborating with medical specialty societies and federal health policy staff and large health systems to advance the concept of rapid learning in cancer, pediatrics, and Alzheimer’s disease. For example, Etheredge supported the development of the National Pediatrics Learning Network, including by meeting with federal health policy staff and pediatric leaders, hosting conference calls, reviewing drafts, and writing a report. He also is credited as being the instigator of the American Society of Clinical Oncology’s CancerLinq.

- Collaborating with and informing federal health policy staff, health care executives, and researchers, Etheredge showed how rapid learning applies to federally funded programs such as Medicare, Medicaid, and a variety of research. Specifically, he collaborated with federal staff from:
  - Agency for Health Care Research and Quality
  - Center for Medicare & Medicaid Services (CMS)
  - National Cancer Institute, including helping to plan a workshop on rapid learning in cancer care and speaking at the National Cancer Policy Summit
— National Institutes of Health, helping to plan its agenda for an initiative to make it easier for researchers to access biomedical data

— National Institutes of Health’s Office of Rare Disease Research

— National Science Foundation, serving on the planning committee for and making a presentation at a National Science Foundation workshop to identify the challenges of creating a new science of learning systems

— Patient-Centered Outcomes Research Institute

“Lynn is a master networker. He will take ideas and move them into NIH, or into the FDA, or a health plan, or into Medicare thinking. It might be the smallest detail, such as the criteria for data that will be collected, or something as major as a policy shift. He can see and understand all of the working parts, how they need to contribute, and how they need to change. He used his network to develop all the pieces that need to be in place to create this larger systems vision.”—Nancy Barrand

For more information about these activities and other examples of ways the project spread rapid learning, see Appendix 2.

RESULTS

The Concept of a Rapid-Learning Health System Has Spread

Rapid learning is now part of the lexicon of researchers, health systems, government agencies, medical specialty societies, and other organizations, says RWJF’s Barrand.

Etheredge “has been successful in framing the vision—which didn’t exist when he started—and in moving it out into the field, and having it resonate with lots of different people; with lots of different institutions,” she says. “It was not that people hadn’t thought about the pieces of it, but he created the vision that gave you the picture for what it could be. Now people use the term—a rapid-learning health system—regularly.”

The Field is Embracing Rapid Learning

Rapid-learning ideas, investments, and initiatives are becoming part of mainstream health care, something few people believed possible when Etheredge started this work.
“The system is much more open than most people would have expected to new ideas and new paradigms.”—Lynn Etheredge

The following examples show how the field is embracing rapid learning.

**The Federal Government**

**Applying Rapid Learning to Producing and Using New Knowledge**

When the project began in 2005, few people believed it was possible to dramatically accelerate the rate of producing and applying new knowledge to improve health care. By 2013, the federal government was doing this across many health activities from NIH basic research, to learning what treatments work best (called comparative effectiveness research), to improving care for Medicare and Medicaid patients.

The national initiatives (2007–2013) include:

- The $10 billion Center for Medicare & Medicaid Innovation, included in the Patient Protection and Affordable Care Act (ACA) of 2010, which is charged with rapidly researching, testing, and disseminating information on new models for health care payment and service delivery to provide better care for patients, better health for communities, and lower health care costs.

- $1.1 billion in funding from the 2009 stimulus bill (American Recovery and Reinvestment Act) and the establishment of the Patient-Centered Outcomes Research Institute (PCORI), with $650 million of funding per year

  Established in 2010 under the ACA, PCORI funds and disseminates comparative effectiveness research. In 2013, the institute formed the National Patient-Centered Clinical Research Network, to provide real-time, standardized, clinical data for use in comparative effectiveness research. The data is from up to 100 million patients and is received from:

  — Health care systems (e.g., hospitals, health plans, and practice-based networks)

  — Groups of patients with specific conditions and their partner organizations (e.g., patients who belong to the Rare Epilepsy Network work with the Epilepsy Foundation).

**Applying Rapid Learning to Clinical Research**

Far ahead of Etheredge’s 2005 prediction, the NIH implemented several large-scale projects to incorporate rapid learning into clinical research.

“‘When we launched the ‘Rapid-Learning Health Care System’ initiative, I recall thinking about the ultimate goal—that NIH would eventually adopt rapid learning using electronic
health record systems as a fundamental strategy for the future of clinical research. My own (always optimistic) guess was at least 10–20 years,” Etheredge says.

But the actual transformation happened much faster—by 2012, according to Etheredge.

“NIH how has the leadership, vision, and commitment to create a new national clinical research system, has successfully enrolled key stakeholders, and has launched implementation,” he says.

The Big Data to Knowledge (BD2K) initiative supports the development of standardized policies, practices, software, and competencies to organize and integrate biomedical data so that researchers can easily access them. Established in 2013, BD2K focuses on four areas:

- Enabling the use of data
- Analysis methods and software
- Enhancing training
- Establishing centers of excellence in big data.

Other NIH rapid learning projects are:

- A pilot project by the Office of Rare Diseases Research to build a Global Rare Diseases Patient Registry and Data Repository will integrate 15 established patient registries for use by investigators in various biomedical studies. Launched in 2012, this project was an outgrowth of an international workshop held in 2010 where Etheredge was a panelist. He also provided informal technical consulting services to the Office of Rare Diseases Research.

- The Health Care Systems Research Collaboratory, which rolled out in 2012, is designed to improve the way clinical trials are conducted by incorporating health care delivery systems, including data from electronic health records, into the process. It now shares an overall coordination center with the PCORI-funded networks, as part of the new rapid-learning clinical research system.

For more examples of how the government is embracing rapid learning, see Appendix 3.

**Advancing Rapid Learning in Specific Diseases and Patient Populations: Cancer, Pediatrics, and Alzheimer’s Disease**

**Cancer**

ASCO is developing CancerLinQ™ (Learning Intelligence Network for Quality), a rapid-learning network for cancer care. CancerLinQ will “aggregate and analyze a massive web of real-world cancer care data, thus revolutionizing how we care for people with cancer,” says the society’s website.
“By enabling us to learn from the millions of individual patients living with cancer nationwide, CancerLinQ will improve the quality and value of cancer care for all.”—American Society of Clinical Oncology

CancerLinQ is the prototype of a rapid-learning model. “Someone has to be first. Someone has to do it and show it can be done, and get all of the pieces together, and that is what I find most exciting about ASCO and its initiative. These are all the pieces and they are coming together just the way the theorists, like myself, said we hoped they would,” said Etheredge. With support from the RWJF grant, he proposed a rapid-learning cancer system in Health Affairs (2009) and worked with the National Cancer Policy Forum (at the IOM) to develop a national workshop of cancer experts that further developed the concept.

ASCO began developing CancerLinQ after staff attended the IOM workshop on rapid learning in cancer care that Etheredge had helped organize. He has provided the society with ongoing, informal guidance in developing CancerLinQ.

As of May 2014, ASCO was seeking a service provider to assist with the development of CancerLinQ.

Once complete, the system will:

- Provide real-time quality feedback to providers, enabling them to measure their care against guidelines and their peers based on aggregated reports of quality
- Feed personalized, real-time clinical insights to doctors to help them choose the right therapy at the right time for each patient, based on clinical guidelines and the experiences of many similar patients
- Uncover patterns in patient characteristics, treatments, and outcomes that can improve care

_The idea is to create a “continuous cycle of quality improvement, so we can get better and better as we practice,”_—Allen Lichter, MD, Chief Executive Officer, ASCO

“Cancer is still the nation’s leading cause of death and most cancers occur in older populations. With large new databases that include genetic information and leadership from ASCO, cancer care for Medicare’s patients can advance much more rapidly and physicians and patients can have real-time access to the best information,” says Etheredge. (View an RWJF video on the rapid learning cancer system, CancerLinQ.)
Pediatrics

The National Pediatrics Learning Network (PEDsNet), part of the Patient-Centered Outcomes Research Institute, is developing a clinical data research infrastructure that enables participants to collaborate in producing new knowledge and improving pediatric health and health care delivery.

Established in 2013, the pediatric network includes:

- Eight of the nation’s largest children’s hospital health systems, serving 2.1 million children per year
- Disease-specific pediatric networks in pediatric inflammatory bowel disease, hypoplastic left heart syndrome (a rare heart disorder present at birth), and childhood obesity
- Data partners Express Scripts (a pharmacy benefit-management company) and IMS Health (a data analytics company)

PEDSNet will initially focus on inflammatory bowel disease, hypoplastic left heart syndrome, and obesity. The Medicaid program, the nation’s largest health program for children (more than 31 million enrollees) will be a major potential user of this research.

Alzheimer’s Disease

Rapid learning in Alzheimer’s disease is a top priority for the Medicare and Medicaid programs, says Etheredge. And the data bear out their concern. One out of every eight Baby Boomers is expected to develop the disease, according to the Alzheimer’s Association, for an estimated 10 million people.

Etheredge briefed policy staff at the U.S. Department of Health and Human Services Secretary’s Office and members of the Advisory Council on Alzheimer’s Research, Care, and Services on Alzheimer’s disease and presented proposals for rapid-learning initiatives in Alzheimer’s disease at a meeting in December 2013. The meeting supported a call for international data-sharing and public disclosure of publicly funded research in Alzheimer’s disease.

RWJF’s Support for Other Rapid-Learning Projects

Building on the growing interest in rapid learning during this project, RWJF made other grants to support pieces of a rapid-learning health system between 2007 and 2009. Although Etheredge did not bring these projects to RWJF, “he has done more to promote them than any dissemination strategy we could have funded,” says RWJF’s Barrand. The projects include:
• **Building a health care simulator to learn the effects of interventions**: A five-year, $15.6 million grant\(^2\) in 2007 to Archimedes, Inc., to build a reasonably priced health care simulator, ARCHeS, for use in answering questions about the effects of clinical and administrative interventions on health and logistics and economic outcomes in specific groups of people. Using the simulator, investigators can get answers to questions in minutes without the obstacles they face in traditional research projects. (See the Program Results Report for more information.)

• **Creating a biobank to study factors linked to certain diseases**: A three-year, $8.5 million grant\(^3\) in 2008 to the Kaiser Foundation Research Institute (part of Kaiser Permanente) to help fund the creation of a biobank to determine which behavioral, environmental, and genetic factors are linked to certain diseases. RWJF’s investment was followed by a $24.8 million NIH grant in 2009. (See the Program Results Report for more information.)

• **Using telehealth to train primary care providers to treat complex health conditions**: Three grants totaling $5.2 million\(^4\) from February 2009 to May 2012 for Project ECHO (Extension for Community Healthcare Outcomes)\(^5\) to train primary care providers in best practices for complex health conditions to expand access to specialized care for vulnerable populations and those living in underserved areas without specialists, using state-of-the-art telehealth technology and clinical-management tools that help to build capacity among community-based providers. (See the Program Results Report for more information.)

**SIGNIFICANCE OF THE PROJECT**

“This was a breakthrough idea, meaning it is transformational and systems changing,” RWJF’s Barrand says. She calls Etheredge a visionary who developed the concept of a rapid-learning health system and how it could work, and then served as the catalyst to create momentum around the concept.

When this project started in 2005, most people thought the federal government would not embrace new ways to learn, special interests would block initiatives, and it would take the health system decades to learn new, better practices.

“The project’s work has contributed to all aspects of the health system, introducing new rapid-learning policy thinking, and resulted in new institutionalized learning initiatives. Much has started to change”—Lynn Etheredge

\(^2\) ID# 57707.  
\(^3\) ID# 64362.  
\(^4\) ID#s 63945, 69313, 69723.  
\(^5\) Etheredge has helped disseminate Project ECHO to the U.S. Department of Veterans Affairs and other places, according to Barrand.
RWJF’s Barrand agrees:

“Five or 10 years from now, will we be able to point to a cure for cancer because of this? No. It will never be that blatant a cause and effect. But, yes, five years from now, we can look back and say, ‘All of this work accelerated the science that went into that cure or next major breakthrough.’”—Nancy Barrand

LESSONS LEARNED

1. **It is possible to rise above partisan politics.** “Much of Washington has been caught up for decades in health policy as a partisan, contentious, and highly politicized endeavor with endless budget debates—ideologies about markets versus regulations. People said to me, ‘This will never work,’” Etheredge says. But it did.

2. **Implementing a vision requires the flexibility to take advantage of opportunities.** For example, “when the Affordable Care Act was being developed, Lynn looked for opportunities and ways to promote the concept of a rapid-learning health system in how the policy itself would play out—whether that was with the Center for Medicare & Medicaid Innovation, which Lynn had a major role in shaping, or the Patient-Centered Outcomes Research Institute,” Barrand says.

AFTERWARD

“Rapid Learning: A Breakthrough Agenda,” an article by Etheredge, appeared in the July 2014 issue of *Health Affairs*. The article reviews rapid-learning developments between 2007 and 2013 and proposes new national initiatives to realize the benefits of a rapid-learning health system.

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APPENDIX 1

RWJF’s Support for the Health Insurance Reform Project

RWJF’s support has included the following:

- Three grants totaling $1,784,457 from 1995 through 2001\(^6\) 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 coverage. (See the Program Results Report for more information.)

- Three grants totaling $1,007,042 from 2001 through 2003\(^7\) 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 the Program Results Report for more information.)

- A $214,129 grant from 2003 through 2004\(^8\) to continue to work with officials from CMS to design Medicare Health Support. In 2005, CMS launched Health Support with nine regional programs. (See the Program Results Report for more information.)

APPENDIX 2

How the Project Spread the Concept of Rapid Learning in Health Care

Journal Articles

- Content published in Health Affairs has included:

  - A special 2007 issue, A Rapid-Learning Health System,\(^9\) composed of 13 articles, which describe the research potential of rapid learning and the obstacles to overcome in order to implement a rapid-learning health system.

  - A 2009 article, “Medicare’s Future: Cancer Care,”\(^10\) in which Etheredge proposed developing a rapid-learning health system for comparative effectiveness, a quality measurement system, and payment reforms to reward high-quality cancer care.

  - A 2010 article, “Creating a High-Performance System for Comparative Effectiveness Research,”\(^11\) in which Etheredge suggests how the U.S. Department

\(^6\) ID#s 27243, 30390, 35292.
\(^7\) ID#s 41223, 41828, 48295.
\(^8\) ID# 48827.
Health and Human Services, working with collaborators, can build a high-performing comparative effectiveness research system using rapid learning.

- In “Rapid, Responsive, Relevant (R3) Research: A Call for a Rapid Learning Research Enterprise,” in *Clinical and Translational Medicine* (2013), Etheredge and his co-authors call for rapid learning research systems involving “researchers, funders, health systems, practitioners, and community partners” working collaboratively on research “using efficient and innovative research designs, and leveraging rich, longitudinal datasets from millions of patients.”

**Collaborations and Guidance**

**Institute of Medicine**

- Etheredge collaborated with IOM on projects related to the learning health care system and cancer care.
  

  — For the IOM’s National Cancer Policy Forum, Etheredge:
    
    - Served on the planning committee for a workshop on rapid learning in cancer care (October 2009), which resulted in the 2010 summary report, *A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care*, and an article by Etheredge and others in the *Journal of Clinical Oncology*. 

    - Spoke at the National Cancer Policy Summit (November 2013) on “A Rapid-Learning Cancer System: A Breakthrough Agenda,” where he discussed the advantages of a national cancer data system for “finding, accessing, sharing, the world’s best evidence for cancer research.”

**Center for Health Care Strategies**

- Etheredge and Moore worked with the staff at the Center for Health Care Strategies on a conference to present the case for creating a rapid-learning network for Medicaid (April 2008) and a report, *Building a Medicaid Rapid-Learning Network: A Key*

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*Investment for Medicaid's Future*¹⁶ (January 2009). The report outlines ways in which Medicaid could play a leading role in facilitating rapid learning nationally.

The Center for Health Care Strategies is a nonprofit organization in Hamilton, N.J. focused on improving health care for low-income people. It was founded with funding from RWJF.

**Conference Organizing, Presentations, and Reports**

- Etheredge served on a planning committee and then was a speaker at a National Science Foundation workshop to identify the scientific and engineering challenges of building a learning health system (April 2013). Etheredge’s presentation—“A Rapid-Learning Health System: A Behavioral Science-Economics-Public Policy Perspective”—helped set the stage for the group and panel discussions that followed.

  He also served on a committee that drafted a report—*Toward a Science of Learning Systems: The Research Challenges Underlying a National-Scale Learning Health System*—based on the workshop, which describes a learning health system as “an unprecedented, ultra-complex, socio-technical system” that “is best viewed as a high-performing infrastructure supporting a wide range of users and uses, some that can be envisioned today and others that will emerge over time.”

- Etheredge served on a planning committee, chaired a panel on national data-sharing initiatives, and spoke at the 20th annual ECRI Institute conference—“Data BIG and Small: What Healthcare Decision Makers are Using Now” (November 2013). Based in Plymouth Meeting, Pa., ECRI Institute is a nonprofit research organization focused on improving the quality, safety, and cost-effectiveness of patient care.

**APPENDIX 3**

**More Examples of How the Federal Government Embraced Rapid Learning**

**Office of the National Coordinator For Health Information Technology**

- The Department of Health and Human Services’ Office of the National Coordinator For Health Information Technology’s *Federal Health IT Strategic Plan 2011–2015* (November 2011) outlines steps to improve the quality, efficiency, and patient-centeredness of the U.S. health system. One of the five strategic goals is “achieve rapid learning and technological advancement.”

  Etheredge wrote and circulated by email to an influential audience two unpublished papers¹⁷ to promote the adoption of a learning health system in this plan. “The HHS

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adoption of the learning health system objective helped give visibility to the policy ideas,” Etheredge wrote in a report to RWJF.

**Food and Drug Administration**

- In 2008, the FDA launched a pilot database, called Mini-Sentinel, to monitor the safety of FDA-approved medical products. As of 2014, the database had electronic patient data on 150 million people that had been culled from claims and administrative data from participating health plans and health systems.

The FDA, PCORI, and NIH now work together to coordinate their new rapid-learning initiatives into a new clinical research system,

The database was included in the Food and Drug Administration Amendments Act of 2007.

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**Reports**


**Communications or Promotions**


**PROFILE LIST**

- **Incubating Innovation in U.S. Health Care Policy: Lynn Etheredge's Ideas Facilitate Policy to Improve Quality and Reduce Costs** (January 2010)