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Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems: A Message from the Guest Editor

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Abstract

A learning health system is one in which clinical information and research are continually used to improve the processes, outcomes, and quality of care. No matter which definition of comparative effectiveness research (CER) or patient-centered outcomes research (PCOR) is preferred, there is nearly universal agreement that a core feature of these research efforts is the need to engage decision makers, such as patients, providers, and policymakers, in prioritizing and defining research that addresses and resolves important evidence gaps to improve patient care and outcomes. In this set of eGEMs papers focused on decision-making, leaders in scientific fields with an interest in developing the next generation of CER, PCOR, and quality improvement (QI) studies share their perspectives on the potential applications, as well as the short-and longterm challenges, of using electronic clinical data (ECD) to address health care information needs within a learning health system. This commentary introduce eGEMs' first special issue, which was developed through a series of conversations with leading experts, as well as an open call for papers in early summer 2013. The six papers presented represent a first set of papers on decision makers and decision-making using these new data, with other papers (to follow) being currently under development to add to the perspectives provided here.

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Keywords

learning health system, decision making, comparative effectiveness research, patient-centered outcomes research, quality improvement

Disciplines

Health Services Research | Medicine and Health Sciences

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Ways Decision Makers Can Use Evidence to Improve Patient Outcomes in Learning Health Systems: A Message from the Guest Editor

Wade M. Aubry, MD¹

A learning health system is one in which clinical information and research are continually used to improve the processes, outcomes, and quality of care. No matter which definition of comparative effectiveness research (CER) or patient-centered outcomes research (PCOR) is preferred, there is nearly universal agreement that a core feature of these research efforts is the need to engage decision makers, such as patients, providers, and policymakers, in prioritizing and defining research that addresses and resolves important evidence gaps to improve patient care and outcomes. In this set of *eGEMs* papers focused on decision-making, leaders in scientific fields with an interest in developing the next generation of CER, PCOR, and quality improvement (QI) studies share their perspectives on the potential applications, as well as the short- and long-term challenges, of using electronic clinical data (ECD) to address health care information needs within a learning health system.

In my work over the past three years with the Electronic Data Methods (EDM) Forum, sponsored by the Agency for Healthcare Research and Quality (AHRQ), there has been a growing literature and robust discussion of CER methods, clinical informatics, and governance, but only a limited number of published papers on ways that decision makers could take advantage of these new data to develop learning health systems. To address the decision makers' needs, I am pleased to serve as the Guest Editor of this collection of papers discussing new possibilities for using ECD—in ways valuable to users of CER, PCOR, and QI studies—to drive change and improve outcomes. The potential to use data from electronic health records (EHRs) to build learning health systems will greatly benefit from the perspectives of experts on the uses of new types of research and information to guide care. Enhancing the awareness of decision makers' priorities and challenges will help to ensure a greater likelihood of success for the application of research and QI interventions if, at the outset, these efforts are oriented to reflect decision makers' perspectives.

This is *eGEMs*' first special issue, which was developed through a series of conversations with leading experts, as well as an open call for papers in early summer 2013. The six papers presented represent a first set of papers on decision makers and decision-making using these new data, with other papers (to follow) being currently under development to add to the perspectives provided here.

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Data, Evidence, and CER

The first six papers published in the special issue can be broadly grouped into three categories. The first is *frameworks to consider the availability of new data and evidence that are most useful for decision makers*. Each paper addresses ways in which the design, conduct, and dissemination of CER should explicitly engage decision makers at the outset of developing a CER, PCOR or QI study. In his paper, "Moving to a User-Driven Research Paradigm," Dr. Gurvaneet Randhawa from AHRQ draws on extensive experience working with leading national policymakers, including the U.S. Preventive Services Task Force, to propose a framework for thinking about the range of factors and the variability in thresholds used to make decisions. This framework may help researchers in creating actionable information to meet the needs of decision makers, which is needed for the transition to a user-driven research paradigm. Similarly, Dr. Alan Tomines and colleagues from the Los Angeles County Department of Public Health address ways in which electronic health information systems can reshape the practice of public health. Their paper, "Applications of Electronic Health Information in Public Health: Uses, Opportunities and Barriers," frames the potential to use ECD to support the core functions of public health and reviews promising efforts to use ECD to assess individual or community health status, monitor public health issues and concerns, and support public health interventions.

Generating New Knowledge

The second set of perspectives comes from clinicians and researchers working at the forefront of efforts to *generate new knowledge that is useful to clinical and policy leaders*. Benedict Nwachuku et al., in their paper, "Electronic Data Capture through Total Joint Replacement Registries," discuss their experiences integrating electronic data capture and reporting methodology into the California Joint Replacement Registry (CJRR) and American Joint Replacement Registry (AJRR) initiatives. Based on the experience of national joint replacement registries in other countries in improving clinical decision-making and early results in the CJRR and AJRR registries, the use of ECD for joint replacement registries has the potential to better facilitate multi-stakeholder collaboration, improve the quality of care, reduce medical spending, and foster

customized, evidence-based, clinical decision-making. In his paper, “Health-Weighted Composite Quality Metrics Offer Promise to Improve Health Outcomes in a Learning Health System,” Dr. Scott Braithwaite, current president of the Society for Medical Decision Making, discusses the potential of health-weighted composite quality metrics to measure, by synthesizing individual evidence-based quality metrics into a summary measure that reflects the relative benefit conferred by QI efforts, how much “health” is conferred by a health system. Though it has been challenging to create health-weighted composite quality metrics because of methodological and data limitations, the availability of patient-level data from EHRs makes these data more accessible and usable. The paper also discusses necessary attributes, possible uses, and likely limitations and challenges of these health-weighted summary measures.

Developing New Measures to Assess Health System Improvement

The third category of papers come from health technology and quality assessment experts who have experienced the challenges of *developing appropriate measures to assess the dimensions of health systems that are most critical to health care leaders*. Dr. Phyllis Torda et al. from the National Committee for Quality Assurance share their perspectives on the promises and challenges of using EHR data for QI efforts at the national level in their paper, “Achieving the Promise of Electronic Health Record-Enabled Quality Measurement: A Measure Developer’s Perspective.” The authors discuss how local variation (including differences in provider workflow and documentation habits), adoption of advanced EHR functions, and exchange of interoperable data may have an impact on the ability to specify eMeasures, as well as how measure developers are addressing these issues. In their paper, “How Electronic Clinical Data Can Improve Health Technology Assessment,” Dr. Jonathan Treadwell and colleagues from the ECRI Institute discuss current methods and practices for conducting

health technology assessments (HTAs) and note that ECD are captured routinely by clinicians and hospitals but only rarely incorporated into formal HTAs. They describe the potential and opportunity to more fully incorporate ECD into formal HTAs, and they highlight potential benefits and pitfalls of including ECD in HTAs and the implications of this for better medical decision-making.

Next Steps

We hope this selection of papers is only the beginning of an ongoing discussion of these important topics with decision makers and the community through *eGEMs*. As several of the authors of the papers released today suggest, more publications on promising practices and lessons learned from implementation efforts that address the information gaps faced in health care are needed. *eGEMs* is well suited for hosting these discussions, particularly for efforts to establish the methods by which the needed solutions are implemented and tested. For more information on submitting papers to this special collection, please see the *eGEMs* Instructions for Authors.

I encourage you to review these papers and provide your comments to help drive the conversation within the EDM Forum. As a community-led initiative supported by AHRQ, the EDM Forum invites a range of stakeholder perspectives and experiences to the table, including those of patients and their advocates, providers, policymakers, employers, payers, and purchasers. It is critical to further explore the information needs and promising practices of these and other stakeholder groups to orient the emerging use of electronic health data toward addressing the most important questions. I hope you will contribute to this scientific collaborative and join the discussion as we progress toward a more collaborative learning health system through better information and improved decision-making.