

## EDM Forum Supplement Overview

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**Background:** The Agency for Health Research and Quality funded the Electronic Data Methods Forum (EDM Forum) to share the experiences and learnings from 11 research teams funded through three different grant programs, each of which involve the use of electronic clinical data in Comparative Effectiveness Research and Patient-Centered Outcomes Research.

**Objectives:** This overview is meant to describe the context in which the EDM forum was created and to introduce the set of papers in this supplement to *Medical Care* that describe the challenges and approaches to the use of electronic clinical data in the three key areas of analytic methods, clinical informatics and data governance.

**Conclusions:** The participants in the EDM Forum are providing innovative approaches to generate information that can support the building of a “learning health care system.” The compilation of papers presented in this supplement should serve as a resource to others working to develop the infrastructure for collecting, validating and using electronic data for research.

**Key Words:** comparative effectiveness research, Patient-Centered Outcomes Research, analytic methods, clinical informatics, data governance

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The significant investments in comparative effectiveness research (CER) from the American Recovery and Reinvestment Act opened the door to innovative approaches for collecting, validating, and utilizing the growing amount of data made available from electronic clinical data sources. The Agency for Healthcare Research and Quality (AHRQ) awarded grants to 11 research teams working in projects including Prospective Outcome Systems using Patient-specific Electronic data to Compare Test and therapies (PROSPECT), enhanced registries for quality improvement and CER, and scalable distributed research networks (DRNs) with a charge to build infrastructure and methods for collecting and analyzing prospective electronic clinical data and facilitating its use for CER and Patient-Centered Outcomes Research (PCOR).

AHRQ also recognized the potential value of implementing a convening body for the 11 research projects to share lessons learned and advance the science of electronic

clinical data use. The Electronic Data Methods Forum (EDM Forum), managed through a grant from AcademyHealth, was designed to provide practical assistance to support information exchange and dialog, which is particularly important given the short 3-year, 1-time investment to demonstrate proof of concept of the use of electronic clinical data for CER and PCOR. Since its inception, the EDM Forum’s activities have been guided by the EDM Forum steering committee, an 18-member panel that works with EDM Forum staff to convene and foster collaboration between the multiple research sites in response to the project’s mission.

Through webinars and symposia, the principal investigators and members of the analytic teams have shared early lessons learned and common challenges and innovations. This supplement to *Medical Care* is an example of the collaborative efforts of the research teams and provides an opportunity for dissemination of their key challenges and approaches to infrastructure development. In the supplement, we present articles addressing the challenges of building infrastructure for CER with electronic clinical data in topic areas related to each of the initial 3 subcommittees of the EDM Forum: analytic methods, clinical informatics, and data governance.

The analytic methods papers in this special issue address 2 critical challenges when conducting CER with research networks—how to assess data quality and approaches to developing cohorts for CER studies. Kahn and colleagues present a conceptual model for evaluating and investigating data variability and quality in multisite clinical studies, whereas Desai focuses on approaches to developing cohorts for CER using population-based surveillance data from existing electronic data sources collected at multiple sites. In the clinical informatics papers, the authors undertake a variety of practical considerations when using new clinical informatics approaches for CER. Hamilton Lopez and colleagues present a review of the literature intersecting clinical informatics and CER; Hazlehurst and Sittig describe informatics platforms for combining electronic clinical data across networks for the purposes of conducting CER; Kahn and colleagues articulate a set of criteria for selecting data models for CER; and Wilcox and colleagues describe considerations when using mobile technologies for data collection. The data governance papers address approaches to achieve multisite Institutional Review Board approval for CER, including “pathways to success” in the context of building new networks for quality improvement and CER (Marsolo) and a review of the literature that highlights methods that are currently being explored and developed for deidentification and anonymization (Kushida).

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A set of engaging perspectives to connect these papers with other important research and quality improvement efforts are provided by leading experts in the field. We thank Dr Russell Glasgow from the National Cancer Institute at the National Institutes of Health, Dr Mark Frisse of Vanderbilt University, and Dr Harold Luft of the Palo Alto Medical Foundation Research Institute for their insightful comments on analytic methods, clinical informatics, and data governance. These papers are also joined by a set of papers that frame the charge of the research efforts from AHRQ's perspective, by Dr Gurbaneet Randhawa and Jean Slutsky, and a pair of papers that reflect the common set of challenges faced by the research teams on the basis of an environmental scan of project materials and resources, and a series of 6 site visits conducted by the EDM Forum (Holve and colleagues).

In addition to its work with the research teams, the EDM Forum is committed to engaging stakeholders into CER and ensuring widespread promotion of the tools, techniques, and findings from the research projects. To date, the EDM Forum has ongoing connections with relevant projects and entities including: AHRQ's Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) Network, the Observational Medical Outcomes Partnership (OMOP), the Food Drug Administration's (FDA's) Mini-Sentinel program, the Patient-Centered Outcomes Research Institute (PCORI), and the Office of the National Coordinator for Health IT (ONC) Query Health initiative and has reached over 800 stakeholders through webinars, Stakeholder Symposia, and its open community portal <http://www.edm-forum.org>.

The research networks participating within the EDM Forum are arguably some of the most innovative efforts to generate new information to support the idea of building a "learning health care system." Through this compilation of work by members of the various research teams, this supplement is meant to serve as a resource on the various

approaches applied to developing a sustainable infrastructure for collecting, validating, and using electronic clinical data for research. Their experiences with analytical methods, clinical informatics, and data governance should be used for moving the discussion, and ultimately the science, forward.

The EDM Forum is a true collaboration between multiple disciplines and perspectives. I extend my appreciation to Gurbaneet Randhawa, MD, MPH for his leadership as the EDM Forum project officer at AHRQ. He continues to encourage and provide much appreciated direction to the EDM Forum and the PROSPECT, DRN, and enhanced registries grantees. I also acknowledge the support of Carolyn M. Clancy, MD, Director, AHRQ and Jean R. Slutsky, PA, MSPH, director, Center for Outcomes and Evidence (COE), AHRQ. I extend my thanks to Lisa Simpson, MB, BCh, MPH, FAAP President and CEO of AcademyHealth for her continued leadership on the EDM Forum project. The EDM Forum is successful because of the efforts of its PI Erin Holve, PhD, MPH, MPP and her staff. I acknowledge and thank the members of the EDM Forum Steering Committee, especially the Steering Committee Chairs: Lisa M. Schilling, MD, MSPH; John F. Steiner, MD, MPH; and Clete A. Kushida, MD, PhD, RPSGT. Finally, I express my gratitude and appreciation to the members of the PROSPECT, enhanced registries, and DRN research teams, specifically the authors in this supplement for their great work and long-standing contributions to the field.

In near future, the EDM Forum will face new challenges, most notably how to disseminate research findings to a larger audience and promote sustainability and scalability of the participating research projects. By design, the EDM Forum and the participating research projects can act as a catalyst to link different efforts at many levels, funded by AHRQ and other agencies, to pioneer the work in research using electronic clinical data.