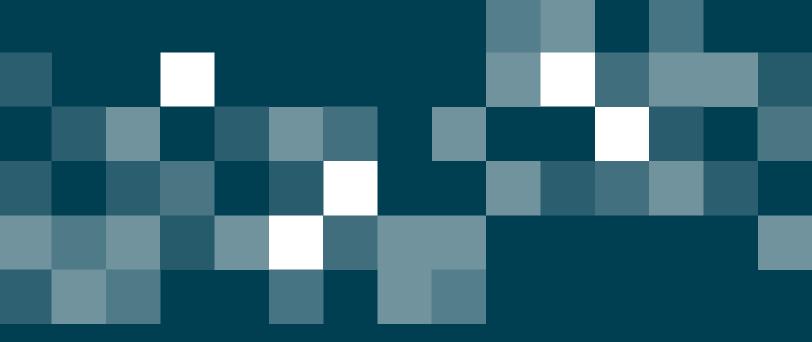
Connect, Collaborate, Communicate

The Story of the EDM Forum







Executive Summary

AcademyHealth, a national non-profit professional organization, works on initiatives focused on innovative ways to make health care work better. This is the story of one of those initiatives.

The Electronic Data Methods (EDM) Forum began as a way to connect 11 Agency for Healthcare Research and Quality (AHRQ) grantees working to improve the use of electronic health data (EHD) to improve health care. The grantees came together at a time of great change in health IT and were funded under the landmark American Recovery and Reinvestment Act (ARRA). This legislation incentivized the meaningful use of electronic health record technology and kicked off a race to harness the power of health data.

While technology is about precision and detail, those who can see the big picture are the most effective overall. AcademyHealth was chosen by AHRQ in 2010 to connect the ARRA-funded grantees in a dialogue around shared issues and challenges related to the rapidly evolving health care system.

What followed over the next six years turned out to be much more than that. By 2016, the EDM Forum had become a community 4,000 strong, built on trust and mutual respect for diverse expertise, and committed to working together to solve some of the most pervasive issues in health care by viewing those issues as shared challenges.

This community would ultimately bring together innovators on the front lines of health care from health care delivery systems and public health agencies; develop and share recommendations before the most influential federal agencies; and lead a national dialogue on critical issues such as governance, data sharing, methods and analytics, and dissemination of findings.

AcademyHealth cultivated and supported this community through a model aimed at fostering collaboration among leaders to generate pragmatic solutions. It began with small convenings to identify shared challenges and grew to collaborative projects scoped to identify and, in some cases, implement solutions, all supported by creative dissemination methods and channels.

Perhaps the most distinctive aspect of this community was its commitment to the common good. Participants were committed to improving the spread of innovation in a transparent and reproducible way. The group's solutions are documented in more than 400 freely accessible analytic products (e.g. issue briefs, reports, peer-reviewed manuscripts) and resources (e.g. webinars, toolkits), as well as in a peer-reviewed, open access journal created during the project.

To learn more about this project and others like it, or to partner with us, visit academyhealth.org.





Introduction

It's hard to imagine a time when only the most high tech doctor's offices had computers, but even as late as 2001, only 18 percent of physicians were using an electronic health record (EHR) system.* The following years saw huge advances in the use of technology to improve health and health care. With the establishment of the Office of the National Coordinator for Health Information Technology in 2004 and the passage of the American Recovery and Reinvestment Act in 2009, the interest in data collection, analysis, and use to improve patient care and outcomes exponentially increased.

But every one of these advancements in health care technology came with its own set of complicated issues and questions: How can we ensure data is collected in a standardized way across organizations and systems so it can be shared more easily? How can we make sure the data we're collecting provides information on the problems we need to solve? How can we ensure patientcenteredness in research? What are the best ways to incorporate patient-reported outcomes (PROs)?

And once we find a good way to do these things, how do we spread that knowledge and encourage others to follow our lead? In 2010, the Agency for Healthcare Research and Quality (AHRQ) awarded 11 grants to research teams across the country to develop electronic health data (EHD) infrastructure to address some of health care's most challenging conditions (e.g. diabetes, asthma, obesity) and populations (low income women and children, and individuals with disabilities). AHRQ made a strategic decision that these projects would be more successful if they could work on their shared challenges together.

Enter the Electronic Data Methods (EDM) Forum. Funded by AHRQ and led by AcademyHealth, the EDM Forum soon grew from 11 grantees representing approximately 200 researchers in 2010, to more than 4,000 diverse stakeholders in 2016. EDM Forum's model of collaboration began with an identification of shared challenges through a comprehensive environmental scan, continued with priority and agenda setting, and initiation of collaborative projects, and finally the generation of solutions. The full body of work is documented in more than 400 reports and resources as well as in a peer-reviewed open access journal created during the project. Read on to learn how, over the course of six years, the EDM Forum convened diverse people, supported their collaborative efforts and disseminated their findings to others.

* Hsiao C-J, Hing E. Use and characteristics of electronic health record systems among office-based physician practices: United States, 2001–2013. NCHS data brief, no 143. Hyattsville, MD: National Center for Health Statistics. 2014.



The Growth of the Network

2010	
Phase 1 launched with 11 AHRQ Grantees	2011
2012	600 members 19 published products
1,700 members47 published products	2013
2014	2,000 members 162 published products 23K downloads eGEMs open access journal launched
3,000 members 294 products 56K downloads	2015
Present	3,700 members 411 products 92K downloads
4,000 members 469 total products 158K total downloads	

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Convene

Perhaps the most important element of the EDM Forum was bringing together delivery system innovators from public and private sectors across a wide spectrum of disciplines and work settings. Participants included embedded researchers, informaticians, data scientists, clinicians, patients and consumers, vendors and developers, and a variety of other thought leaders.

From the beginning, AcademyHealth recognized that collaboration, while powerful, is not easy – especially when the problems you are working to solve cut across settings, sectors, and realms of expertise. AcademyHealth staff dug into the issues of these diverse communities first by listening.

For example, the EDM Forum stakeholder needs assessment, published in September 2012, presents findings from 50 interviews with representatives from the major stakeholder groups. The analysis identified challenges around using health care system data to determine which health care interventions work best for which patients and which pose the greatest benefits and harms. As with many of the issues the EDM Forum addressed, the team highlighted both technical and cultural challenges. How can we assess and manage data quality and what methods can be used to address confounding observational data? When it comes to connecting research to health care delivery, collaboration between different groups will be key. How can we facilitate – and even accelerate - that cultural shift?

After listening to community members and distilling key themes, AcademyHealth built on these budding relationships to cultivate new opportunities for engagement. With an extensive network of patient and consumer advocates, policymakers, researchers, thought leaders, and others, AcademyHealth bridged many stakeholder groups and communities to advance evidence generation, dissemination, and use.

The EDM Forum Model

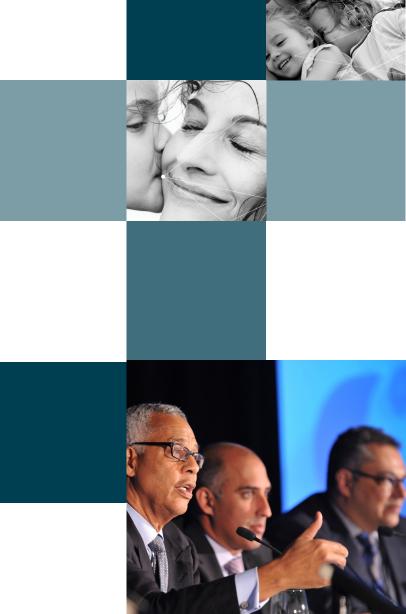
Identification of Shared Challenges	
	Priority & Agenda Setting
Initiation of Collaborative Projects	

The EDM Forum leveraged these relationships to create both real and virtual spaces in which diverse perspectives and experiences could be shared and communities of practice could be sustained over time. On the virtual side, AcademyHealth hosted dozens of public webinars to further develop the EDM Forum as a marketplace of people and ideas. Small to medium-sized, private, web-enabled seminars provided an opportunity for more regular sharing of issues, challenges, and lessons learned among projects building platforms, tools, and best practices to improve patient care and outcomes.

Building trust and a safe space to collaborate was critical from the very first convening. After hosting symposiums to talk about what needed to be done, a critical shift occurred at a workshop in March 2012. Focused on the collection and use of PROs in determining what interventions work best for whom, this workshop was the start of moving from identifying and describing problems to developing solutions. The key to success was when people started to talk about their challenges. Themes began to emerge and projects could then be formed around those shared challenges.

For example, the PROs workshop produced a framework* of challenges in governance, informatics and technology, analytic methods, and the implementation of PROs in learning health systems. The workshop also led to several collaborations, including a webinar presentation for the Center for Medicare and Medicaid (CMS) Measures Forum and an accepted panel for the Institute for Healthcare Improvement (IHI), commissioned papers, and an issue brief based on the proceedings.

* EDM Forum Stakeholder Symposium, Collection and Use of Patient-Reported Outcomes for CER, March 15-16, 2012 - Washington, DC.





Concordium by the Numbers

300 attendees each year	
	20 sessions each year
3 million reached on Twitter in 2016	

After the first few years, it became clear the community needed a bigger meeting to accommodate the growing number of issues and topics being raised. This led to a new national meeting called Concordium, a unique setting for people across diverse sectors to gather and talk about how data and knowledge can transform health care.

Held in 2015 and 2016, each meeting attracted about 300 attendees who were struck by the variety of perspectives invited and welcomed during the conference and by the creative energy that resulted.

Participants attended sessions with physicians and nurses using electronic medical records in innovative ways to help their patients, informatics experts talking about predictive analytics, and policy leaders highlighting challenges and solutions to issues like patient privacy. Meeting participants engaged in hallway conversations with people they would not have met otherwise. Unlike many other meetings where people are segmented by area of expertise, Concordium brought everyone working to advance data methods to transform health together.

The best part was that these relationships and connections extended beyond the confines of the conference center. As an example, conference speaker Gilbert Salinas, M.P.A., Rancho Los Amigos National Rehabilitation Center and Los Angeles County Department of Health Services (pictured at left), was invited to help new colleagues he met at the meeting as they worked on a national strategy to connect information systems and access integrated data from different sectors to improve communities' capacity to improve health. This wasn't just feel-good networking; this was real action.

The action began in meetings – both real and virtual – and was then sustained through intentional collaboration.

Collaborate

With private and public sector forces driving never-before-seen increases in the volume, variety and velocity of health data, there were plenty of methods and infrastructure challenges to address. As health systems began generating more electronic data—and from an increasingly diverse array of IT systems and sources—they struggled with issues related to accurately recording, reconciling, and contextualizing these data in a way that is useful for a variety of purposes. Many of them experimented with new approaches to these challenges to find out what worked and what didn't.

The collaborative projects under the EDM Forum served to connect these innovators with each other to leverage lessons learned and ultimately make forward progress on some of the most persistent data challenges in the field. Originally, the EDM Forum planned to commission manuscripts on these issues, but it soon became clear that members of the forum were far more interested in testing solutions rather than writing about them. So the call for papers shifted to a call for applications for collaborative projects.

AcademyHealth formalized two communities of practice as a part of the collaborative efforts of EDM Forum. As these communities were centered on cutting-edge data-related issues, they represented some of the first of their kind and served to connect otherwise disconnected individuals all working on the frontlines of health system transformation.

One community was formed to focus on challenges within the delivery system, specifically those within systems working to integrate evidence into practice, otherwise known as learning health systems. The Data and Analytics in Learning Health Systems (DALHS) community of practice is made up of experts from diverse backgrounds, including clinicians, health services researchers, economists, epidemiologists, data scientists, and informaticians. Meeting monthly, the group shares lessons learned and prioritizes promising approaches to improve the experience of care and the health of populations while reducing per capita health care costs.

Another community of practice within the EDM Forum focuses specifically on the use of EHD to support the efforts of local and state public health agencies. With ongoing support from the Robert Wood Johnson Foundation, the Population Health Community of Practice, or PopCoP, engages representatives from more than 15 leading local health departments to meet monthly and discuss shared challenges and opportunities to use EHD to improve population health.



A National Network

The EDM Forum included participants from across the country all working to improve the use of health data.



Beyond the communities of practice, the EDM Forum also served as a test bed for the development of new tools and methods to increase collaboration and spread innovation. Transparency is a critical element in cultivating a culture of experimentation. Researchers need easy and secure ways to share data, code and their scientific processes. The EDM Forum needed a more user-friendly way to share data and code for informaticians, implementation scientists, team scientists, data scientists, and health systems researchers.

Members of the EDM Forum collaborated to meet this need and built an open-source platform for data integration and analysis, and software sharing. CIELO stands for Collaborative Informatics Environment for Learning on Health Outcomes, but its acronym, which means "sky" in Spanish, refers to the limitless possibility of the power of collaboration. Many researchers and other health professionals may not know the value of the information they hold beyond their respective projects. By using CIELO, they are exposing their work to other experts with different perspectives and needs, thus expanding its potential impact.

The CIELO platform allows researchers to share software and data and connect with peers, colleagues and specialists to improve the timeliness, efficiency and transparency of data analysis. Projects on the platform range in focus from maternal health to interventions aimed at reducing health disparities – and all leave behind useful data sets and methods that can be adjusted or scaled to help others with similar interests. The project serves to support a broader goal of the EDM Forum to improve dissemination, transparency, and reproducibility of patientcentered outcomes research using EHD.



In addition to encouraging data sharing, the EDM Forum recognized the importance of the quality of the data itself. Health care data provides unique challenges when it comes to quality. It comes from multiple places, occurs in different formats, and exists in different systems. Data collection is not rigorously standardized and data definitions change constantly as the understanding of various health conditions evolve.

The Data Quality Collaborative brought together a group of leading experts to ensure that EHD is credible and high quality. The group had a special focus on comparative effectiveness research (CER) and patient-centered outcomes research. The collaborative published research ranging in focus from transparent reporting to engaging patients and consumers in data stewardship. The collaborative also worked to develop a tool to help standardize data quality checks and hosted a Code-a-Thon where teams competed to create visualizations of data quality results produced by the tool. In addition to this, the group worked to develop a comprehensive data quality assessment framework and guidelines, including draft recommendations that can guide the development of new analytic and reporting methods specifically directed to data quality assessment and reporting. Since then, the collaborative has taken on a life of its own, receiving funding from PCORI to continue its important work.

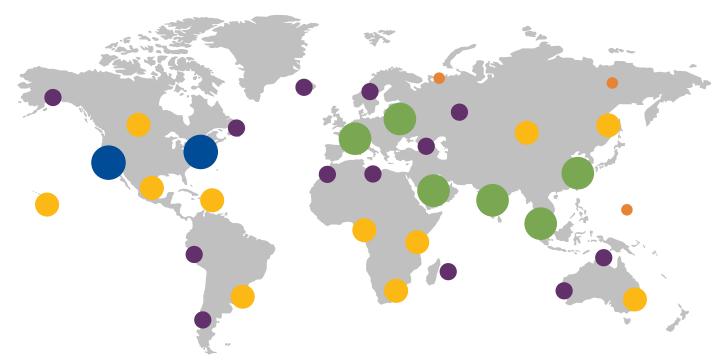
In total, the EDM Forum supported over 35 collaborative papers and projects. But the work didn't stop there. After bringing people together, helping them work together to create new solutions, the EDM Forum worked to provide avenues through which these solutions could be distributed and used by others in the field.



Disseminate

The Global Reach of *eGEMs*

Launched in 2013, *eGEMs* has published over 160 papers with more than 160,000 downloads from readers across the globe. This map shows download data from *eGEMs*' Google Analytics.



Academic researchers often see their primary audience as fellow scholars and thus, scholarly journals and conferences as the best forms of dissemination. But, in order to have an impact on health care delivery, findings need to move beyond the ivory tower of academia and academic medical centers.

The EDM Forum's dissemination strategy built upon AcademyHealth's commitment to getting actionable evidence into the hands of decision makers when they need it and in a format they can use. We know that policymakers and practitioners alike need evidence that is responsive, timely, credible, and efficient. Most people in this audience don't have time to wait the average of 17 years for new knowledge generated by randomized controlled trials to be incorporated into practice.

So rather than go the traditional route, the EDM Forum pushed its members to explore new dissemination methods including social media, an open access online journal, interactive online reports, and toolkits that could go directly to the hands of those on the frontlines.

The EDM Forum cultivated a significant online presence that could support, catalogue, and promote key products and activities, including in-person and virtual meetings, collaborative projects, analytic products, and other related resources of interest to the EDM Forum network. Ultimately, AcademyHealth's management of online dissemination and social media activities supported the growth of the EDM Forum community and generated a Twitter following of over 1,000 people.

The creation of the open access journal, *eGEMs*, was a critical part of our strategy to improve dissemination, transparency, and reproducibility of research using EHD. While researchers have always been able to share study results through existing peer-reviewed journals, the brilliance behind those results is often left in the shadows without a way for the community to disseminate the methods in sufficient detail to replicate and/or adapt them.

As EDM Forum Principal Investigator and *eGEMs*' founding Editorin-Chief Erin Holve wrote in *eGEMs*' inaugural commentary: "We are privileged to be part of a scientific and technical community that is not simply focused on developing individual datasets or specific knowledge on narrow populations and conditions, but has a genuine interest in transforming the way new knowledge is generated and used to benefit patients, their families, and communities."

Launched in 2013, *eGEMs* has published over 160 papers with more than 160,000 downloads — all highlighting cuttingedge projects from leaders in the field and sharing emerging approaches to redesigning the health system. Readers include health services and systems researchers, clinicians, policymakers, patient advocates, and other health system stakeholders from all over the world. Beyond peer review, the EDM Forum also worked to highlight learnings from the community via accessible online publications. In 2015 and 2016, the team released annual reviews highlighting major events, initiatives, key investments, and emerging evidence using EHD to improve patient care and outcomes.

The inaugural edition of the EDM Forum Review tied together several of the EDM Forum's analytic efforts in one central place to tell a story about the rapid progress among the users and producers of EHD. As a digital report and living document, the Review is a resource for the entire community working with EHD, both to chart current progress and highlight emerging trends. The 2015 Review also illustrates the ongoing need for research investment in clinical research informatics and the dissemination and implementation of this research.

The 2016 Review highlights key trends and drivers of change within the EHD ecosystem, including federal government action aimed at leveraging electronic data and reporting, unprecedented investments in big data, an increasing role for community-based data sharing and leadership, and the continued evolution of scientific collaboration.

Previewed at Concordium, the reviews were shared broadly via social media and other digital channels, serving as the go-to guide on the state of EHD-related work across the field.

As might be expected from a forum built around shared challenges, AcademyHealth also provided dissemination tools that were extremely targeted and practical – toolkits aimed at helping solve some of the most pervasive issues in the field.

One of those pervasive issues is the governance of health information. The increase in the collection and sharing of EHD highlights several issues relating to data privacy and security, liability, institutional review board approval, and concerns around proprietary data. While everyone participating in electronic data sharing has to confront governance issues, there was very little guidance available for doing so – especially when it came to community-based initiatives.



In an effort to advance the understanding of effective governance, the EDM Forum created the Governance Toolkit. While the governance work started out as a collaborative project, the toolkit made the work easily accessible to those on the frontlines. This included tools, sample guidance documents, and practical approaches to common challenges, with the overall goal of advancing the national dialogue on governance issues of data and information – particularly for CER, patient-centered outcomes research, and quality improvement.

A key contribution to the field came out of this governance work. In an effort to make it easier for more individuals to participate in patient-centered outcomes research, an EDM Forum team created a breakthrough e-consent process that makes it easy for people to enroll in research trials while also protecting the privacy and data security of their information. The tool is now being used by Apple in their ResearchKit, a framework for running clinical studies on the iPhone.

In another example of a collaborative project dissemination, EDM Forum participants collected resources related to patient-reported outcomes (PROs). While medical technology allows measurement of physical or biochemical data of a patient, it doesn't tell the whole story. For example, some symptoms such as fatigue or headaches are not obvious to observers or easily measured. PROs are measures for understanding the patient experience and the effectiveness of care.

Despite the complexity of PROs, their potential value in improving quality of care and disease outcomes is increasingly acknowledged – by policymakers and the evidence-generating provider community. The purpose of the PROactive Toolkit is to foster open discussion and share resources related to the implementation of PROs in health care. The toolkit includes best practices and a description of common challenges and recommendations. These tools are intended to assist clinicians, administrators, and researchers who are interested in including PROs in their work. Areas of the toolkit address: how to make the case for PROs; how to include their collection in routine workflow; considerations for measure selection; what types of information technology may support PRO collection; and how to involve patients.

Through it all, the EDM Forum spearheaded knowledge management for the community, hosting and organizing all its outputs – from webinars to issue briefs to peer-reviewed papers – on a searchable and accessible website, http://www.edmforum.org.

Conclusion

Through a model focused on bringing innovators together, supporting them in priority-setting and collaboration, and enabling them to disseminate their findings to a broad range of audiences, AcademyHealth's EDM Forum helped shape the next generation of learning health systems. Growing from a small group of individual projects to 4,000 engaged contributors, the EDM Forum has left a lasting mark on health care delivery systems research through hundreds of resources that will continue to serve the field for years to come.



The People of the EDM Forum

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