

Project Title

AcademyHealth Electronic Data Methods (EDM) Forum for Comparative Effectiveness Research

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Structured Abstract

Purpose: The EDM Forum is charged with advancing the national dialogue on the infrastructure and methods of health research and quality improvement using electronic clinical data, with the goal of improving patient care and outcomes.

Scope: The EDM Forum supports investigators conducting the Prospective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapist (PROSPECT) studies, Scalable distributed Research Networks (DRN) for CER, and Enhanced Registries for CER and QI. EDM Forum meetings, products, and other activities also convene interested stakeholders to address challenges and discuss promising approaches to the analytic methods, clinical informatics, and governance needed for health research and QI using ECD.

Methods: The EDM Forum pursued four specific aims to advance learning and exchange among the PROSPECT, DRN, and Enhanced Registry studies and other stakeholders: (1) discussing with key advisors best practices for collecting and analyzing ECD for CER, PCOR, and QI; (2) cultivating stakeholder discussion of new ideas and potential solutions to infrastructure and methods challenges; (3) developing products on specific challenges; and (4) disseminating information on infrastructure and methods developments based on EDM Forum activities, and findings from the research projects.

Results: Collaborating with AHRQ, AcademyHealth rapidly developed the EDM Forum into a marketplace of people and ideas. The EDM Forum's work well exceeds the level initially proposed for the first three years. The EDM Forum produced more than 150 high-quality deliverables, reaching more than 2,000 stakeholders and leaders through meetings and webinars and engaging additional audiences through a portfolio of diverse online resources.

Key Words: comparative effectiveness research, patient-centered outcomes research, quality improvement, collaborative science, methods, governance, clinical informatics, learning health system

I. Purpose

The AcademyHealth Electronic Data Methods (EDM) Forum is charged with advancing the national dialogue on the infrastructure and methods of health research and quality improvement (QI) using electronic clinical data (ECD), with the goal of improving patient care and outcomes. As a cooperative agreement initiated by the Agency for Healthcare Research in Quality (AHRQ) in 2009, the EDM Forum collects, synthesizes, and shares lessons learned from the Prospective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapist (PROSPECT) studies, Scalable distributed Research Networks (DRN) for CER, and Enhanced Registries for CER and QI studies.

The goals of the EDM Forum were to engage and support the PROSPECT, DRN, and Enhanced Registry projects' efforts to develop and use ECD for comparative effectiveness research (CER), patient-centered outcomes research (PCOR), and quality improvement (QI) by providing opportunities for collaborative learning to accelerate the exchange of information and uptake of promising practices among the research projects; brokering connections with stakeholders to engage the community in identifying issues and priorities for the projects and the EDM Forum to address; and ensuring widespread awareness and promotion of the tools, techniques, and findings from the research projects.

To achieve the mentioned goals, AcademyHealth pursued the following aims for Phase I of the EDM Forum:

1. Convening key advisors to discuss best practices for collecting and analyzing ECD for CER, PCOR, and QI;
2. Engaging stakeholders at a series of meetings to cultivate discussion of new ideas and potential solutions that address challenges related to the development of infrastructure and methods for CER, PCOR, and QI;
3. Developing and commissioning products on a range of topics, including scientific, clinical, technical, organizational, and governance challenges; and
4. Disseminating information on current developments in infrastructure and methods based on the EDM Forum, as well as research findings from the research projects.

II. Scope

Background and Context

Throughout the United States, patients, their families, and their healthcare providers are faced with numerous options when making decisions about their health.¹ Limited evidence on the relative effectiveness of treatments can inhibit the ability to make truly informed care decisions. To address this lack of adequate information, the American Recovery and Reinvestment Act (ARRA) of 2009 provided \$1.1 billion for comparative effectiveness research (CER).¹ CER studies compare the benefits and harms of different healthcare treatments and interventions in specific, “real-world” settings.¹

Several key issues have historically impacted the ability to conduct CER (as well as patient centered outcomes research, PCOR, and quality improvement, QI). First, the data infrastructure—including governance, data, methods, and training—is often insufficient to capture detailed person-level data needed for CER because it lacks the ability to capture high-quality longitudinal data across sources of care.² For example, many administrative claims-based databases are optimized for billing, not clinical workflow, and are difficult to harmonize (or bring data together) across multiple settings.² This lack of data harmonization, among other challenges, has contributed to substantial gaps in knowledge. Second, there is a need for robust data and information systems that enable the creation of new methods and rigorous studies in CER.³ These innovations were noted by the Institute of Medicine as one important component of building a “learning health system” in which each encounter with the healthcare system is based on knowledge generated through prior experiences.

To help address these issues, data infrastructure was proposed as a primary area of investment for ARRA funds allocated to the Office of the Secretary in the U.S. Department of Health and Human Services (HHS).¹ In 2010, AHRQ allocated more than \$100 million of the ARRA investment 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.”¹

Simultaneously, the Health Information Technology for Economic and Clinical Health (HITECH) Act, and passage of the Patient Protection and Affordable Care Act provided national imperatives—as well as strong economic incentives—to facilitate collection and sharing of data at an unprecedented scale. In healthcare, the value of this ‘big data,’ which is high volume, produced and turned around quickly, and highly diverse (e.g. billing information, clinical data as free text and images, etc.) is the promise of the leveraging data from electronic health records for new insights, discovery, and care improvement.

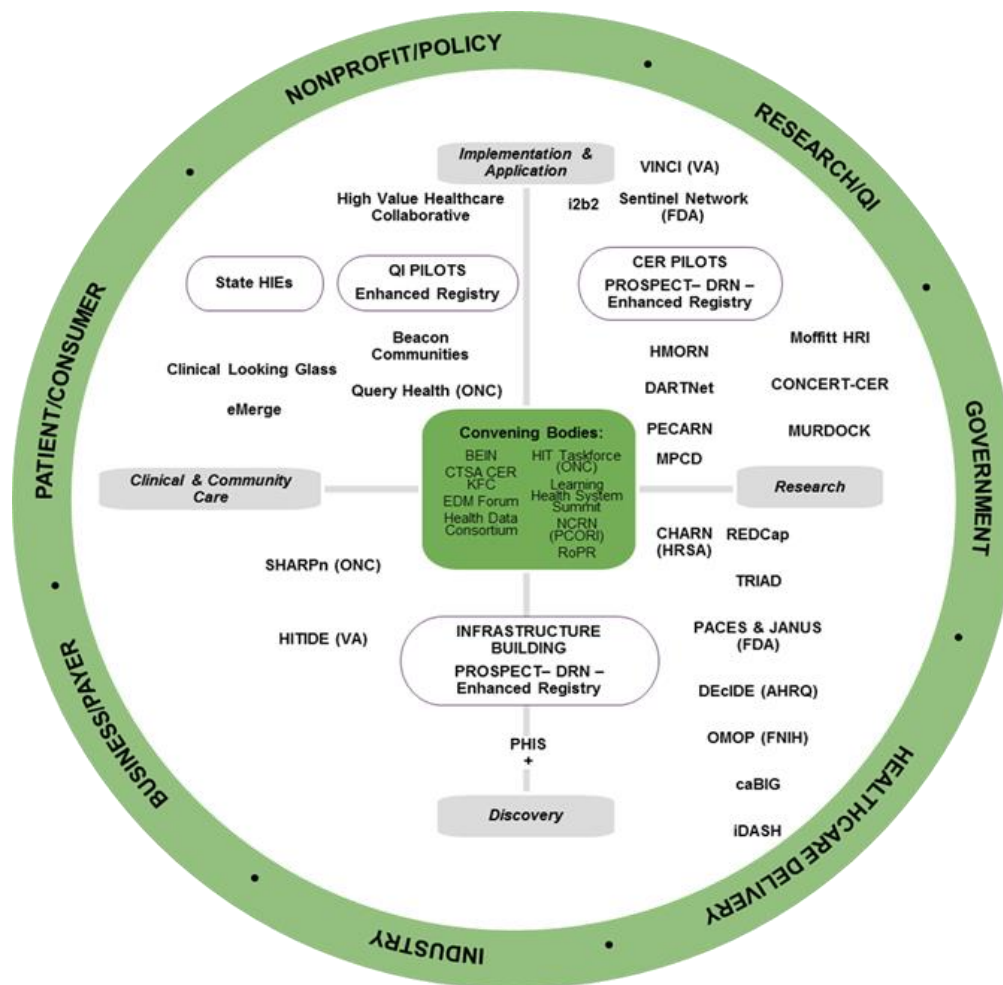
To maximize the lessons learned from this unprecedented investment in new infrastructure for health and healthcare, AHRQ created the EDM Forum to foster dialogue on lessons learned by networks with diverse goals and partners. The EDM Forum facilitates exploration of natural variation in governance, informatics, and methodological approaches using electronic health data for CER, PCOR, and QI and promotes collaboration among groups working on complementary strategies in this space.

Settings

The EDM Forum represents research projects and stakeholder groups that touch a wide range of research and care delivery settings, including primary care or ambulatory clinics, inpatient facilities, emergency departments, specialty clinics, academic medical centers, community health centers, long-term care facilities, and community households.

The eleven ARRA-funded research projects that were engaged in the first phase (September 2010 – August 2013) of the EDM Forum represent a range of partnership models and geographic areas, and vary substantially in size. Some are national networks, while others are regionally focused. Two of the eleven projects are contained within their respective states, Washington and Indiana, and one project focuses locally on a specific community in New York City. In total, 32 states are represented (see Figure 1).

Figure 1. EDM Forum landscape diagram. ^{a,4}



^a Electronic Data Methods (EDM) Forum Landscape Diagram. Web-based tool. *Publication forthcoming.*

Participants

Stakeholder groups that participated in the EDM Forum Phase I include government, business/payer, industry, healthcare delivery, patients and consumers, nonprofit/policy, and research.

The EDM Forum represents eleven research projects that cover an estimated total population of more than 21 million patients. Many of these projects belong to larger networks, such as the HMO Research Network (HMORN), Indiana Network for Patient Care (INPC), or the DARTNet Institute, which collectively reach more than 51 million patients.

The eleven research projects are undertaking a set of specific research studies to demonstrate the feasibility of using ECD for CER and PCOR. The studies address all of AHRQ’s priority populations and conditions (see Figure 2), with several projects focused on low-income populations, racial and ethnic minorities, and disease areas such as hypertension and asthma.

Figure 2. AHRQ priority populations and conditions addressed by the CER studies conducted by the PROSPECT, DRN, and Enhanced Registry projects. ^{b, 7}

Categories	Projects:	CER Hub	COMET	Indiana PROSPECT	PEAL	SUPREME-DM	WICER	Cincinnati Enhanced Registry	SCOAP CERTN	SCANNER	SAFTNet	SPAN
AHRQ Priority Populations												
Low-income groups		♣		♣		♣	⌘	♣	⌘	⌘	♣	
Minority groups		♣	♣	♣		♣	⌘	♣	♣	♣	♣	♣
Women			♣	♣		♣		♣	♣	♣	♣	♣
Children						♣		⌘	♣		⌘	⌘
The elderly			♣	⌘		♣	♣		♣	♣	♣	
Individuals with disabilities			♣				♣			♣		
Individuals who need chronic care		♣		♣	♣	♣	♣	⌘	♣	♣	♣	♣
Individuals who need end-of-life care				♣								
Individuals who live in inner-city areas			♣			♣	⌘		♣	♣	♣	♣
Individuals who live in rural areas						♣		♣	♣	♣	♣	♣
AHRQ Priority Conditions												
Arthritis and nontraumatic joint disorders (Muscle, bone, and joint conditions)												
Cancer (Cancer)						♣		♣				
Cardiovascular disease, including stroke and hypertension (Heart and blood vessel conditions)			♣			♣	⌘	⌘	⌘	⌘		
Dementia, including Alzheimer's Disease (Brain and nerve conditions)				⌘								
Depression and other mental health disorders (Mental health)			♣				♣					♣
Developmental delays, attention-deficit hyperactivity disorder, and autism (Developmental delays, ADHD, autism)												⌘
Diabetes mellitus (Diabetes)			♣			⌘	♣		♣	⌘		
Functional limitations and disability (Functional limitations and physical disabilities)			♣				♣		♣			
Infectious diseases, including HIV/AIDS (Infectious diseases and HIV/AIDS)												
Obesity (Obesity)			♣			♣	♣		♣			⌘
Peptic ulcer disease and dyspepsia (Digestive system conditions)								⌘				
Pregnancy, including preterm birth (Pregnancy and childbirth)						♣	♣					
Pulmonary disease/asthma (Breathing conditions)		⌘	⌘		⌘		♣			⌘	⌘	
Substance abuse (Alcohol and drug abuse)		⌘	♣				♣					

⌘ indicates a primary topic of focus for the project; ♣ indicates a secondary topic addressed by the project

^b Forum, EDM. Building the Electronic Clinical Data Infrastructure to Improve Patient Outcomes: CER Project Profiles. EDM Forum Issue Briefs and Reports. http://repository.academyhealth.org/edm_briefs/7/. Accessed November 21, 2013

III. Methods

As a cooperative agreement, AcademyHealth worked closely with AHRQ to develop well-designed strategies and resources to fulfill the stated aims of the EDM Forum. The following sections will detail the methods employed to meet the aims of the project, including study design, interventions, measures, and limitations for each aim as applicable.

All methods and strategies were applied according to EDM Forum thematic domains of analytic methods, clinical informatics, governance, and the learning health system (as defined by AHRQ) in addition to seven stakeholder groups (government, business/payer, industry, healthcare delivery, patients and consumers, nonprofit/policy, and research). Stakeholder groups were identified based on a thorough

review and synthesis of stakeholder groups developed for previous AcademyHealth projects,⁵ and 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. In addition to drawing on contacts and connections from AcademyHealth's extensive network, the stakeholder groups were defined in a series of environmental scanning activities including literature reviews, site visits, and key informant interviews.

1. Convene key advisors to discuss best practices for collecting and analyzing ECD for CER, PCOR, and QI.

In the first year of the grant, EDM Forum staff worked closely with AHRQ to identify groups of advisors that would provide guidance and oversight on various aspects of EDM Forum topics and activities. Staff relied on an advising group consisting of the AHRQ project officer and project consultants who were experts in the areas of methods, clinical decision-making, biomedical informatics, and clinical informatics. The consultants were convened through weekly calls—which included the project officer on an as-needed basis—to inform agendas for the project year and day-to-day activities of the Forum.

The project officer and consultants also informed the creation of a Steering Committee, an advisory group responsible for outlining an agenda and scope of work for EDM Forum staff to conduct or commission, as well as providing feedback on analytic products and dissemination strategies. To ensure adequate representation by key stakeholder groups, the composition of the committee included the 11 principal investigators from the research programs. In addition, five experts representing perspectives on patient and consumer issues, clinical perspectives, legal and ethics issues, and healthcare delivery were included. Steering Committee Meetings were held semi-annually in person and by web-enabled conference call.

Four subcommittees were established to extend the work of the Steering Committee, focusing on key subtopics within each of the Forum's thematic domains. These groups discussed key challenges and questions relevant to each of the projects and CER stakeholders. The charge of each subcommittee was to: 1) provide input on priority topics for EDM Forum products; 2) identify potential authors or speakers; 3) review proposals from potential authors; and 4) review draft materials on an as-needed basis. Conference calls were held as needed.

2. Engage stakeholders at a series of meetings to cultivate discussion of new ideas and potential solutions that address challenges related to the development of infrastructure and methods for CER, PCOR, and QI based on ECD.

The EDM Forum engaged stakeholders with experience and interest in the infrastructure and methods challenges of using ECD to conduct CER, PCOR, and QI. These efforts included a series of calls with research team members, symposia and workshops, and ongoing meetings with other diverse stakeholder groups to find opportunities for engagement in the EDM Forum.

The following resources and convening activities were developed to further engage stakeholders and include them in discussions on topics of relevance:

- **Research Team Virtual Brown Bags.** AcademyHealth staff held monthly web-enabled calls, using Adobe software, with the researchers from the PROSPECT, DRN, and Enhanced Registry teams to facilitate discussion of useful resources, methods, and emerging research findings. These web-based calls were also an opportunity to provide project status updates for EDM Forum activities. When appropriate (or when requested by the AHRQ project officer or research teams), staff invited guest experts to present on a topic of relevance (e.g. sustainability).
- **Symposia and Workshops.** AcademyHealth organized larger in-person invitational meetings and symposia to involve additional stakeholder groups in the Forum and interact with the research teams. When needed and approved by AHRQ, AcademyHealth organized smaller workshops that were more focused on a topic of interest to researchers in the Forum. AHRQ compiled and

informed invite lists. In the second and third project years, staff leveraged the symposium to hold a call for abstracts in an effort to engage more stakeholder groups.

- **Stakeholder Outreach Meetings.** In each project year, AcademyHealth staff held in-person meetings and conference calls to discuss opportunities for collaboration with representatives from research and QI organizations, university-based health services research (HSR) departments and programs, journals, business/payer organizations, government agencies, healthcare delivery systems, industry, non-profit/policy organizations, and patient and consumer groups. Over the course of the grant, a series of more than 100 outreach meetings were conducted with groups including state learning networks (e.g. the Medicaid Medical Directors Learning Network), federal partners (e.g. various departments within AHRQ, the Centers for Medicare and Medicaid Services, the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services, and the Department of Veterans Affairs), professional associations (e.g. Association of American Medical Colleges (AAMC) and the College of Healthcare Information Management Executives), consumer and patient organizations (e.g. Consumers United for Evidence-based Healthcare), representatives from industry (e.g. the National Pharmaceutical Council, Pacific Business Group on Health, and Target Inc.), national funding agencies (e.g. Patient-Centered Outcomes Research Institute, and the Robert Wood Johnson Foundation), and other potential research partners (e.g. American Institutes for Research, the Center for Medical Technology Policy, the Lewin Group, Committees within the Clinical Translation Science Award program, Duke University Medical Center, and the High Value Healthcare Collaborative).

3. Develop and commission products (needs assessments, issue briefs, papers, reports, and other analytic products) on topics including scientific, clinical, technical, organizational, and governance challenges.

EDM Forum staff developed assessments based on the research team needs and stakeholder needs, reviews of the peer-reviewed and grey literature, and issue briefs on topics relevant to the Forum's thematic domains. Of these, the research team needs assessment and stakeholder needs assessment were research activities involving human subjects (interviews) and, as such, received IRB exemption from Western IRB. The Forum was also actively involved in soliciting and reviewing commissioned work that directly responded to the wide array of issues and challenges identified by the Steering Committee and stakeholder groups.

The following sections detail the process used to collect, analyze, and synthesize the knowledge that contributed to developing the EDM Forum issue briefs, reports, and publications:

- **Research Team Needs Assessment.** In Year One, AcademyHealth conducted a needs assessment to understand issues and challenges research teams faced, and to identify activities/topics the EDM Forum should explore in greater depth. Findings were based on six exploratory site visits conducted under naturalistic inquiry in the spring of 2011. Themes, challenges, and innovations were identified in the visit summaries through coding, keyword searches, and review for complex concepts. This environmental scan helped characterize the impact of changes in infrastructure and methodology for CER using ECD.
- **Stakeholder Needs Assessment.** AcademyHealth staff conducted 50 stakeholder interviews with a diverse set of individuals representing the seven stakeholder groups or perspectives. Notes and transcripts were analyzed using NVivo software. Individuals for interviews were identified by building an initial set of experts based on their work in the published literature, conference proceedings and personal knowledge of relevant project leads. A snowball sampling strategy was employed to achieve relative balance among stakeholder groups. Because they were exploratory in nature and the interviewees represented diverse perspectives, the interviews followed a semi-structured format. In addition, participants were asked a set of eight short survey questions

designed to better understand stakeholder perspectives on the relative value of specific attributes of CER studies.

- **Literature Review.** The first review of the peer-reviewed literature examined publications at the intersection of CER and clinical informatics. A 3-step systematic literature search was conducted, including a structured search of PubMed, manual reviews of articles from selected publication lists, and manual reviews of research activities based on prospective ECD. Details on the search strategy employed for the project are available through the EDM Forum website.⁶ In total, 2,435 citations were identified as potentially relevant. Ultimately, a full-text review was performed for 147 peer-reviewed papers. Of those, 132 were selected for final analysis.

At the suggestion of the EDM Forum Steering Committee leadership, a follow-on review of the grey literature was conducted to evaluate the state of the grey literature at the intersection of clinical informatics and CER. This process combined a structured search of specific keywords with related medical subject headings (MeSH) concepts within websites and Google, as well as a manual review of websites and resources for known CER projects and platforms. The list of keywords from the peer-reviewed search was used to characterize areas of focus for the grey literature review. After the records were retrieved, each document and web page was reviewed and coded with a primary keyword to assess the extent to which specific topics are currently addressed in the grey literature. Detailed information on the replicable search strategies employed for the grey literature review are available in the grey literature issue brief.⁶

- **Issue Briefs.** AcademyHealth staff and project consultants collaborated on a series of issue briefs that summarized or explored key topics of interest to stakeholders. All of the issue briefs draw on exchanges with the PROSPECT, DRN, and Enhanced Registry projects through the site visits and convening activities. The briefs provide a review of research and policy concepts, and highlight micro-case examples from the PROSPECT, DRN, Enhanced Registry projects and other key initiatives, often presenting organizing frameworks for important and diverse topics such as [stakeholder engagement](#); [security and privacy with protected health information](#); [analytic methods](#); [patient-reported outcomes](#); a review of ECD infrastructure investments in CER; and [informatics platforms and tools](#).^{6,7,8,9,10,11,12,13,14,15,16,17}
- **Commissioned Work.** AcademyHealth consulted the Steering Committee to determine which topics under the EDM Forum's four thematic domains to address through commissioned papers. In Year One, a call for commissioned work was conducted among the 11 research projects in the Forum. In Year Two, AcademyHealth released an open call for papers at AcademyHealth's Annual Research Meeting (ARM) to identify the second set of commissioned papers. In response, AcademyHealth received 42 submissions, of which 15 were selected for support.

Early in the process of working with the investigators in the EDM Forum, it became apparent that there was a need to extend collaborative efforts beyond commissioned papers. As a result of these discussions, the EDM Forum supported a set of three collaborative methods projects involving investigators from the EDM-affiliated projects. Building on the success and publication of the commissioned papers in years one and two, in Year Three, with AHRQ's permission, AcademyHealth commissioned five collaborative projects to address a subset of issues. The subcommittees reviewed all abstracts received through the call for papers process for the symposium and also reviewed submissions for collaborative papers and projects.

4. Disseminate information on current developments in infrastructure and methods based on the EDM Forum, as well as research findings from the research projects.

AcademyHealth employed a multi-pronged approach, leveraging a number of dissemination vehicles, to disseminate EDM Forum products and resources to a broad and diverse group of stakeholders.

Specifically, AcademyHealth disseminated work of the EDM Forum and its stakeholders through public webinars, presentations at national meetings and conferences, and several online tools.

Two websites were built to promote bi-directional information exchange using Higher Logic, a social networking platform. A private research portal was developed for the 11 research teams and a public community portal was created to facilitate broader access and discussion. The private research portal stores recordings of the virtual brown bags, discussion forums on relevant topics, and private announcements for the research teams. AcademyHealth worked closely with a list of 120 project staff, provided by the research teams, who were permissioned to access the community. The public community portal is intended to jumpstart dialogue on key topics with stakeholders in CER, PCOR, and QI. Special features include announcements, publications, upcoming and archived events, a wikiGlossary, a list of commonly used acronyms, a list of electronic health initiatives for research, and a blog.

In response to stakeholder needs, the following additional resources were designed in response to stakeholder needs to support and enhance AcademyHealth's dissemination strategy and encourage collaboration among stakeholder groups:

- **Repository.** The EDM Forum established an open access, online Repository to electronically organize and disseminate the numerous papers, visualizations, and other media that have been developed through the Forum.
- **eGEMs (*Generating Evidence and Methods to improve patient outcomes*).** Stakeholders and researchers in the EDM Forum identified the need for an online, peer-reviewed, open access publication mechanism for disseminating the 'journey' of research, or the strategies, tools, and innovations that are developed over the course of conducting research. AcademyHealth formed a working group to identify a process and timeline for creating the online journal, which was ultimately named *eGEMs*.
- **EDM Monthly Update.** This newsletter was originally created to keep the eleven research projects abreast of EDM Forum announcements, funding opportunities, and other relevant activities. Over the course of the project, the reach and scope of the newsletter expanded to include members of the other seven stakeholder groups. AcademyHealth uses a service called MagnetMail to disseminate the newsletter on a monthly basis.
- **Social Media.** The EDM Forum Twitter account was created to inform stakeholders and the broader public about EDM Forum activities, news items, and publications related to key topics.

IV. Results

Over the past three years, the EDM Forum has facilitated opportunities to share strategies and provided appropriate incentives for sharing innovations among researchers and other stakeholders who are working to build electronic infrastructure to conduct research and QI using electronic health data. The EDM Forum has brought new perspectives to the table from stakeholders not directly involved in the ARRA CER research activities, both to understand key needs of the research, and to identify areas for future collaboration. The resulting trust among these groups is a defining feature of the effort, and is due to investigators' willingness to share experiences and engage in collaborative solutions to shared challenges. The result has been the development of new solutions to further advance methods development and increase knowledge about methods, informatics, and governance strategies to support learning health systems.

Principal Findings and Outcomes

Collaborating with AHRQ, AcademyHealth rapidly developed the EDM Forum into a marketplace of people and ideas. The EDM Forum's work well exceeds the level initially proposed for the first three years. The EDM Forum produced more than 150 high-quality deliverables, reaching more than 2,000

stakeholders and thought leaders through meetings and webinars and engaging additional audiences through a web portal, open access online journal, speeches, presentations, and social media.

The following sections highlight the principal findings and outcomes for each of the EDM Forum activities, organized by aim. All resources referenced in the following sections are listed in Section V. List of Publications and Products.

1. Convene key advisors to discuss best practices for collecting and analyzing ECD for CER, PCOR, and QI.

AcademyHealth held calls and meetings as needed with the AHRQ project officer and on a weekly basis with project consultants.

By project year three, the EDM Forum had secured 19 Steering Committee members, including representation from AcademyHealth and AHRQ. A total of six in-person Steering Committee meetings and five subcommittee calls were held during the project. In-person meetings were held in Washington, DC, at the AHRQ Conference Center in Rockville, MD, and adjunct to AcademyHealth's Annual Research Meeting in Seattle, WA.

2. Engage stakeholders at a series of meetings to cultivate discussion of new ideas and potential solutions that address challenges related to the development of infrastructure and methods for CER, PCOR, and QI based on ECD.

As mentioned, the scope of engagement with research teams increased from five PROSPECT grantees to 11 grantees, including the DRN and Enhanced Registry studies. The participation of the principal investigator from each of the project in the Forum's Steering Committee played a key role in creating more buy-in of the EDM Forum, its role, and value for the projects. The same is true of external representatives included from each of the broader stakeholder groups. Furthermore, their connections to other research networks (e.g. the HMO Research Network) increased the awareness of the EDM Forum and the work it was doing to share information among the projects.

With regards to outreach, staff held a total of 112 stakeholder outreach meetings by the end of the project period. Because the number of stakeholder meetings influenced the awareness of the Forum, AcademyHealth made a focused effort to conduct as much outreach as possible, informed by suggestions from AHRQ and the EDM Forum's advisory groups. Outreach meetings were structured to be interactive, encouraging bi-directional exchange of information with stakeholder groups. Ultimately, the AcademyHealth team determined that actively listening to stakeholders and providing them with specific opportunities for EDM Forum participation that was relevant to their work was key to forming successful partnerships and buy-in. The team learned early in its outreach about the need of for a tangible opportunity or asset to offer stakeholders. This insight led to the development of multiple professional opportunities (e.g. call for abstracts) and resources designed to stimulate dialogue (e.g. symposia and workshops) and accelerate dissemination of knowledge (e.g. *eGEMs* journal).

- **Research Team Virtual Brown Bags.** A total of 20 web-enabled calls were held with the research teams. The virtual brown bags explored topics including approaches to building infrastructure, sustainability, informatics tools and platforms, governance, dissemination, and CER research findings. An average of 34 unique participants attended these sessions. Three of the sessions featured outside speakers.

3. Symposia and Workshops. AcademyHealth initially proposed to hold six symposia (two per year). To adequately address issues raised by Steering Committee members, the research teams, and stakeholder groups, in project year three (with approval from AHRQ), AcademyHealth held one symposium and substituted the second workshop for four smaller workshops. In total, the EDM Forum held five symposia and 5 workshops. The fifth workshop was held to carry out a session on sustainability, a topic raised at the 2013 Steering Committee meeting. Forum meetings engaged

a total of 231 unique meeting participants. **Develop and commission products (needs assessments, issue briefs, papers, reports, and other analytic products) on topics including scientific, clinical, technical, organizational, and governance challenges.**

The EDM Forum developed a total of 17 issue briefs, reports, and published manuscripts that synthesize efforts to understand the landscape of electronic health initiatives for research and QI.

Findings from these efforts are detailed below:

- **Research Team Needs Assessment.** The first set of site visits were analyzed and synthesized into a manuscript based on the visits, and also contributed to a paper on issues and challenges when using ECD for research and QI.^{18,19} The first of these highlights four primary challenges and emerging opportunities faced by the PROSPECT, DRN, and Enhanced Registries projects, including: 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 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 multi-site studies; and 4) the new opportunities and challenges of achieving meaningful patient and consumer engagement and working collaboratively with multi-disciplinary 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; and 5) the importance of assessing how far networks have come to achieve the vision of becoming “learning health systems,” and what the next steps may be to achieve this goal. Preliminary findings from the second analysis were presented at the 2013 AcademyHealth Annual Research Meeting,²⁰ and a manuscript is pending submission.

- **Stakeholder Needs Assessment.** The stakeholder needs assessment (SNA) was developed into a manuscript entitled “A Tall Order on a Tight Timeframe: Stakeholder Perspectives on CER Using Electronic Clinical Data” and was published in the *Journal of Comparative Effectiveness Research* in September 2012.²¹ The needs assessment was also presented as a poster at the 2012 AcademyHealth Annual Research Meeting (ARM) in Orlando on June 25, 2012.²²

The joint analysis of the SNA interview and survey data revealed five core themes:

1. Stakeholders have substantial expectations for CER using ECD, both with respect to addressing the limitations of traditional research studies and generating meaningful evidence for decision-making and improving patient outcomes;
2. Stakeholders are aware of many challenges related to implementing CER with ECD, including the need to develop appropriate governance, assess and manage data quality, and develop methods to address confounding in observational data;
3. Stakeholders continue to struggle to define ‘patient-centeredness’ in CER using ECD, adding complexity to attaining this goal;
4. Stakeholders express that improving translation and dissemination of CER, and how research can be ‘useful’ at the point of care, can help mitigate negative perceptions of the CER ‘brand’; and
5. Stakeholders perceive a need for a substantial ‘culture shift’ to facilitate collaborative science and new ways of conducting biomedical and outcomes research.

- **Literature Review.** The literature review was developed into a manuscript entitled “Building the informatics infrastructure for comparative effectiveness research (CER): a review of the literature,” and published in *Medical Care* in July 2012.²⁰ A complete annotated bibliography is available on the EDM Forum website.²³

As mentioned earlier, a full-text review was performed for 147 peer-reviewed papers. Of those, 132 articles were selected for final analysis, of which 88 articles were selected to characterize three types of articles: (1) articles providing historical context or frameworks for using clinical informatics for research; (2) articles describing platforms and projects, and (3) articles discussing issues, challenges, and applications of natural language processing. In addition, two cross-cutting themes emerged: the challenges of conducting research in the absence of standardized ontologies and data collection; and unique data governance concerns related to the transfer, storage, de-identification, and access to ECD. Finally, the authors identified several current gaps on important topics such as the use of clinical informatics for cohort identification; cloud computing; and single point access to research data.

The EDM Forum Steering Committee initially hypothesized that the material accessible in the peer-reviewed and grey literature might be complementary, and that some of the topics not currently covered in the peer-reviewed literature might be available in the grey literature. In fact, there was close alignment between the topics that emerged in the grey versus peer-reviewed literature. The majority of peer-reviewed *and* grey literature documents and web pages focused on “research networks” and “standardized data collection.” Both shared three similar gaps in coverage – no literature in either search was identified as focusing on “single point access” to research data, “cloud computing”, or “cohort identification.” However, the term “Natural Language Processing” was less prevalent in the grey literature compared to the peer-reviewed literature, while a focus on concepts related to “Security” or “the learning health system” were more common in the grey literature compared to the peer-reviewed literature.

- **Issue Briefs.** The EDM Forum developed 12 issue briefs to emphasize variation in approaches to common challenges and explore topics that frequently emerge in the conduct of CER and PCOR using ECD. Among the issue briefs, which highlight micro-case examples from the PROSPECT, DRN, Enhanced Registry projects, and other key initiatives, topics include [stakeholder engagement](#); [security and privacy with protected health information](#); [analytic methods](#); [patient-reported outcomes](#); a review of ECD infrastructure investments in CER; and [informatics platforms and tools](#). Notably, all of these briefs provide frameworks or new ways of characterizing the emerging landscape:
 - The stakeholder engagement briefs represent one of the first efforts to identify concrete opportunities for researchers to meaningfully engage patients and consumers in critical phases of research development and execution. Developed in partnership with consumer and patient representatives and AcademyHealth’s Methods Council, the issue brief and eBook present stages of the research lifecycle at which engagement is viewed to have the most impact to ensure CER, PCOR, and QI are patient-centered.^{12,13}
 - The analytic methods brief provides an overview of current methods of designing next-generation studies in QI and research, such as CER and PCOR.⁹ The brief explicitly addresses the potential for experimental as well as observational studies, and analytic methods indicated by specific designs to answer questions of interest to key decision-makers.
 - The informatics issue brief considers the types of tools required to ‘reverse engineer’ learning health systems.¹⁰ The brief proposes four key sets of activities facilitated by informatics – person-level data collection; data access, exchange, and aggregation; population level analytics; and provider, researcher or patient-facing decision support –

and highlights the development of 31 tools or approaches developed by the PROSPECT, DRN, and Enhanced Registry projects to build next generation learning health systems.

In addition, the Forum commissioned 27 papers and projects that examine current challenges and opportunities for conducting CER, PCOR, and QI using ECD. Specific areas of focus have included aspects of the data governance, clinical informatics, and analytic issues that are crucial to the design and use of ECD for research and QI. The following sections elaborate on the issues raised through the commissioned work:

- **Commissioned Papers.** The EDM Forum commissioned a total of 22 papers in order to examine current challenges and opportunities for conducting research and QI using electronic health data. The first set of seven commissioned papers, along with three invited commentaries, was 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*. The two supplements represent 41 investigators and 23 organizations/institutions, and 55 investigators and 39 organizations respectively that have contributed a wealth of knowledge and expertise generated through the EDM Forum.

Collectively, the papers in the first *Medical Care* supplement have been cited more than 75 times. The Sittig et.al paper from the first supplement, “A survey of informatics platforms that enable distributed comparative effectiveness research using multi-institutional heterogeneous clinical data,” was recently selected for inclusion in the “Best Papers in Clinical Research Informatics” in the 2013 *International Medical Informatics Association Yearbook*.²⁴ Papers from the second supplement, published in July 2013, have been viewed more than 10,000 times.

- **Commissioned Projects.** The EDM Forum commissioned five projects. The first three projects addressed strategies for assessing data quality as part of the Data Quality Collaborative (led by Dr. Michael Kahn, University of Colorado); piloting a user-interface for distributed analytics (logistic regression) (led by Dr. Xiaoqian Jiang, University of California, San Diego); and developing a Governance Toolkit (led by Deven McGraw, the Center for Democracy and Technology). An additional two commissioned projects focused on advancing human-computer interaction research to enable a learning healthcare system (Dr. Philip Payne, the Ohio State University); and generalizable lessons learned for future research and QI networks based on the evidence generation and knowledge management experiences of the HMO Research Network (Dr. John Steiner, Kaiser Permanente Colorado Institute for Health Research).

In October 2013, the DQC investigators received a 3-year methods award from the Patient-Centered Outcomes Research Institute to continue and expand their work. Importantly, the PCORI data quality project includes 3-year support (through 2016) for the EDM Forum to continue convening this group. The DQC investigators were also invited to lead an Institute of Medicine workshop on data harmonization to guide processes for the Patient Centered Outcomes Research Institute (PCORI) National Clinical Research Network (NCRN). The extension of DQC project illustrates the value and impact of the EDM Forum in terms of incubating collaboration, and is a promising indication of the EDM Forum’s future sustainability.

4. Disseminate information on current developments in infrastructure and methods based on the EDM Forum, as well as research findings from the research projects.

Over 150 products have been disseminated by the EDM Forum through a variety of channels. The following sections highlight the metrics that demonstrate the overall impact and reach of the EDM Forum:

- **Public Webinars.** The EDM Forum conducted a total of 12 public webinars during the reporting period, touching on topics including patient and consumer engagement; mixed methods in delivery system settings; governance, methods, and clinical informatics topics; open access

publication; user experience research; data quality; and sharing data, code, and tools to accelerate the science of healthcare. Faculty included 38 presenters from 33 organizations.

- **Presentations at National Meetings and Conferences.** AcademyHealth staff gave 28 presentations on EDM Forum activities and presented findings at 19 national meetings and conferences over the course of the project. Notable examples of invited presentations include presentation of the landscape of infrastructure efforts for research and QI at the PCORI Data Infrastructure Workshop;²⁵ a panel presentation at the AAMC;²⁶ and an overview of the intersection between improvement science, health services research, and the EDM Forum at the research methods-focused 2013 Improvement Science Research Network Summit.²⁷
- **Websites.** Both the research portal and community portal were launched in April 2011.^{28,29} Approximately 100 investigators were permissioned to use the research portal, though it was ultimately determined that traffic and participation in a public website was more effective and efficient. As a result, AcademyHealth developed additional public resources (the Repository and *eGEMs*) to respond to the needs of the research community.

The Community Portal had received 69,558 page views and 18,738 visits by the end of the project period.

- **Repository.** The Repository houses 13 collections of papers, visualizations, and other media that provide guidance on the conduct of research and QI.³⁰ Products hosted on the Repository have been downloaded more than 20,000 times. Four communities within the Repository were created to facilitate more collaboration among stakeholders:
 - **Project Snapshots.** Community-curated resources submitted and maintained by project or network staff. All research or QI projects using electronic health data are invited. A total of 26 snapshots were submitted and published as of the end of the project period. Fifteen snapshots are included in the eHealth Data Initiatives for research and QI collection. The EDM Forum Affiliated Project Snapshots collection highlights the 11 ARRA-funded CER studies that are a part of the EDM Forum network.
 - **Data Quality Collaborative Writing Community.** A community to solicit feedback on the working draft white paper developed by investigators of the DQC collaborative methods project.³¹ The community has received 399 downloads of the draft documents collectively, generating comments on the web site as well as comments and questions sent directly to the project leads.
 - **EDM In Progress.** A collection of EDM Forum issue briefs and reports that are in draft form to obtain feedback from the community. One document has been posted and has been downloaded 453 times.
 - **Governance Toolkit.** A curated collection of tools, sample guidance documents, and practical approaches to common governance challenges. The toolkit includes five published resources and eight resources are pending review.³²
- ***eGEMs (Generating Evidence and Methods to improve patient outcomes).*** Forty-six submissions were received by the end of the project period (within the first nine months after the journal was launched). Of those, a total of 22 have been published (12 by the end of the project period), 11 are under review, five were withdrawn, and eight have been rejected. Two calls for special issues were released during the reporting period. One of the special issues, *Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems* with guest editor Dr. Wade Aubry, was released on October 28. Another special issue on *Methods for CER, PCOR, and QI Using EHR Data in a Learning Health System* will be released in December 2013.

- **EDM Monthly Update.** As of August 31, the EDM Monthly Update had accumulated nearly 2,000 subscribers.
- **Social Media.** As of August 31, the EDM Forum had sent out a total of 564 tweets and had 277 followers.

Discussion and Conclusion

Since its inception, the EDM Forum has focused on building a community to help make health research and QI resources more discoverable and comparable. 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. As a result, the EDM Forum’s approach and products have changed both the vocabulary and dialogue in this nascent field, enabling a broader set of stakeholders to contribute and advance science in this area. The EDM Forum’s publications, presentations, and other resources further demonstrate that there is important natural variation CER, PCOR, and QI, and that “one size”—or approach—to health data infrastructure does not fit all partners or networks.

Over the past three years, the EDM Forum team and collaborators have learned several important lessons that have implications for the EDM Forum’s strategies moving forward. As discussed below, these focus on the importance of creating open resources that provide value to community members, the deep value of convening and relationship building, and the importance of collaborative methods projects to advance science by demonstrating where individual approaches can scale.

1) The EDM Forum must create open, accessible resources that have clear benefits to participants

In the early stages of the EDM Forum’s development, there was active discussion about the need to create value for participants that responds to the current structures for rewarding and recognizing scientific contributions. While collaboration and team science are laudable goals in their own right, competing demands for experts’ time and resources is an equally compelling rationale to limit collaborative efforts. And while the EDM Forum’s early products and convening activities generated discussion and value for those who were already engaged, it was clear that providing more opportunities for public recognition of promising practices would be a helpful resource *by and for* the community.

The result of these discussions with AHRQ and the EDM Forum Steering Committee was the decision to create an open access, peer-reviewed publication, *eGEMs*, and the EDM Forum Repository. Peer-reviewed publication offers a tangible benefit to researchers and many other stakeholders as well. This is particularly important since *eGEMs* publishes non-traditional articles that enable the members of these diverse, multi-disciplinary networks to explain why they have implemented certain practices in the networks, and how they have succeeded—or revised initial plans—in improving efficiency and outcomes. Providing an opportunity to peer-review presentations and posters for the EDM Forum annual symposium is an analogous effort to create more opportunities for public recognition of important work.

Finally, consistent with more recent experience in other private social networks, password-protected research networks can face substantial challenges generating active participation. Though a closed platform may appear to confer advantages of exclusive membership, the practical constraints of password recall and competing communication and content management systems that are already established in individual networks is a substantial barrier for busy professionals. Open communication and platforms extend the ability for broader dissemination, and promote sharing despite rigorous outreach to understand the collaboration needs of the research teams and to increase engagement.

2) *Convening that is inclusive of diverse stakeholder perspectives facilitates trust and collaboration.*

Virtual convening activities are valuable and can successfully exchange information on progress to date, however, as a new field of inquiry develops, in-person convening is crucial to foster early relationships. These efforts must enable meaningful opportunities for introductions among individuals with diverse backgrounds in a way that contextualizes relevant points of common interest. Particularly as patient and consumer groups are integrated into discussion of research and QI, it is important to provide an appropriate introduction to the complementary contributions of researchers and patients, among other diverse stakeholders.

The structure of convening activities must be thoughtful to maximize the value of convening relevant experts. In the EDM Forum's experience, all convening activities and workshops should provide an opportunity to actively discuss and debate emerging—sometimes competing—approaches, with an emphasis on complementary or joint areas of exploration for the future. At many EDM Forum events, a subset of investigators would meet separately to discuss potential future proposals, or explore in-kind opportunities to work together. In many cases, relationships developed over the course of the program, as stakeholders had repeated interactions and became more familiar with one another's work. Once these relationships had been established, virtual communication and information exchange was extremely efficient, requiring less frequent interaction among collaborators. However, this foundation of trust benefited greatly from early convening.

3) *Collaborative methods projects are an important strategy to advance science because and where innovation has the potential to scale.*

In the last five years, the opportunities to use electronic clinical data for research and QI have expanded dramatically. Both HITECH funding and support from AHRQ as a result of ARRA provided large-scale implementation efforts to build learning health systems. In the earliest part of the EDM Forum's work there was a clear need to generate papers and develop a common language and understanding of the landscape of efforts. However, the community has evolved rapidly to the point that EDM Forum contributors have started to generate concrete ideas and opportunities to work together on their own.

The concept of collaborative methods projects co-evolved with these discussions. As a result, it became apparent that by providing support for specific activities and pilot programs, it would be possible to share resources and ideas more dynamically than is possible with a single manuscript. In the future, the collaborative methods project model provides a promising mechanism to incubate collaborative efforts, particularly to conduct light tests of scalability (e.g. GLORE) and community standards for emerging methods (e.g. the DQC).

Over the last three years, the EDM Forum has demonstrated expertise in engaging multiple and diverse stakeholders. The EDM Forum has conceived, organized, and executed high-quality scientific and technical meetings; created high-quality research and resources to support the community; and disseminated useful and usable resources (both paper-based and electronic) to accelerate discovery and use of research findings in practice. Each of these efforts alone would not have been sufficient to bring the community together, but collectively, the set of support and resources envisioned by AHRQ and executed by AcademyHealth has facilitated a fabric of trust and subsequent level of productivity that demonstrates the utility of the EDM Forum. Moving forward, the EDM Forum's continuing efforts to accelerate research and QI through joint methods projects, as well as expand understanding of ways the community is learning from ECD through novel dissemination and translation strategies, show great promise in extending the sustainability of this unique scientific collaborative.

V. List of Publications and Products

A list of EDM Forum publications and products is available on the EDM Forum Repository: http://repository.academyhealth.org/edm_briefs/12.

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