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Learning How to Learn: How AcademyHealth is Supporting Evidence Generation in a Transforming World

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Abstract

The field of health services research faces significant challenges as it aims to address pressing issues of quality and cost in the US healthcare system. Major advances in the availability of electronic clinical data (ECD) provide the opportunity to address questions that are important to the recipients, providers, and purchasers of health care. This is where eGEMs has a role to play, meeting an expressed need in the scientific community by disseminating approaches and methods for using ECD. eGEM's efforts can help researchers answer these important questions and consider strategies to further improve the US healthcare system.

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Keywords

health services research, electronic clinical data, learning health system, translation, dissemination

Disciplines

Health Services Research

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Learning How to Learn: How AcademyHealth is Supporting Evidence Generation in a Transforming World

Lisa Simpson, MB, BCh, MPH, FAAP¹

Abstract

The field of health services research faces significant challenges as it aims to address pressing issues of quality and cost in the US healthcare system. Major advances in the availability of electronic clinical data (ECD) provide the opportunity to address questions that are important to the recipients, providers, and purchasers of health care. This is where eGEMs has a role to play, meeting an expressed need in the scientific community by disseminating approaches and methods for using ECD. eGEMs can help researchers address these important questions and consider strategies to further improve the US healthcare system.

In the face of growing pressure on the healthcare system to provide better care and cut costs, the production of relevant, timely evidence on what works is increasingly more important. The field of health services research has a tremendous opportunity to meet this challenge but it will require some important changes in how we approach our work. As Reed Tuckson, MD, Senior Vice President at UnitedHealth Group, stated at our recent 2012 Annual Research Meeting, “*This is your moment! You better deliver.*” We believe the field of health services research can deliver, but it will take some significant shifts in our thinking.

There are three areas where we are especially being asked to step up our game and “deliver.” First, the field is being asked to more directly address the questions that patients, delivery systems, and purchasers care about. Second, we have to improve our methods and capabilities to use vast new amounts and types of data in our research. Indeed, the data and information infrastructure of our field is shifting beneath our feet. We are no longer dependent only on national surveys and administrative datasets to do our work. We can leverage the explosive growth of electronic clinical data (ECD) and the ability to link these data across very large institutions, settings, and data types and combine them with new types of data from genomics, biometric monitoring, and crowd sourcing applications to generate far larger and richer analytic samples that can answer critical questions. Furthermore, with new and improved analytic tools and methods we have the potential to generate credible conclusions. The third area where we clearly have to do a much better job is the dissemination and translation of our findings. It really is time for us to make Andy Balas’ oft quoted “17 year translation gap” a memory.¹ We simply can no longer afford as a society to have the products of research languish on metaphorical bookcases. We need to disseminate our findings far more quickly to policy and practice audiences in ways that actually inform decisions and achieve real care improvement.

eGEMs is an integral part of our strategy to work with our members to address these challenges. Health services researchers have always been able to share the results of their studies through the many existing peer-reviewed journals and grey literature outlets. What we have been less able to do is disseminate the approaches and methods that yielded those results in sufficient detail to replicate and/or adapt them. Whether it is how to engage patients, map and merge electronic clinical datasets, or translate findings to stakeholders, we need a forum where successes and failures can be reviewed and published quickly. As the professional society for the field, AcademyHealth supports innovation, adaptation, and learning to advance research itself. We are launching eGEMs in response to the expressed needs of our members and partners as part of helping our field “*learn how to learn*” and capitalize on the opportunities in the present research environment.

Asking the Right Questions by Engaging Users

Much attention is being paid these days to the importance of engaging patients and their caregivers in identifying and prioritizing research topics and throughout the conduct of the research itself.² However, this trend toward user engagement is far broader than the individual patient or clinician. For over 30 years, the field of community-based participatory research has been refining methods for engaging community representatives in research design and execution.^{3,4,5} Researchers focused on policy relevant questions have long recognized the importance of connecting with policymakers early on at the federal, state and local levels.^{6,7,8} Increasingly, delivery system leaders are building “embedded” research units to apply rigorous HSR methods to the study of the operational questions system leaders have. What these user groups have in common is a desire to play a substantive role in setting the agenda for the research community as well as sometimes being involved in the research itself. However, doing this effectively will require significant

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changes in how many investigators approach their work which will entail changes in how research is funded and knowledge of which user engagement approach is effective for which research. AcademyHealth convenes the Consumer Patient Researcher (CPR) Roundtable as a collaborative forum to explore these issues and has recently published a report on the many phases of consumer/patient engagement in research.⁹ *eGEMs* extends our work in this area and is an opportunity to share what the field is learning about truly engaging patients and other users in our research.

Navigating the Expanding Ocean of Data

Recent investments in health information technology and comparative effectiveness research (CER) have provided substantial capital to make meaningful progress toward building an infrastructure (governance, data, methods, and training) capable of addressing many of the challenges of traditional study designs and data sources used in outcomes research and quality improvement (QI). Of the \$1.1 billion provided for CER in the American Recovery and Reinvestment Act, approximately 38 percent¹⁰ supported infrastructure development (including data, methods, governance, and training). The PROSPECT, DRN, Enhanced Registry studies (representing a \$100 million investment to build ECD infrastructure for multiple uses), as well as the EDM Forum are all funded through this mechanism and offer key lessons that are important for others to learn from if we are to accelerate CER and QI and use the knowledge to improve clinical care and patient outcomes. The proliferating numbers of research and QI networks are each confronting fundamental issues and challenges in all aspects of using ECD including access, governance, management, and linkages. While the lessons they are learning are not the stuff of traditional peer-reviewed journals, they do have tremendous scientific import. We need to exchange these lessons as rapidly as possible to benefit the growing community of researchers grappling with problems that, more often than not, are similar. Our HSR community needs a platform like *eGEMs* to make this happen. Without this type of dissemination and sharing, researchers are doomed to keep ‘re-learning’ the same lessons in study after study, network after network.^{11,12,13,14}

Having an Impact

The challenges of translating and disseminating HSR, CER, PCOR, and QI are anything but new.^{15,16,17,18} What is new is the urgency of the need to change “business as usual” in health care. Policymakers, employers, health system leaders, and patients have made it clear that costs cannot continue to increase and that better quality and outcomes must be achieved. The research community can not stand apart from this demand: we need to “deliver” answers more quickly and effectively. To do so, we need to test and share lessons about how to translate and disseminate. We need to learn together how to respond to the imperative to improve health and health care. To that end AcademyHealth is launching a new Translation and Dissemination Institute to extend our capacity to have an impact. As a research community we have much to learn in the coming years for us to effectively “seize our moment.” *eGEMs* is another new tool to help all of us accelerate this learning together. To borrow from Ralph Waldo Emerson,

“learning is also a journey, not a destination, and *eGEMs* can help us share our journeys.”

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