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Using Electronic Health Data for Research and Quality Improvement: A Summary of Innovations, Achievements, and Lessons Learned from the Electronic Data Methods (EDM) Forum, 2010–2013

EDM Forum

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EDM Forum

Using Electronic Health Data for Research and Quality Improvement

A Summary of Innovations, Achievements, and Lessons Learned from the Electronic Data Methods (EDM) Forum, 2010–2013

About the EDM Forum

The EDM Forum was established in 2010 with support from the Agency for Healthcare Research and Quality to advance the national dialogue on the use of electronic health data for research and quality improvement. The EDM Forum facilitates learning and collaboration among researchers and other key stakeholders who are generating the data, methods and evidence needed to build learning health systems that will improve patient care and outcomes.

AcademyHealth

Executive Summary

The rapid pace of development in health information technology holds great promise to improve health and health care. As new models of health delivery reform emerge, new strategies for aligning informatics with a culture of continuous improvement are generating new and relevant evidence that can help transform systems to deliver more efficient, effective, and patient-centered care. The network of diverse innovators and implementers who are building learning health systems of the future needs new ways to share information and collaborate on these system-level improvements.

In 2010 AcademyHealth received a three-year cooperative agreement to direct the EDM Forum as a part of the investments made by the Agency for Healthcare Research and Quality in comparative effectiveness research (CER) infrastructure; these investments were funded by the American Recovery and Reinvestment Act of 2009. The EDM Forum was charged with facilitating information exchange, accelerating collaboration in research and quality improvement (QI), and advancing the national dialogue on CER, patient-centered outcomes research, and QI efforts using electronic health data.

This summary highlights the EDM Forum's work to cultivate collaboration and innovation; accelerate the translation and dissemination of promising approaches; and spread innovations in governance, informatics, and analytic methods needed to build learning health systems. The EDM Forum's growing network includes the nation's leading experts and has generated more than 150 products and other resources to share best practices on the use of electronic health data, including more than 60 peer-reviewed articles by leading experts.

All of the resources discussed in this summary are available through the EDM Forum's primary website, www.edm-forum.org; the EDM Forum Repository, which houses publications (http://repository.academyhealth.org); or by request (edm-forum@academyhealth.org). Feedback, suggestions, and contributions are always welcome.

Overview of National Investments

The American Recovery and Reinvestment Act of 2009 (ARRA) provided $1.1 billion for comparative effectiveness research (CER), which compares the benefits and harms of different health care treatments and interventions in specific, "real-world" settings.[i] The investment was intended to help address gaps in medical evidence about the relative effectiveness of different treatment strategies and to help patients, families, and providers make more informed decisions about the diagnosis, prevention, and treatment of disease. ARRA included the Health Information Technology for Economic and Clinical Health (HITECH) Act, with financial incentives for clinical providers to adopt electronic health records (EHR) and other electronic data systems that could be used for clinical care improvement and research.

Historically, several key factors have had an impact on the ability to conduct CER, and they also have an impact on the fields of patient-centered outcomes research (PCOR) and quality improvement (QI). First, existing data systems are not organized in a way that makes it possible to capture detailed person-level data over time or across sources of care. For example, many administrative claims-based databases are optimized for billing, not clinical work flow, and they are difficult to harmonize (or bring data together) across multiple clinical settings.[ii] This lack of "data harmonization," among other challenges, has contributed to substantial gaps in knowledge.

AcademyHealth's EDM Forum was created through a cooperative agreement from the Agency for Healthcare Research and Quality (AHRQ) Grant #U13 HS19564-010.
Ongoing support for the EDM Forum comes from AHRQ Grant #U18 HS022789-01.

Second, new research methods are needed to conduct studies in CER.[iii] These research innovations were noted by the Institute of Medicine as one important component of building a learning health system, in which each encounter with the health care system is based on knowledge generated through prior experiences.

In 2010, the Agency for Healthcare Research and Quality (AHRQ) allocated about $100 million of the ARRA investment in CER to build "a flexible infrastructure that can be leveraged to address some of the common problems in traditional research studies (both randomized controlled trials and observational studies) and data sources (administrative claims data and electronic health records)"[iv] (see Figure 1). Grant awards were supported through three portfolios: Prospective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapies (PROSPECT) Studies; Scalable Distributed Research Networks for CER (DRN)); and Enhanced Registries for QI and CER.

The 11 projects funded through these efforts serve at least 21 million patients across the United States and reflect an unprecedented mix of patient types (e.g., pediatric, adult, elderly, low income, disabled), conditions (e.g., asthma, diabetes, hypertension), and care settings (inpatient, outpatient, long-term care). More than 70 health care institutions share data via the networks, and many of the projects process multi-terabytes of data on a weekly or monthly basis. Under any definition of "big data," these projects qualify.

Subsequent to HITECH and ARRA, passage of the Patient Protection and Affordable Care Act provided a national imperative—as well as strong economic incentives—to facilitate collection and sharing of data on an unprecedented scale. The value of this high-volume, high-velocity, and highly diverse (e.g., billing information, clinical data as free text and images) big data is the promise of leveraging data from EHR to provide new insights and discovery that lead to care improvement.

The Value of the EDM Forum

AHRQ created the EDM Forum to advance knowledge and maximize the sharing of relevant lessons learned from the nation's unprecedented ARRA investment in new infrastructure for health and health care. Since 2010, the EDM Forum has provided incentives for researchers to share innovations by facilitating dialogue and creating opportunities for networks with diverse goals and partners to collaborate in this new space.

At the same time, the EDM Forum brings new perspectives to the table from stakeholders not directly involved in ARRA-CER research activities, both to understand key needs of the research and to identify areas for future collaboration. The information exchange and interactions occurring through the EDM Forum provide a perspective on lessons being learned in the field and highlight natural variation in governance, informatics capabilities, and methodological approaches using electronic health data for CER, PCOR, and QI.

The EDM Forum Steering Committee members include distinguished experts from some of the nation's leading institutions and organizations. Dr. Ned Calonge (The Colorado Trust) and Dr. Suzanne Bakken (Columbia University) serve as co-chairs. For a complete list of current and former steering committee members, please see www.edmforum-org.

As noted by one investigator, the EDM Forum's efforts have been successful because there is a pressing need to work collaboratively to understand promising approaches to governance, information technology, methods, and implementation to facilitate the best use of electronic clinical data (ECD):

> *It is critically important that we are working together on this effort … Clearly there is a gigantic gap in the entire domain of quality and there is a lot more work to do. But just the fact that we're all sitting around this room is a testament to the progress we're making.*

The resulting trust among the group is a defining feature of the effort, and it is due to investigators' willingness to share experiences and engage in collaborative solutions to shared challenges. Throughout this process, the EDM Forum has provided thought leadership and undertaken analyses that respond directly to questions raised by AHRQ, the research teams, and the stakeholder groups.

The EDM Forum has succeeded in developing a "marketplace of people and ideas" to advance thinking about how to build learning health systems capable of improving patient care and outcomes. The value proposition of EDM Forum is demonstrated in the activities pursued to meet the following three goals:

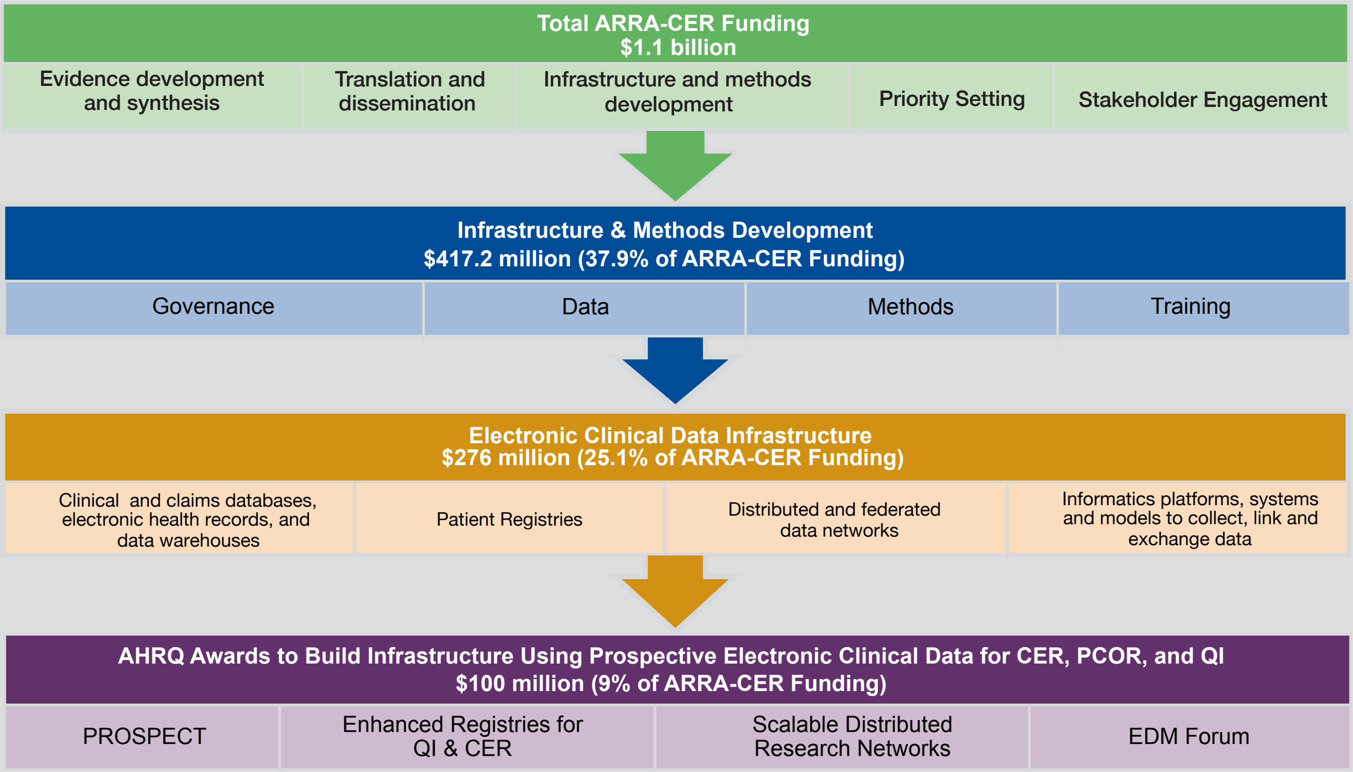
1. *Understanding the landscape of ongoing work in the field, including literature reviews, site visits, and a series of stakeholder needs assessments;*
2. *Engaging stakeholders and incubating collaboration using web and social media tools, virtual and in-person meetings and symposia, and collaborative methods projects; and*
3. *Accelerating translation and dissemination of new knowledge through issue briefs, special supplements with peer-reviewed journals, and the creation of a new, open-access journal, eGEMs.*

For a detailed list about the more 150 resources produced by the EDM Forum, including more than 60 peer-reviewed publications, please see Appendix A.

Figure 1: An Unprecedented Investment in Infrastructure for Health Data and Analytics

Of the $1.1 billion in ARRA funding for CER, about $417.2 million (nearly 40 percent) was allocated to support infrastructure and methods development. The chart below breaks down the distribution of ARRA-CER funds, highlighting investments on the AHRQ CER Data Infrastructure portfolio, which represents nearly 10 percent of the funding, including the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects. (For more information on these three projects, please see www.edm-forum.org.) To date, these infrastructure investments have generated more than 100 new informatics tools or data resources and more than 300 peer-reviewed manuscripts.

Electronic Clinical Data Infrastructure Funds from the Total ARRA-CER Funding



Segal C, Holve E. CER Infrastructure Investments to Support Evidence Generation in a Learning Health System. http://repository.academyhealth.org/edm_briefs/3/.

Post-ARRA investments have continued to provide opportunities to improve data infrastructure and leverage electronic health data. In 2013, AHRQ provided additional funds to build on the ARRA-CER investments. Seven awards were provided to the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects and the Clinical and Health Outcomes Initiative in Comparative Effectiveness (CHOICE) grants, with the objective of enhancing existing data infrastructure, enhancing stakeholder engagement, and assessing the capability of the data infrastructure to meet stakeholder needs.

Another significant investment in 2013 came from the Patient-Centered Outcomes Research Institute, which awarded $93.5 million to develop PCORnet, a national network to support more efficient patient-centered research. More funding opportunities are anticipated in the near future, including allocation of up to $200 million from the PCOR Trust Fund to further support development of data infrastructure.

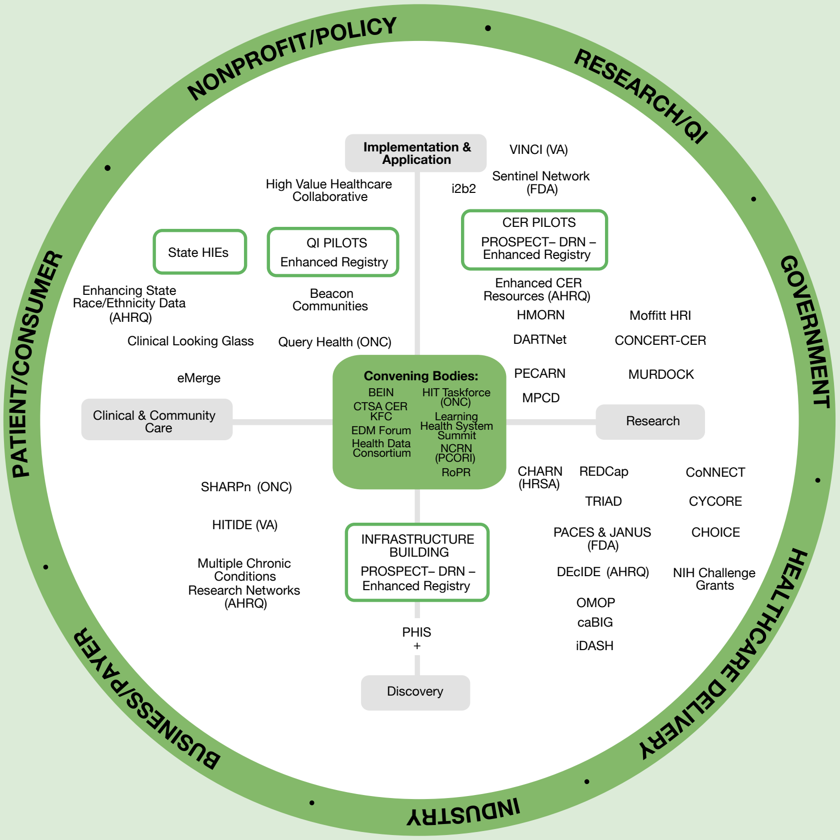
Understanding Electronic Health Data Initiatives and the Stakeholder Landscape

A key first step in achieving the EDM Forum's goals was to understand the landscape of ongoing work and identify the community of stakeholders engaged in efforts to use electronic health data for research and QI. A series of environmental scans and needs assessments were undertaken to highlight specific products (methods, data, research, and tools) that the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries teams—as well as other groups and stakeholders—were developing. These scans clarified stakeholder views on electronic health data infrastructure development; helped in the assessment of technical and nontechnical challenges; and identified current gaps in knowledge. In addition, the assessments revealed opportunities for new collaborations that had not previously been considered—some among researchers working at neighboring institutions. Figure 2 illustrates the emerging landscape as a result of these efforts.

Engaging Stakeholders and Incubating Collaboration

The EDM Forum planned several activities to foster more engagement and information sharing among the community as new networks developed. After some stakeholders expressed an interest in formal opportunities to collaborate on critical infrastructure issues, AcademyHealth worked with AHRQ to develop a mechanism for collaborative methods projects, including a series of dynamic workshops to generate new ideas and relationships among innovators. These projects included collaborations

Figure 2: Understanding the Landscape



The EDM Forum's meta-analyses and environmental scans provided the first comprehensive overview of infrastructure investments in research and QI using electronic health data. As of August 2013, 42 programs or networks and more than 90 unique projects have been identified (Figure 2).

This work also led to the development of key products that demonstrate value and define members and key stakeholders of the Forum. They include:

- **Building the ECD Infrastructure to Improve Patient Outcomes: CER Project Profiles**
  The 11 CER Project Profiles provide an overview of the diverse dimensions of the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects within the AHRQ-ARRA infrastructure portfolio. The profiles describe the specific aims and elements for each project, including the infrastructure and research aims, outcomes of interest, priority populations and conditions of focus, and key partners involved in the projects.

- **Project Snapshots Community**
  Building on the Project Profiles report, the Project Snapshots highlight and disseminate work from networks and projects beyond the AHRQ-ARRA infrastructure portfolio. This community-curated resource provides a home for information about research and QI projects using electronic health data; it includes more than 25 profiles submitted by members of the community.

- **CER Infrastructure Investments to Support Evidence Generation in a Learning Health System**
  In 2012 and 2013, a review of ARRA grant information was conducted to identify relevant efforts to build data infrastructure to support CER, in line with the goals of the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects. This effort identified over 80 research projects to engage and invite to participate in the EDM Forum.

- **Informatics Tools and Approaches to Facilitate the Use of Electronic Data for CER, PCOR, and QI**
  This brief serves as an organizing framework for the informatics tools needed to build learning health systems. More than 31 informatics platforms and tools that have been developed, adopted, or adapted by the PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects are described.

around data quality issues, distributed analytics, governance, and user experience.

As described in Figure 3, the Data Quality Collaborative (DQC) brought researchers together to develop approaches to assess data quality in EHR data, particularly across research and QI networks. To facilitate engagement, the EDM Forum built and maintained a diverse set of Web and social media tools as well as virtual and in-person meetings and symposia.

The DQC project is a highly successful example of future pathways for collaboration that has generated an increased number of collaborators and new sources of support over the last few years.

Accelerating Translation and Dissemination of New Knowledge

To further advance knowledge and dialogue, the EDM Forum developed new strategies to disseminate information in innovative ways to various audiences. Chief among these was the creation of a new open access e-journal, *eGEMs* (*Generating Evidence and Methods to improve patient outcomes)* to share the "journey" of research and QI with these new data sources and methods. *eGEMs* was created to meet an unfulfilled need in the research community. The EDM Forum promotes it as a new, collaborative, community-based approach to publication. Published articles include new approaches to governance using electronic health data, as well as generalizable lessons based on implementation. *eGEMs* facilitates the review of diverse submissions, from manuscripts, to code, to video demonstrations (see *eGEMs* text box).

All publications, as well as recordings from meetings and presentations are available at http://repository.academyhealth.org.

Looking Into the Future

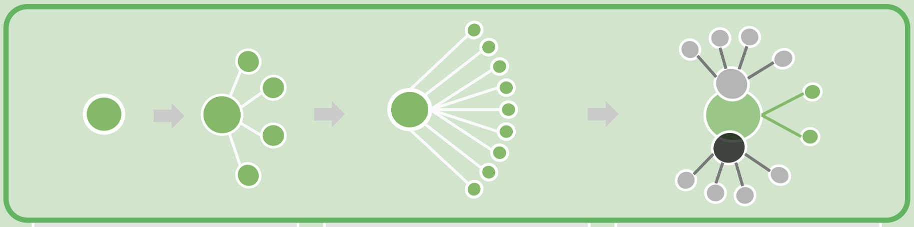
As demonstrated by its many successes to date, the EDM Forum has cultivated a network of interest that makes research, QI, and analytic resources more discoverable and comparable. The unusual openness as a result of these connections and collaborations has advanced the dialogue around CER and PCOR and has

Figure 3: Spotlight on Collaborative Projects

Data Quality Collaborative

EDM Forum staff worked closely with the Steering Committee and partners on an ongoing basis to identify shared interests and encourage a sense of shared responsibility for infrastructure issues that could have easily been marginalized by competing priorities within each of the grants. The progress of data quality assessment as a shared priority and collaborative effort is instructive.

The data quality issue emerged as a priority area at the first meeting of the Steering Committee in 2010. A subsequent 2011 peer-reviewed paper by Michael Kahn and investigators from six of the research teams addressed data quality considerations for multisite networks. With this work in progress, a breakout session in the October 2011 Methods Symposium led to a rich discussion and ultimately led to relationships that were formalized as a collaborative methods project in the summer of 2012. Through a series of in-person and virtual convening activities, the number of collaborators and investigators continued to grow, resulting in a richer discussion and growing awareness of the challenges of evaluating data quality, as well as a shared vocabulary for discussing the issue. These activities culminated in a series of workshops and subsequent methods project proposal to the Patient-Centered Outcomes Research Institute (PCORI), which was funded in the fall of 2013. Under the terms of the three-year project with PCORI, AcademyHealth will continue to help convene the data quality collaborators via the EDM Forum.



Nov 2011: EDM Forum commissions paper on "data model considerations for clinical effectiveness researchers"

Jul 2012: Data model paper published in Medical Care special supplement

Aug 2012: EDM Forum commissions project to develop a comprehensive framework for data quality assessment in CER

Dec 2012: Workshop on data quality assessment and presented initial framework in public webinar on "Tackling Practical Methodological Challenges of Using Electronic Data for CER & PCOR"

May 2013: Data Quality grant submission to the Patient-Centered Outcomes Research Institute (PCORI)

Aug 2013: Dr. Kahn and DQC members invited to serve on IOM Data Harmonization roundtable for the Data Harmonization for Patient-Centered Clinical Research on October 31-November 1

Sep 2013: Dr. Kahn et al awarded funding for a 3-year project on Building PCOR Value and Integrity with Data Quality and Transparency Standards

Nov 2013: Submission to eGEMs (under review)

Governance Toolkit

Despite enthusiasm for national research and QI networks, skepticism has persisted regarding the feasibility of multisite research with large, complex datasets. Specifically, the challenges of successfully navigating policies and relationships across local institutions and policies had been considered a substantial impediment to infrastructure development.

To better understand the characteristics of successful data-sharing efforts, Deven McGraw and Alice Leiter from the Center for Democracy and Technology worked with EDM Forum researchers to generate a broader perspective on "pathways to success" for conducting multisite clinical research. In addition to PROSPECT, Scalable Distributed Research Networks, and Enhanced Registries projects, representatives from other relevant initiatives such as the VA Informatics and Computing Infrastructure (VINCI) and Mini-Sentinel participated. The result was a comparative case study integrating lessons learned from nine major networks, titled, **"Pathways to Success for Multisite Clinical Data Research."** In addition, a **Governance Toolkit** was created for investigators to share resources related to privacy, security, ethics, and other issues. Together, these activities will improve the efficiency and timeliness of future policy and governance development by encouraging researchers to adopt and adapt existing policies to meet their specific needs.

created a new vocabulary that enables a broader set of stakeholders to contribute to and advance science in this area.

For example, the EDM Forum has encouraged multi-institutional implementation and pilot projects that build on one another, learn from one another, and contribute practical knowledge back to the community. The EDM Forum's publications, presentations, and other resources further demonstrate that there is important natural variation of CER, PCOR, and QI, and that "one size"—or approach—to health data infrastructure does not fit all partners or networks.

EDM Forum built on AcademyHealth's core expertise in engaging multiple and diverse stakeholders; conceiving of, organizing, and executing high-quality scientific and technical meetings; and rapidly creating and disseminating accurate, useful, and usable resources (both paper-based and electronic). None of these efforts alone would have been sufficient, but, collectively, the set of support and resources envisioned by AHRQ and executed by AcademyHealth has facilitated a fabric of trust among members of the network, and subsequent levels of productivity demonstrate the utility of this unique collaborative.

Moving into the future, defining a successful approach to sustainability is among the most notable challenge for the networks and for the EDM Forum. Based on conversations with EDM Forum stakeholders, four "pillars" of sustainability have been identified: (1) trust and value, (2) governance, (3) management, and (4) support (both financial and administrative).[vii] These pillars rest heavily on the adaptive capacity of the network and on trust among its members.

eGEMs' History

Early on, many investigators engaged in the EDM Forum reported that there were few opportunities to publish early -stage work about new methods and approaches for research and QI networks in traditional peer-reviewed journals. Their observation was supported by the environmental scan, stakeholder interviews, and discussions with the EDM Forum Steering Committee.

Over the course of many discussions with AHRQ and the Steering Committee, a decision was made to create a new publication venue for sharing lessons learned about the process of using ECD to build learning health systems. The preference was for an open-access journal that could encourage and publish peer-reviewed submissions in nontraditional formats (e.g., interactive visualizations, code) on pragmatic topics critical to data management and analysis.

After consulting with several leading editors from traditional journals in the field, in the winter of 2013 the EDM Forum launched eGEMs, an open-access, peer-reviewed e-publication. eGEMs was designed to provide publish useful, innovative, and timely information to advance the science of using electronic health data. Innovations, new tools, and novel approaches to methods less likely to appear in traditional peer-reviewed journals were explicitly invited, as were submissions to take advantage of eGEMs' publishing platform, which can manage the review and publication of new formats, such as visualizations and videos.

As described by Dr. Lisa Simpson in an early eGEMs editorial,

> *…health services researchers have always been able to share the results of their studies through the many existing peer-reviewed journals and grey literature outlets. What we have been less able to do is disseminate the approaches and methods that yielded those results in sufficient detail to replicate and/or adapt them.*[vi]

Thirty-one articles were published in eGEMs' first year, resulting in more than 12,000 downloads. Paper topics range from effect identification in CER to institutional review board–approved approaches to use tablet computers for community-level data collection. Of the published articles, an October 2013 special supplement on Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems was guest edited by Dr. Wade Aubry from University of California, San Francisco. A second special supplement, Methods for CER, PCOR, and QI Using EHR Data in a Learning Health System was guest edited by Dr. Michael Stoto from Georgetown University. To complement peer-reviewed publications, the EDM Forum offers a digital archive and collection of resources in the grey literature including issue briefs, research project profiles, webinar archives, and other resources. This platform can also be used to promote document sharing and support social media. In all cases, resources posted on the Repository are consistently tagged and offer proposed citations—two features the network values highly.
At present, eGEMs is indexed in Google Scholar, Bing, the Directory of Open Access Journals, and EBSCOhost. The EDM Forum is actively pursuing inclusion in PubMed. That said, many senior researchers have found eGEMs to be the most effective resource for disseminating research because of the open-access status and access to a diverse community of stakeholders.

To better understand how networks grow and develop—particularly with new partners—it will be important to understand the barriers, opportunities, and incentives that affect the long-term sustainability of multipurpose ECD networks. The funding landscape will change, and new entrants will present new opportunities to continue development of systems and initiatives that leverage electronic health data for patient-centered research and QI. The commitment of the Patient-Centered Outcomes Research Institute to the development of a national distributed research network, called PCORnet, is one notable development.[viii] Health system adaption to the concept of Accountable Care Organizations, and the role of analytics and evidence in these health systems, is another.

The EDM Forum must be poised to adapt and respond with useful products and resources. Contributing to this growing discussion of how the field "learns how to learn" from big data is the driving goal of the second phase of the EDM Forum's AHRQ-funded efforts, which will continue through 2016. Concurrently, the EDM Forum, with AHRQ's support, will seek new partners to identify priorities and projects that can accelerate progress in the field.

How to Get Involved

The EDM Forum is open to all stakeholders who are committed to learning how to use electronic health data for research and QI in an open and collaborative model that supports the need for rigorous, patient-centered evidence. The work is evolving rapidly, and the next three to five years will undoubtedly bring new lessons, partners, and scientific advances. With these changes in mind, the EDM Forum anticipates tremendous opportunities to foster collaborative science using electronic health data to improve outcomes and patient care.

All of the EDM Forum's analytic work, including links to publications with Medical Care, and the open-access journal eGEMs are available at www.edm-forum.org and http://repository.academyhealth.org/egems, respectively. We hope stakeholders will join the discussion as authors and reviewers for eGEMs; contribute to discussions on www.edm-forum.org; participate in the EDM Forum symposium; or get involved in a myriad of other ways to contribute to this growing community of practice working together to generate the evidence base needed to improve patient care and outcomes.

About AcademyHealth

AcademyHealth is the leading national organization serving the fields of health services and policy research and the professional who produce and use this important work. Together with our members, we offer programs and services that support the development and use of rigorous, relevant and timely evidence to increase the quality, accessibility, and value of health care, to reduce disparities, and to improve health. A trusted broker of information, AcademyHealth brings stakeholders together to address the current and future needs of an evolving health system, inform policy, and translate evidence into action.

Acknowledgements

AcademyHealth acknowledges the Agency for Healthcare Research and Quality (AHRQ) for its support of this work. The EDM Forum was created through a cooperative agreement from the Agency for Healthcare Research and Quality (AHRQ) Grant #U13 HS19564-010. Ongoing support for the EDM Forum comes from AHRQ Grant #U18 HS022789-01. AHRQ's mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. As 1 of 12 agencies within the Department of Health and Human Services, AHRQ supports research that helps people make more informed decisions and improves the quality of health care services. For more information, visit www.ahrq.gov.

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ii Holve E, Segal C, Hamilton Lopez M, et al. The Electronic Data Methods (EDM) Forum for Comparative Effectiveness Research (CER). Med Care. 2012 July;50(7):S7-S10.

iii Institute of Medicine (IOM). Initial National Priorities for Comparative Effectiveness Research. Washington, DC: The National Academies Press; 2009.

iv Federal Coordinating Council for Comparative Effectiveness Research, loc.cit.

v The EDM Forum defined seven key stakeholder groups to engage: government, business/payer, industry, health care delivery, patient/consumer, nonprofit/policy, and research. Stakeholder groups were identified based on a thorough review and synthesis of stakeholder groups developed for previous AcademyHealth projects ix and were reviewed by project consultants, the AHRQ project officer, and a steering committee of 19 experts who provided strategic oversight and thought leadership throughout the meeting.

vi Simpson L. Learning How to Learn: How AcademyHealth is Supporting Evidence Generation in a Transforming World. *eGEMs (Generating Evidence & Methods to improve patient outcomes)* 2013 Jan 17;1(1).

vii Holve E. Ensuring Support for Research and Quality Improvement (QI) Networks: Four Pillars of Sustainability — An Emerging Framework. eGEMs (Generating Evidence & Methods to improve patient outcomes) 2013 Jan 17;1(1).

viii PCORnet. Web-based Tool. http://www.pcornet.org/ Accessed March 17, 2014.

ix Holve E and Pittman P. A First Look at the Volume and Cost of Comparative Effectiveness Research in the United States. AcademyHealth. 2009 June.

Appendix A: Major Deliverables

The following list of major deliverables is organized by the three aims of the grant: understanding the landscape of ongoing work in the field; engaging stakeholders and incubating collaboration; and accelerating translation and dissemination of new knowledge.[vi]

Understanding the Landscape

Literature Review

To assess the emerging literature at the intersection of electronic health data and comparative effectiveness research (CER), patient-centered outcomes research (PCOR), and quality improvement (QI), the EDM Forum conducted reviews of both the peer-reviewed literature and the grey literature. The literature reviews are part of a comprehensive effort to characterize the literature and promote timely exchange of strategies to use electronic health data for CER, PCOR, and QI. These resources will be useful in the future as an influx of new research supported by the American Recovery and Reinvestment Act of 2009 (ARRA), the Health Information Technology for Economic and Clinical Health (HITECH) Act, and the Patient-Centered Outcomes Research Institute (PCORI) generates a new wave of scholarship using electronic health data. For example, the number of articles that are retrievable using this search grew tremendously from the time of the original peer-reviewed search in 2011, which applied no time limit restrictions (132 papers met inclusion criteria), to an update one year later (341 papers met inclusion criteria and are currently under review).

Contributions from this review include:

- Building off of resources developed by the National Library of Medicine (NLM) for CER, a reproducible set of search strings for PubMed to identify articles on the challenges and opportunities for using clinical informatics in research and QI;
- A structured methodology for searching the grey literature at grey-literature producing organizations, as well as websites produced by known CER projects and platforms relevant to the EDM Forum; and
- An abstraction form with a coded vocabulary that may be useful for sorting the emerging body of literature, available upon request.

Research Team Site Visits

To assess the challenges facing the research projects and emerging lessons, the EDM Forum conducted two series of exploratory site visits in the spring of 2011 and winter of 2012–2013 to identify common challenges and opportunities shared by the three portfolio teams: PROSPECT (Prospective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapies) Studies; Scalable Distributed Research Networks for CER (DRN); and Enhanced Registries for QI and CER.

The first set of site visits highlighted four primary challenges and emerging opportunities: [i]

1. The substantial effort and resources to establish and sustain data-sharing partnerships
2. The range of clinical informatics tools, platforms, and models (e.g., i2b2) being developed to enable research with electronic clinical data (ECD), and the need to understand the strengths and limitations of each
3. The need for rigorous methods to assess data validity, quality, and context for multisite studies
4. The new opportunities and challenges of achieving meaningful patient and consumer engagement and working collaboratively with multidisciplinary teams.

The second set of site visits generated five major cross-cutting themes:

1. The reflection that while technology is an enabling tool, learning health systems are "networks of people" first and foremost
2. The need to carefully assess how "distributed" networks can be structured so that they retain utility for CER, PCOR, and QI
3. The importance of thinking now about long-term sustainability of CER, PCOR, and QI networks
4. The need to coordinate meaningful stakeholder engagement with other activities and project priorities
5. Thinking about the future of learning health systems, in part to figure out if the networks have achieved the vision of becoming "learning systems."

Stakeholder Needs Assessment

To understand diverse perspectives on the CER landscape, the EDM Forum completed a stakeholder needs assessment,[ii] consisting of 50 interviews.[iii] Part of this project entailed defining the key stakeholder groups in CER using electronic health data (see Figure 2). AcademyHealth ultimately defined the key stakeholder groups as government, business/payer, industry, health care delivery, patient/consumer, nonprofit/policy, and research.

The assessment revealed stakeholders' optimism about the potential for electronic health data–based CER to address the limitations of traditional research studies to generate valuable evidence for patients and clinicians. Other key themes were the significant challenges of developing appropriate governance, data quality, and methodological approaches to conduct CER with electronic health data; and stakeholders' difficulty defining and achieving patient-centeredness. Stakeholders also acknowledged the need to be aware of public concern and resistance to the "CER brand," which many perceived could be mitigated by improving translation and dissemination of CER, as well as the need to work collaboratively in multi-disciplinary partnerships to solve complex problems in this nascent field.

Fostering Engagement and Incubating Collaboration

Research Portal

AcademyHealth used a social networking platform to launch a private extranet for research teams called the EDM Forum Research Portal (www.edmforumresearchportal.org). The purpose of the Research Portal was to provide a secure online space to collaborate within and across the 11 research teams. Although we devoted significant staff time to this effort, the portal was only modestly successful. In retrospect, obtaining input from the research teams at the outset regarding the selection, customization, and desired features of the platform may have led to greater success in terms of frequency of use. On the other hand, the community website www.edm-forum.org has experienced more user activity, which is likely due to the amount of and frequency with which information is posted on the site.

Local Outreach

Along with its connections to the 11 ARRA-CER infrastructure grants, the EDM Forum has fostered relationships with over 100 federal projects and partners, including PCORI, the Food and Drug Administration's Mini-Sentinel program, and Consumers United for Evidence-Based Healthcare.

Virtual and In-Person Meetings

The EDM Forum has engaged the research teams through regular "virtual brown bags" or Web-enabled conference calls that provide an opportunity for the teams to hear more about each other's projects. When appropriate, AcademyHealth has brought in external experts to present related work that may have bearing on the teams' research activities. These virtual events have helped to create a sense of community among the research teams.

The EDM Forum has also convened stakeholders for in-person meetings, including five symposia that address issues relevant to conducting CER, PCOR, and QI using electronic health data. These symposia, which have focused on issues such as analytic methods and patient-reported outcomes, are an opportunity to convey how the work of the EDM Forum–affiliated research teams contributes to building a learning health system that can improve care and outcomes, to focus on generalizable lessons learned with a broad audience of stakeholders, and to facilitate trust and collaboration between participants. As noted by one investigator:

> *The EDM Forum has brought TREMENDOUS value to me and my efforts because of its extensive outreach into related CER communities and individuals that I, on my own, would NEVER have had access to for interactions and collaborations … at every EDM Forum face-to-face meeting that I have attended, I met individuals that I did not know from organizations that I would not normally work with and that these interactions have enriched my thinking and my own professional network for the future.*

In 2013, the EDM Forum held its first Call for Abstracts as a way to broaden participation in the symposia. Sixty-three abstracts were submitted for consideration. Ultimately, 59 presentations (panels and posters) were selected through a peer review process. The Call for Abstracts was very well-received and is the planned model for future symposia. Overall, more than 600 participants have been engaged in these in-person meetings, including the premier experts in the field. All of the symposia have been structured to balance cutting-edge updates with opportunities for discussion.

Commissioned Papers and Collaborative Projects

Commissioning papers among the research projects and broader stakeholders served as another successful mode of engagement. By the third project year, the EDM Forum had commissioned a total of 22 papers on examining current challenges and opportunities for conducting research and QI using electronic health data. The first set of papers was commissioned based on suggestions for key topics and authors identified by EDM Forum Steering Committee members, including data quality, data models, a comparison of informatics platforms, and strategies for de-identification of data across research networks. The second set was selected through an open call for papers and a peer review process to select papers on topics of greatest interest to the community, broadening the range of topics to include patient-reported outcomes, the potential for information loss as a result of sharing data across networks, and approaches to consent.

Early in the process of working with investigators in the EDM Forum, it became apparent there was a need to address a subset of timely topics in a collaborative way. As a result of these discussions, the EDM Forum supported a set of collaborative methods projects involving investigators from at least three of the EDM-affiliated projects. Topics included:

- Strategies for assessing data quality as part of the **Data Quality Collaborative**;
- Piloting a **user-interface for distributed analytics** (logistic regression); and
- Developing a **Governance Toolkit**.

These collaborative projects demonstrated success in bringing together groups around high-leverage topics of mutual interest, and convening investigators from multiple projects was considered a highly successful strategy for each. For each project, the EDM Forum convened at least one workshop per project for up to 25 stakeholders. Virtual communities and resources were also created—two on data quality and governance hosted on the EDM Forum's online **Repository**, and another by Dr. Jiang from University of California, San Diego, which included access to statistical code.

Disseminating New Knowledge

Issue Briefs

The EDM Forum translated and disseminated the knowledge gained through scanning and convening activities through issue briefs that touched on key topics like **stakeholder engagement**, **security and privacy with protected health information**, **analytic methods**, **patient-reported outcomes**, and **informatics**. Notably, all of these briefs provide frameworks or new ways of characterizing the emerging landscape.

Special Supplements

The first set of seven commissioned papers, along with three invited commentaries, were published in a July 2012 special supplement in Medical Care; another 15 commissioned and invited papers were published in an August 2013 special supplement in Medical Care Recently the paper by Sittig et al. on informatics platforms"[iv] was selected for inclusion in the "Best Papers Selection" in the Clinical Research Informatics section of the International Medical Informatics Association Yearbook of Medical Informatics 2013.[v]

Websites and Social Media

The EDM Forum has a strong virtual presence, including websites and social media:

- A private research portal for the research teams;
- A public web presence (www.edm-forum.org) that allows the research teams and the broader community of stakeholders the opportunity to view upcoming Forum activities and other updates;
- A repository for EDM publications (http://repository.academyhealth.org) where all interested participants can provide comments, share resources, and participate in open writing collaboratives;
- A Twitter account (@edm_ah), which, as of March 2014, has more than 358 followers and 694 tweets;
- The EDM Forum Monthly Update e-newsletter with more than 2,000 subscribers;
- Facebook and LinkedIn, which are used to announce and link to events and publications, both through AcademyHealth and staff accounts; and
- Blog postings, which have received more than 5,379 views collectively since February 2013.

Conferences and Public Webinars

To engage new audiences, EDM Forum staff participated in 18 national meetings between 2010 and 2013 to present the Forum's work and disseminate information on the research projects. Examples of these conferences include:

- Association of American Medical Colleges Annual Meeting,
- PCORI's National Workshop to Advance the Use of Electronic Data in Patient-Centered Outcomes Research,
- Improvement Science Research Network Summer Institute on QI,
- American Medical Informatics Association Summit on Clinical Research Informatics, and
- the Clinical Research Forum Information Technology Roundtable.

The Forum also engages the research teams and other experts in the field to disseminate their work through public webinars. A total of 12 webinars have been hosted on a variety of topics; recordings are archived in the Repository.

Appendix Endnotes

i Holve E, Segal C, Hamilton Lopez M. Opportunities and challenges for comparative effectiveness research (CER) with electronic clinical data. Medical Care. 2012 July;50(7):S11-S18.

ii Holve E, Hamilton Lopez M, Scott L, Segal C. A tall order on a tight timeframe: stakeholder perspectives on comparative effectiveness research using electronic clinical data. Journal of Comparative Effectiveness Research. 2012 September;1(5):441-451.

iii AcademyHealth also released the questions used to assess stakeholders' relative priorities for CER using electronic health data. Copies of the *Journal for Comparative Effective Research* publication (including the survey instrument) are available upon request.

iv Sittig DF, Hazlehurst BL, Brown J, et al. A Survey of Informatics Platforms That Enable Distributed Comparative Effectiveness Research Using Multi-institutional Heterogenous Clinical Data. Medical Care 2012 July;50(Suppl 1):49-59. DOI: 10.1097/MLR.0b013e318259c02b.

v McCoy A, Wright, Malin B, et al. State of the Art in Clinical Informatics: Evidence and Examples. IMIA Yearbook of Medical Informatics 2013. 2013:13-19.

vi For a complete list of products generated in Phase I of the EDM Forum, please visit: http://repository.academyhealth.org/edm_briefs/12/.