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EDM Forum Review 2015

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EDM FORUM REVIEW

2015

electronic health data, science, health IT, policy
& the health care marketplace

<http://www.edm-forum.org/review/>

EXECUTIVE SUMMARY

Over the past several years, increasing availability of electronic health data (EHD) and use of these data to support health system transformation point toward exciting possibilities for health and health care. A great many individuals and organizations in the public and private sectors are contributing to drive this transformation, and the rapid pace of change and diversity of contributors make it challenging to keep up with new innovations and opportunities. In the context of this dynamic environment, our inaugural *EDM Forum Review* highlights major events, initiatives, and emerging evidence using EHD to improve patient care and outcomes.

For 2015, the *EDM Forum Review* focuses on a new innovation imperative for health data and knowledge to drive system improvement. The *Review* details investments over the past five years that have cultivated an EHD infrastructure now primed to support new goals for value-based payment from the Department of Health and Human Services (HHS). It also highlights a number of key trends, investments, and initiatives that are promoting this evidence-based system transformation, including:

- Significant support from the public and private sectors investing in EHD infrastructure and science;
- The adoption of electronic health records (EHRs) as a result of the Health Information Technology for Economic and Clinical Health (HITECH) Act and Meaningful Use program;
- Patient engagement and a growing marketplace for mobile health technology; and
- Value-based payment goals to ensure that Medicare and other payers are paying for care based on quality rather than volume.

The sections that follow feature a [timeline](#) of significant events with implications for EHD and system transformation; a synthesis of relevant trends and drivers within the EHD ecosystem ([We Are Here](#)); and the findings from a recent EDM Forum literature review of the [evidence base](#), including comparative effectiveness research (CER) and patient-centered outcomes research (PCOR).

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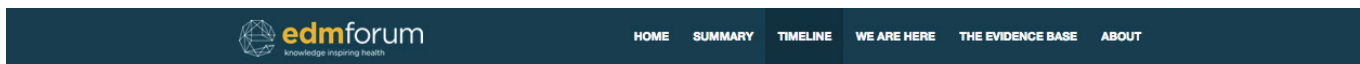
We Are Here

The last few years have been truly remarkable for the health care community. The availability of electronic health data (EHD) and the new ways in which stakeholders are using these data is beginning to shape health system transformation. Like all great, evolving social endeavors, many individuals and organizations from the public, nonprofit, and private sectors are making contributions to drive this transformation, and the pace of change is fast enough that it can be a challenge to keep up with the tremendous innovation and new opportunities in the field.

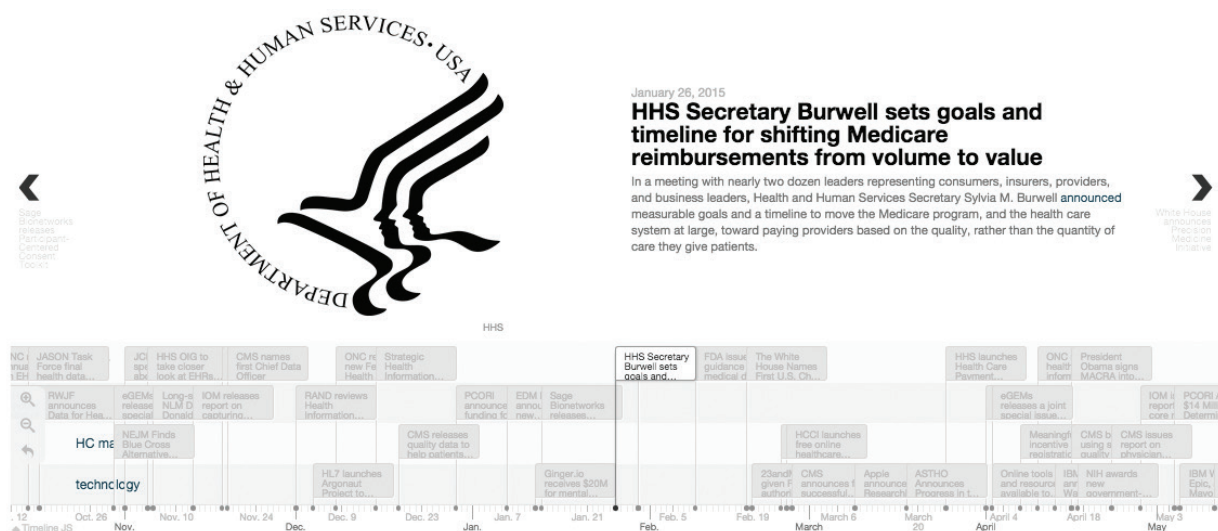
In the context of all this activity, the *EDM Forum Review* highlights major events, initiatives, and emerging evidence using EHD to transform the U.S. health system. This year the Review addresses the convergence of EHD infrastructure investments - which have arguably reached a tipping point to enable rigorous analysis - along with a recent EHD innovation imperative stemming from the Department of Health and Human Services' new goals for value-based payment.

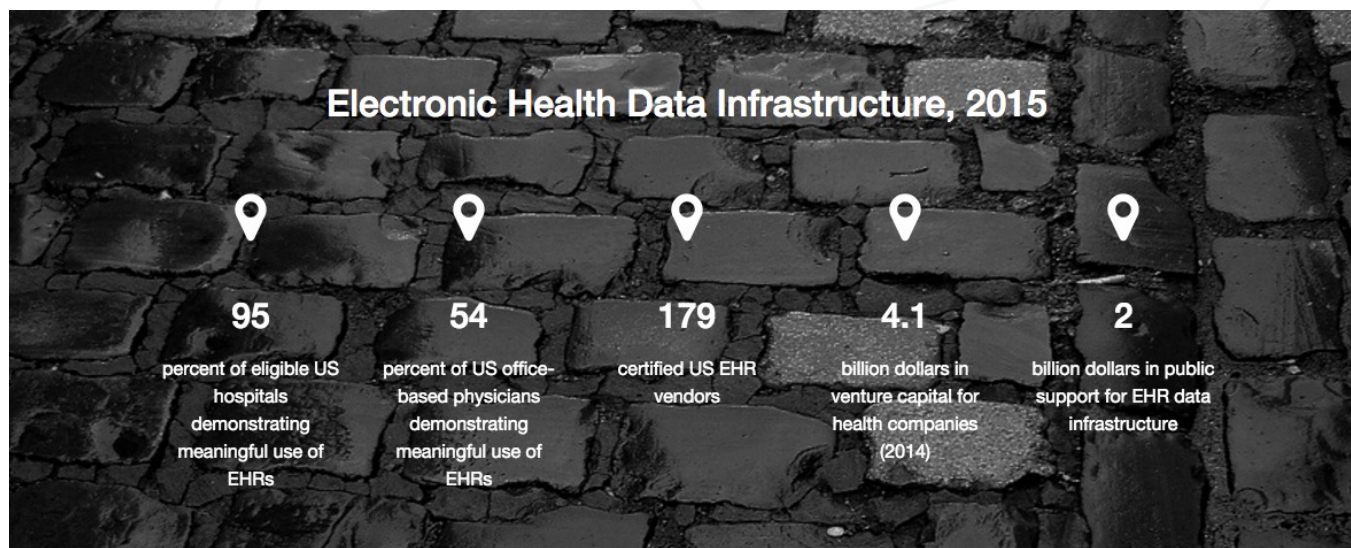
2014-2015 Timeline

Click the screenshot below to access the Review's online [timeline](#) of significant events with implications for EHD and health system transformation.



The Electronic Health Data Ecosystem January 2014 - September 2015





A number of key investments and initiatives are promoting this evidence-based system transformation, including:

- Significant new investments from the public and private sectors in EHD infrastructure and science;
- The adoption of electronic health records (EHRs) as a result of the Health Information Technology for Economic and Clinical Health (HITECH) Act and Meaningful Use program;
- Patient engagement and a growing marketplace for mobile health technology; and
- Value-based payment goals to ensure that Medicare and other payers are paying for care based on quality rather than volume.

The Review addresses each of these efforts below in the context of the evolving EHD infrastructure and new payment reform goals that together create a unique opportunity to improve health systems.

An Infrastructure to Facilitate Transformation

Based on the EDM Forum's scanning efforts, the events, trends, and innovations over the last 12 to 18

months show a maturing EHD infrastructure and a growing momentum toward more effective uses of EHD within the U.S. health system. This new energy is increasing the diversity within the community using EHD and is helping create stronger connections across sectors and disciplines. Examples include:

- **Expanding networks and collaborations**
 - (e.g. the Patient Centered Outcomes Research (PCOR) Network, the Observational Health Data Sciences and Informatics program, the Precision Medicine Initiative million volunteer cohort, and the High Value Healthcare Collaborative);
- **New and improved tools to promote interoperability and collaborative work**
 - (e.g. the Commonwell Alliance, Fast Healthcare Interoperability Resources, CIELO, and the Office of the National Coordinator's Interoperability Roadmap);
- **Increasing access to richer sources of data**
 - (e.g. Centers for Medicare and Medicaid Data Navigator);
- **Private sector innovation and business intelligence**

- (e.g. ResearchKit from Apple, Inc., OptumLabs Research and Innovation Center, the Data Incubator fellowship, and FlatIron Health)
- **Personalized medicine and the integration of data from sectors outside of health care**
 - (e.g. Sage Bionetworks Synapse, 23andMe, purplebinder).

Significant Public and Private Investment

Both public and private investments are building on the foundation laid by earlier public investments to increase health IT adoption and build collaborative networks to transform EHD into knowledge and discovery. In the last ten years, over two billion dollars in public support for clinical research networks, quality improvement efforts, informatics, and novel approaches to build learning health systems has contributed to improving the capacity to conduct rigorous analyses.

Continued Commitment from Public Sources

Among these efforts, funding from the Food and Drug Administration (FDA) for the [Sentinelⁱ](#) program (formerly [mini-Sentinel](#)) in 2009, and the [ONC Beacon Community](#) program, along with Agency for Healthcare Research and Quality (AHRQ) [grants](#) for CER using EHD in 2010, provided foundational support to bring collaborators together to answer key effectiveness and quality questions. Similarly, the National Institutes of Health's (NIH) [Health Care Systems Research Collaboratory](#) was initiated in 2012 to implement a series of pragmatic trials on topics ranging from hemodialysis to suicide prevention and strategies to reduce healthcare associated infections. New support from CMS, AHRQ, NIH and other federal sources has also supported the continued development of national collaboratives such as the [High Value Health Care Collaborative](#) and the HMO Research Network, which changed its name to the [Health Care Systems Research Network](#) in 2015 to reflect the needs of organizational members, the

breadth of partnerships, and diversity of health systems within the network.

Over the last 18 months, the most significant new investment related to EHD has come from the Patient-Centered Outcomes Research Institute (PCORI) for the development of [PCORnet](#), as a 'network of networks' bringing together 30 health systems and organizations to conduct CER. PCORnet integrates large clinical data research networks (CDRNs) with a set of Patient Powered Research Networks (PPRNs) to find new ways to bring the patient voice to PCOR.

Since May 2015, PCORI's board has approved the first set of three PCORnet demonstration studies. The first is a [clinical trial](#) comparing the benefits and harms of a low- and regular-strength daily doses of aspirin among heart disease patients. The second and third are [studies](#) on obesity - one focused on the health benefits and safety of bariatric surgery and another focused on the influence of antibiotic use on weight gain in childhood. Recently, [Phase II funding](#) for PCORnet was awarded to 34 data networks (13 CDRNs and 21 PPRNs), many of which participated in Phase I.

Private Sector Deepening Its Engagement

Meanwhile, in the private sector, stakeholders are already hard at work to capitalize on new business opportunities leveraging EHD to improve patient engagement and the quality, efficiency and value of health care. EHD is a prime resource for entrepreneurs, startups, and well-established big businesses alike who have sought to bring new analytic and information products - broadly referred to as 'business intelligence' tools - to health care. 2014 was a 'record breaking' year for digital health funding, which surpassed \$4.1 billion, according to a [report](#) on digital health funding from Rock Health, and 2015 appears poised to far exceed 2014 for U.S. medical startups.

ⁱSee <http://www.fda.gov/Safety/FDASentinelInitiative/ucm2007250.htm>.

Other large companies are making significant health and data related investments, including some to launch new companies. According to the *Wall Street Journal*, “one-third of the money Google Ventures invested in 2014 went to health care and life-sciences companies, up from 9% each of the prior two years.” More recently, in August 2015, Google’s leadership [announced](#) a major corporate restructuring, creating Alphabet Inc., a holding company within which Google’s existing and future subsidiaries, projects, and products will exist. Life sciences is expected to be one of Alphabet’s major focus areas, and the company has already released [plans](#) for a standalone company within Alphabet.

This year also saw the Department of Defense (DoD) award a mammoth \$4.3 billion [contract](#) to a partnership between government contractor Leidos and Cerner Corporation. The ten-year contract will support the overhaul of the DoD’s EHR system for active military members and retirees.

Open to Open Data

Over the past few years there has also been a substantial increase in the amount of health data available for research. Notably, the Centers for Medicare & Medicaid Services (CMS) has continued to increase the accessibility of their data. The agency has a mandate from the Affordable Care Act to [share](#) claims data to help consumers evaluate provider and supplier performance, which has led CMS to increase access to the data that are available to researchers to now represent approximately half of Medicare spending.

The CMS [Data Navigator](#), managed by the relatively new [Office of Information Products and Data Analytics](#), now contains over 400 data sources organized and searchable by program, setting/type of care, topic, geography, and document type. The data include more than just claims data, providing

researchers with more robust resources to generate evidence and analyses about the health system.

There are three different types of data files available. Most are publicly [available](#) for free, others are available for purchase, while remaining files — many of which include identifiable data — are [restricted](#) for use only for use under certain conditions. In September 2015, CMS agreed to [enable access](#) to Medicare data for researchers interested in creating predictive models or care management products and tools, a significant shift in policy to make CMS data more available to all sectors.

This move toward more open health data and better data sharing has been bolstered by leaders in the personalized health movement who are calling for more power for patients to contribute to and control their own health data for care as well as for research purposes. For example, Kathy Giusti, founder and executive chairman of the Multiple Myeloma Research Foundation, recently [testified](#) before the Senate’s [HELP](#) committee about the improved patient outcomes her foundation has seen after working to improve data sharing and use related to the blood cancer multiple myeloma. Building in part on the [Blue Button](#) initiative, [Get My Health Data](#) is the newest entrant into this effort as of this summer, and seeks to make it easier for patients and consumers to compile their own health information and use it to improve their health and care.

Another step forward toward ensuring patient’s autonomy and voice is recognized in research and quality improvement is the formalization of the Patients Included charter. [Patients Included](#) provides a mechanism to ensure conference organizers can demonstrate their events are committed to incorporating the experience of patients as experts in living with their condition while ensuring they are neither excluded nor exploited. Concordium 2015 is pleased to be [one of the first](#) health research

conferences to be accredited using this self-assessed process. Concordium meets [all five](#) of the charter's clauses.

Data for Health, Beyond Health Care

As demonstrated by [Tomines and colleagues](#), EHD is a powerful resource for public health to successfully monitor the health of populations, conduct real-time surveillance, and facilitate appropriate public health interventions. Yet, working from the realization that health means more than just the absence of disease, innovative efforts such as [purplebinder](#), which organizes information on community services, will become increasingly important to bring to bear in addressing community health needs.

Similarly, the integration of data from sectors outside of health care is being emphasized by organizations such as the Robert Wood Johnson Foundation as part of its new mission to build a [Culture of Health](#) (COH). Among new culture of health initiatives, the RWJF's new initiative [Data Across Sectors for Health](#) (DASH) seeks to support collaborations among community organizations to improve health by sharing data and information with entities outside of health care.

And It's Getting Personal

Many in the private sector are now also increasingly focused on the personal aspect of health. What was once defined as the 'health care system' is becoming much more dynamic and data-driven, bringing in data from a host of consumer markets that influence wellness. For patients and care providers alike, these changes are redefining the concept of how to achieve health. As noted by a recent Consumer Reports brief, [Your Medical Data: What you Need to Know Now](#), there is growing awareness of opportunities for consumers and patients to get involved in using their own information to promote health.

Demand for wearable devices is helping drive this trend. Gartner [reports](#) that 68.1 million wearable devices will be shipped this year, with many of them being used by consumers to track data related to health and wellness. *The Washington Post* [reported](#) earlier this year on the growing trend for consumers and patients tracking their health using wearable devices, while the [surge](#) of thousands of early volunteers willing to participate in projects using Apple's ResearchKit demonstrates a strong public interest using health data to promote health.

The Innovation Imperative to Generate Value

The most significant signal of impending health system transformation in 2015 was HHS' [announcement](#) in January that CMS is rapidly transitioning away from paying for volume of services to paying for value. Secretary Burwell set specific goals to achieve transformation in the way the U.S. pays for care by:

"...tying 30 percent of traditional, or fee-for-service, Medicare payments to quality or value through alternative payment models, such as Accountable Care Organizations (ACOs) or bundled payment arrangements by the end of 2016, and tying 50 percent of payments to these models by the end of 2018."

As part of her announcement, the Secretary also launched the [Health Care Payment Learning and Action Network](#), which will work with payers, employers, consumers, providers, states and state Medicaid programs, and other partners to expand alternative payment models into their programs and help the private sector shift toward value-based payment.

This shift toward paying for value rather than the volume of services provided will require coordinated and collaborative efforts in both the public and

private sectors, and by necessity will rely upon access to EHD that can be shared, analyzed, and used rapidly in meaningful ways. The development of electronic clinical quality measures (eCQMs) that can capture value-based concepts is an effort in which CMS, measure developers, the National Quality Forum, and collaborators from the EDM Forum are actively engaged.

Major corporations and technology providers are also investing and building partnerships with health systems to provide services built on new innovations for which consumer and patient data play a central role in defining health. ResearchKit from Apple, Inc., OptumLabs Research and Innovation Center, and software platforms like those developed by Flatiron Health and Ginger.io were notable examples in 2015.

Health Data Specialists Wanted!

In this transition toward systems designed to respond rapidly to diverse sources of data and new evidence, it is important to recognize a dependency on highly skilled knowledge workers. There is a new and growing cadre of individuals who are designing and executing strategies for delivery system transformation, mirroring a national emphasis on the importance of data science, as indicated by the appointment of the first U.S. [Chief Data Scientist](#) and the creation of the [U.S. Digital Service](#) within the White House.

New job titles are proliferating in response. Some groups identify more than 70 titles associated with data science, and have provided interesting insights into [career pathways](#) for health information management.

These new leadership positions reflect a diverse and evolving set of employers and job functions - all with the common goal of leveraging EHD to drive business intelligence and improve outcomes. Integrating diverse perspectives into the EHD

ecosystem in a way that facilitates team science and draws the best ideas from across disciplines is a compelling, near-term opportunity for the field.

It remains to be seen how these data science needs will be met, and to what extent to which software, consulting services, or in-house experts within health systems are required to generate the insights needed to improve the quality, safety, and value of care. Nonetheless, there is an expressed need among health system leadership for data experts and knowledge workers with domain expertise in health.

Your Next Job in Health Data Science?

EDM Forum contributors from delivery systems have identified eight key roles they see as the individuals designing and executing strategies for health system transformation.

- Chief Learning Officer
- Chief Data Scientist
- Vice President of Population Health
- Business Intelligence Developer
- Data Architect
- Vice President of Quality
- Biostatistician
- Chief Medical and Quality Officer

Shared Challenges Create New Opportunities

There is a long and exciting road yet to traverse to transform the U.S. health system using EHD and analytics. Along the way, we will need to overcome many shared challenges to achieve a fully-interoperable health system that learns from every interaction between patients, providers,

and the public health system to promote health improvement. As a starting point, the EDM Forum has identified a priority set of challenges:

- understanding and improving EHR data quality for QI and research;
- improving the efficiency and utility of patient reported outcomes (PROs) in practice;
- accelerating the efficiency of electronic clinical quality measures (eCQMs) while improving the representativeness of eCQMs;
- improving the dissemination, transparency, and reproducibility of PCOR using EHD
- advancing clinical decision support and system redesign;
- advancing understanding of effective approaches to governance in learning health systems, QI, and research;
- integrating public health data and systems with data on health care.

In the past few years, the EDM Forum has made substantial progress in bringing the EHD community together to address each of these challenge priorities. A key part of this progress has been the creation of *eGEMs* (*Generating Evidence and Methods to improve patient outcomes*), the EDM Forum's open access, peer reviewed journal which was created explicitly to provide a venue for translating and disseminating novel and useful EHD methods and approaches to redesign health systems.

Examples of unique areas of emphasis for *eGEMs* include a special issue on [clinical decision support](#) and user interface to improve patient outcomes with guest editor Tom McGinn of Northwell Health, and a special issue on [using Health IT](#) to enable community-level transformation - the largest collection of papers on lessons learned from the ONC Beacon Communities. A [toolkit](#) of governance resources and a forthcoming *eGEMs* special issue

on health data governance is also underway, as is a toolkit on the use of PROs in practice. Ongoing work to characterize the [quality of EHR data](#) has resulted in several papers, and this work is continuing as a PCORI methods project in collaboration with the EDM Forum. In all, the EDM Forum's collaborative projects have fostered a productive set of activities to advance progress against shared challenges, engaging nearly 200 collaborators from diverse backgrounds.

Some of these projects have led to functional changes in the nature of patient-centered research such as improving "informedness" of individuals at the point they consent to participate in research. Sage Bionetworks worked with members of the EDM Forum community and staff to create a design template and consent loop that was ultimately used in all five of the first [ResearchKit](#) apps released by Apple Inc. By combining the practical experience of the research, patient, and policy communities, the portable consent process is proof of concept that the consent can be simpler and potentially more informative with respect to study objectives and potential risks. Similarly, ongoing work on a new platform for sharing data and code, called [CIELO](#), is being linked to a collaborative project to more rapidly develop, test, and implement electronic clinical quality measures in diverse settings and populations.

Sustaining Collaboration

Over the past five years the EDM Forum has been privileged to engage several thousand leaders from research, patient, government, policy, health care delivery, industry (e.g. purchasers, delivery systems, pharmaceutical and life sciences or other), and payer communities. This experience has affirmed our philosophical commitment to collaboration and open science.

Whether your perspective is research, analytic methods, patient engagement, public health, or clinical care, improving health care in the U.S. is fundamentally a team sport for which transdisciplinary perspectives and public-private collaboration is critical to progress.

By working together we can doubtless travel farther and are more likely to make sustainable progress. For this reason it is important to get oriented within the ecosystem and identify the potential partnerships and efforts that can best support rapid progress.

We welcome your continued interest, engagement, and collaboration, and hope the *EDM Forum Review* is a useful resource to help map the journey forward.

Literature Review: An Expanding Evidence Base

With substantial investment in developing data research infrastructure and tools to analyze EHD, the production of evidence is accelerating, as indicated by a doubling in the literature on EHD between 2011 and 2013 - driven in part by the creation of the EDM Forum's peer-reviewed e-journal, *eGEMs*.

Furthermore, as comparative effectiveness research (CER) studies funded by the American Recovery and Reinvestment Act of 2009 (ARRA) are completed, additional peer-reviewed papers are being generated with applicable findings on a range of topics.

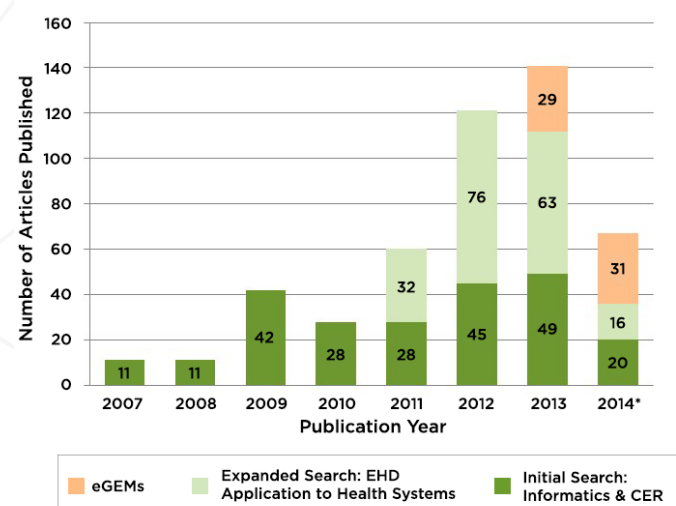
The EDM Forum has examined the published literature on EHD to explore the growth in new evidence across domains, indicate emerging themes, innovations, and applications; and identify gaps in the current evidence base. The EDM Forum's two reviews - conducted in 2011 and 2014 - include 520 peer-reviewed (1991-October 2014) manuscripts identified by PubMed queries, in addition to articles published in *eGEMs*. While the initial review captured core articles focused on clinical informatics and CER,

the 2014 review was broadened to reflect emerging themes, particularly the potential to use EHD for health system improvement. *eGEMs* publications are included from 2013, when the journal was launched, through fall of 2014. A complete list of articles in the literature reviews is available in the *EDM Forum Review* [bibliography](#).

Taken together, the literature on uses of EHD provides a proximate view of the field's evolution. Corresponding to major federal investments through ARRA along with private sector activities in clinical informatics, the two reviews indicate a tremendous growth in the literature focused on clinical informatics and CER, with rapid acceleration starting in 2007 (Figure 1).

Figure 1.

Growth in Literature (2007-2014)



* Corresponding to the timing of the search (October 2014), the 2014 figures only include the number of articles published between January and October.

Closer examination of all manuscripts (1991-fall 2014) provides insights into major themes in this evolving field, which is largely still focused on lessons learned in the process of building new infrastructure and methods. Nearly 19 percent of papers focus

on developing the capacity to conduct CER using EHD by building appropriate tools or platforms, projects, and research networks; while 20 percent promote the use of EHD and provide frameworks for conducting CER. Approximately 11 percent address ways to optimize data collection and use. Another relatively prominent area of focus includes methods, predominantly alternatives to randomized controlled trials to leverage EHD for CER (19 percent).

The review also highlights persistent gaps in the literature. Articles on data governance, IRB protocols, and patient health data security and confidentiality together comprise only 6 percent of the literature. Another 6 percent focuses on text processing, which is used to interpret information in 'free text' or clinical notes and is often referred to in the literature as 'natural language processing.'

Finally, in the open science paradigm that we hope will drive the EHD ecosystem, it is clearly not enough to evaluate the peer reviewed and grey literature as traditionally defined. New digital documents using digital object identifiers (DOIs) will soon be linked to federally funded grants and contracts. This will enable the community to track contributions to open data, open source code, and other digital products associated with publicly funded resources.

Emerging Results of Comparative Effectiveness Research (CER) Studies Using Electronic Health Data (EHD)

Since the literature review explicitly sought to identify papers on informatics approaches for CER, the identified studies were not primarily focused on CER and PCOR results generated using EHD. To highlight emerging discoveries, CER studies funded by ARRA were reviewed. Connected with [ARRA CER infrastructure projects](#) (n=65), 537 manuscripts were published between 2011-2015 (as of June 2015). Of these, 53 papers focus on epidemiological or clinical results associated with the ARRA grant

number. Approximately half of the papers addressed a priority population identified by the Agency for Healthcare Research and Quality (AHRQ).

The ARRA CER studies reflect not only the potential to leverage large EHD sources to generate evidence on most effective treatment approaches pertaining to specific conditions and populations, but they also indicate the ability of CER to tell nuanced stories about the effectiveness of interventions in complex, real-world settings. Ideally, this evidence will enable more personalized and effective treatments for subgroups, as demonstrated by the following examples.

Bariatric or 'weight loss' surgery. A 2014 retrospective cohort study by [Arterburn et al.](#), compares two common bariatric surgical procedures – laparoscopic Roux-en-Y gastric bypass (RYGB) and laparoscopic adjustable gastric banding (AGB) – and indicates the nuanced nature of results due to benefits and harms of both treatments. While the RYGB patients experienced greater BMI reduction and lower risk of long-term intervention procedures than patients who underwent AGB, the former group had higher risk of short-term adverse events and long-term re-hospitalizations. Despite the mixed results, the CER evidence can be a starting point in making informed treatment decisions about bariatric procedures while weighing the benefits and risks of treatment options.

Imaging for low back pain. As part of the Back Pain Outcomes Using Longitudinal data (BOLD) project, a prospective cohort study by [Jarvik et al.](#), compares the effectiveness of early imaging to non-early or no imaging among older adults (ages 65 and older) with back pain. Results indicate that early imaging was not associated with improved outcomes (low back or leg pain related disability) during a one year follow-up. This result could be germane in patient decision-making regarding timing of imaging

(radiographs, computed tomography, and magnetic resonance imaging) to detect injury or morbidity.

Smoking cessation. The CER/PCOR results generated are indicative of the meaningful evidence EHD can provide with potential to improve health care and outcomes. A recent 2015 cohort study by [Stevens et al.](#) summarized the results of a 35,000 person cohort in six diverse health systems to assess smoking use. Results show that one in seven patients who smoked achieved long-term cessation after four years, demonstrating the practicality of using EHD for monitoring patient status and the potential impact of organizational and operational programs over time.

Visualizing patient-centered outcomes. In addition to studying the comparative effectiveness of specific therapies, many of the ARRA CER infrastructure awards sought to identify the most effective strategies for providing information on outcomes and health status back to the individuals participating in QI and research activities. Many of these efforts are highly iterative, as demonstrated by [Hartzler et al.](#), which focused on the ways patients and providers want to see surgical outcome data visually summarized. Likewise, [Arcia et al.](#), describe the development of a style guide to integrate patient reported outcome data from a community health survey into a personalized report for individuals participating in the study that was both comprehensible and actionable.

It is also worth noting the range of journals in which CER is being published. The 53 articles from the ARRA-CER awards were published in 40 journals. Of these, 12 (*Ann Internal Med*, *Cancer*, *Eur J Cancer*, *Hawaii J Med Public Health*, *JAMA*, *JAMA Surg*, *JCER*, *J Am Board of Fam Med*, *J Natl Cancer Inst*, *J Urol*, *Med Care*, and *The Laryngoscope*) published more than one article. While the representation of diverse journals likely indicates an appropriate

dissemination strategy given the diverse clinical audiences authors wish to reach, it also underscores potential challenges of collecting and synthesizing the growing body of literature from disparate sources on an ongoing basis.

In addition to ARRA-funded projects, CER studies funded by PCORI represent a major source of evidence for the future. Given the stringent requirements within the Affordable Care Act (ACA) to summarize and share PCOR findings with the public within 90-days of a study's completion, a new influx of results from PCORI-funded studies will emerge soon. Already [results](#) from several PCORI projects have been published.

Acknowledgments

AcademyHealth's staff gratefully acknowledges the Agency for Healthcare Research and Quality's vision and ongoing support for the EDM Forum. In particular, the guidance of our Project Officer, Dr. Gurneet Randhawa has been instrumental to ensuring the project reflects the Agency's mission as well as the initial intent of the EDM Forum.

Our great thanks to the always engaged and thoughtful EDM Forum [Steering Committee](#), co-chaired by Dr. Ned Calonge and Dr. Suzanne Bakken. And the EDM Forum's terrific [key advisors](#). Both groups made substantial contributions to the design and content of the report.

Finally, our thanks to the EDM Forum community of authors, reviewers, workshop and program participants. It is our goal to reflect and amplify your work, while fostering open science principles within the community. Your contributions and willingness to engage in collaboration to drive health system transformation is the key to lasting progress. It is a privilege to work with you to create the data, methods, and evidence to shape the next generation of health systems.

Appendix A: Methods

To support the electronic health data and analytics community, the EDM Forum regularly undertakes environmental scanning efforts and needs assessments. These scanning efforts have helped build a body of knowledge, identify challenges and opportunities related to using EHD to produce evidence and support learning health systems, and have created connections between collaborators across sectors and disciplines. Specific activities undertaken by staff for this year's Review included the following, each of which is described below in further detail:

- key informant interviews with steering committee members, key advisors, and selected thought leaders
- a focused media review
- peer and grey literature reviews
- a portfolio analysis of federal funding for CER data infrastructure

For all reviews staff applied consistent inclusion criteria to identify the subset of projects, trends, or events that fall within the scope of the Review. The report limits items listed on the Timeline or shown in the Landscape to those that are both:

- using electronic health data or are relevant to future uses of electronic health data, and
- generating or using evidence to transform the U.S. health system.

Key Informant Interviews

EDM Forum staff conducted in-person and phone interviews with many of the EDM Forum's Steering Committee members and key advisers. In addition, a select set of interviews were conducted with key thought leaders representing the EDM Forum's seven stakeholder groups:

- government
- business/payer

- industry
- health care delivery
- patient/consumer
- nonprofit/policy and research

Each semi-structured interview sought insights into key trends, events, programs and projects, as well as emerging opportunities and shared challenges over the last year and a half. All participants were encouraged to share what they saw as the most important factors influencing the use of EHD and health system transformation.

Interviewees from clinical settings were also asked to characterize their organization's relative maturity with respect to using EHD for strategic decision-making. All interviews were coded using NVivo 10 to look for recurring themes and mentions of specific events or activities.

Peer-reviewed Literature and Grey Literature

Staff undertook two reviews of the literature on electronic health data, in 2011 and 2014. The 2011 [review](#) was conducted using a MeSH search augmented with keywords to identify relevant projects, coupled with a manual evaluation of articles (please see the 2011 review for additional details on search terms). The second review conducted in October 2014 employed an expanded set of search terms to identify concepts related to the use of EHD for health system improvement employing a novel Phrase Utilization in MEDLINE Abstracts search (PUMAsearch) system, which was developed by Dr. Neil Sarkar at the University of Vermont. PUMAsearch uses ranked MeSH descriptors and keyword phrases to rapidly search and retrieve articles.

In the 2011 review, out of the 2,435 citations that were initially identified as relevant, 132 (5 percent) articles were selected for inclusion. In the 2014 review employing PUMAsearch, 698 articles were

retrieved, of which 528 articles with abstracts were reviewed, demonstrating good recall and precision of the PUMAsearch strategy. Of these, 328 articles met inclusion criteria. In addition to the manuscripts identified in PubMed, 60 *eGEMs* articles (from January 2013 when the journal was launched through October 2014 when the PUMAsearch was conducted) were included. Nine *eGEMs* articles were excluded because they were editorials or commentaries. A [bibliography](#) of all papers selected for review is available on the EDM Forum website.

Staff undertook a coding process based on a classification scheme initially developed for the 2011 review, modified to include emerging themes identified by the authors in the second review. The coding represents the primary concept being addressed by a paper, with some not being classified to a major theme (unclassified) but still being relevant to EHD.

The list of codes is provided below.

- General Overview
- Clinical Informatics Infrastructure
- Data Use and Quality
- Standard Data Collection
- Governance
- Security
- Institutional Review Boards (IRBs)
- Identifiers and De-identifiers
- Natural Language Processing
- Metadata
- Library of Phenotypes
- Patient Involvement
- Engagement
- Learning Healthcare System and CER
- Cohort Identification
- Cloud Computing
- Unclassified
- CER and Systematic Reviews
- Methods

A [review](#) of the grey literature was conducted in 2012 and is also available on the EDM Forum website.

Media Review

Staff performed a structured media review of events from January 2014 to the present. A thorough review of the news archives of [iHealthbeat](#) and [Health Data Management](#) was conducted – both highly curated outlets focused on health care, EHD, and related policy. In addition, other prominent health focused news outlets were reviewed.

Staff also considered material from “years in review” from within the field, including, for example, the annual Clinical Research Informatics (CRI) Years-in-Review by [Peter Embi](#) and the annual review by [William Hersh and Joan Ash](#). Finally, relevant special issues released by major health and health IT journals such as *Health Affairs*, *JAMIA*, *JCER*, and *Medical Care* were included.

Portfolio Analysis: Federal Funding for CER Data Infrastructure Investments

A review of the data infrastructure investments supported by ARRA was conducted to understand and quantify ‘productivity’ from the awards in terms of published literature, reports, and tools – of which the literature is featured in the Review. Keyword searches in HSRProj, AHRQ Gold Database, and NIH Reporter were conducted to identify electronic clinical data infrastructure projects. Search terms focused on those related to electronic clinical data infrastructure (based on descriptions of ‘data infrastructure’ from the AHRQ website) and included:

- electronic health record(s), electronic medical record(s);
- data, database(s), warehouse;
- distributed data network(s);
- link(s), linking, linkage(s);
- collect, collection;

- claim(s);
- exchange(s);
- informatic(s),
- bioinformatic(s);
- (health information) technology;
- repository, repositories; and,
- registry, registries.

A structured query using the MeSH tag for grant numbers, “gr,” was performed in PubMed to identify publications tagged with the grant ID numbers. The full abstract and summary information was extracted for the identified articles indexed in PubMed. The primary goals of the publication review was to a) identify the number of articles produced by each project; and b) identify the articles that present CER study findings versus papers that discuss infrastructure development. Links to publications and reports that resulted from the series of efforts to understand the landscape are available on the [repository](#) as well as a [summary report](#) of the EDM Forum’s activities in its initial 3 years.

Classification of Resources

Across all of the data collection activities supporting the *EDM Forum Review*, staff developed and applied the following definitions to organize content:

- Science: Includes entities, projects, or events using EHD to promote discovery with the goal of improving care and outcomes for patients and populations. Includes QI, CER, PCOR, clinical decision support and other novel approaches to generating new evidence.
- Technology: Involves entities, projects, or events related to emerging health IT (e.g. new technologies, technical infrastructures, and tools) that influence the creation and use of EHD, or the health system.
- Policy: Refers to entities, projects, or events involving the federal government, regulatory agencies, or standards development organizations that influence the creation and use of EHD, or the health system.
- Healthcare Marketplace: Includes the entities, projects, or events related specifically to the marketplace for health systems and services in the U.S. (e.g., payers, purchasers, ACOs, and hospitals).

About the Review and the EDM Forum

This Review is the culmination of a number of the EDM Forum's analytic efforts, including a set of structured literature reviews; a review of relevant media, agency, and journal announcements; a portfolio analysis of EHD infrastructure investments; and a select set of interviews with the EDM Forum's [key advisors](#), [steering committee](#) members, and prominent thought leaders in the field. The Review highlights major efforts and entities contributing to the vision of true learning health systems.

This Review does not attempt to provide an exhaustive list of all events, initiatives, and findings from the past few years focused on health IT, health reform, research, or quality improvement. Rather, the goal of the *EDM Forum Review* is to synthesize results of our scanning efforts to inform stakeholders, foster awareness, and promote new connections among innovators with an interest in improving care and outcomes in the U.S. health system. Additional information on the specific methods used to develop this Review are available in our methods appendix. We welcome feedback and questions, so please contact us.

Since 2010 the EDM Forum has worked with leaders at the cutting edge of research and quality improvement using EHD. As a cooperative agreement with the Agency for Healthcare Research and Quality (AHRQ), the EDM Forum was initially charged with serving as a convening entity for eleven [comparative effectiveness research \(CER\) grants](#)ⁱⁱ — each pushing the boundaries of CER using EHD — by engaging key stakeholders and facilitating synthesis and the dissemination of lessons learned.

Beginning in 2013, the second phase of the EDM Forum's AHRQ-funded work has focused on outreach to a broader community of innovators using EHD to drive rapid collaboration between the diverse stakeholders who create the data, methods, and evidence to shape the next generation of health systems. Overall the EDM Forum aims is identify and address the shared challenges experienced by those using EHD, with an emphasis on disseminating the methods and results of PCOR.

The inaugural [Concordium](#) meeting — held September 21-22 in Washington, D.C. — is one indication of the EDM Forum's efforts to build a community for this emerging field. Concordium will feature more than 100 presentations, posters, and demonstrations highlighting findings in delivery system science and PCOR, in addition to methodological innovations and new approaches to engaging consumers and patients. *eGEMS*' Winter 2016 special issue will continue the conversation by publishing a subset of papers on Concordium presentations selected by a jury of peers. And many more webinars and workshops are planned for 2016 to capitalize on the current momentum.

ⁱⁱSee http://repository.academyhealth.org/edm_briefs/7/.

For more information on the EDM Forum, and to access more than 350 resources developed by the Community, please visit our website at www.edm-forum.org or refer to the following 'quick links':

- [Project Overview](#)
- [Resource Repository](#)
- [Steering Committee](#)
- [Key Advisors & Core Staff](#)

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