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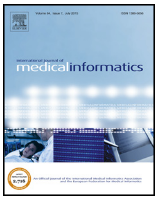

Health information exchanges—Unfulfilled promise as a data source for clinical research

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ABSTRACT

Objective: To determine the use of health information exchange organizations (HIEs) to support and conduct clinical research.
Materials and methods: This scoping review included US-based studies published between January 2003 and March 2014 that used data from an HIE to address at least one of three categories of research: clinical or epidemiological research, financial evaluation, or utilization of health services. Eligibility was not restricted to research on HIEs. Studies with research questions outside of the evaluation of HIEs themselves were sought.
Results: Eighteen articles met final study inclusion criteria from an initial list of 847 hits. Fifteen studies addressed a clinical or epidemiological research question, 6 addressed a financial consideration, and 8 addressed a utilization issue. Considerable overlap was found among the research categories: 13 articles addressed more than one category. Of the eighteen included studies, only two used HIE data to answer a research objective that was NOT specific to HIE use. Research designs were varied and ranged from observational studies, such as cohort and cross-sectional studies, to randomized trials. The 18 articles represent the involvement of a small number of HIEs; 7 of the studies were from a single HIE.
Discussion: This review demonstrates that HIE-provided information is available and used to answer clinical or epidemiological, financial, or utilization-based research questions; however, the majority of the studies using HIE data are done with the primary goal of evaluating the use and impact of HIEs on health care delivery and outcomes. As HIEs mature and become integrated parts of the health care industry, the authors anticipate that fewer studies will be published that describe or validate the role of HIEs, and more will use HIEs as multi-institutional data sources for conducting clinical research and improving health services and clinical outcomes.
Conclusion: Articles identified in this review indicate the limited extent that HIE data are being used for clinical research outside of the evaluation of HIEs themselves, as well as the limited number of specific HIEs that are involved in generating published research. Significant barriers exist that prevent HIEs from developing into an invaluable resource for clinical research including technological infrastructure limitations, business processes limiting secondary use of data, and lack of participating provider support. Research to better understand challenges to developing the necessary infrastructure and policies to foster HIE engagement in research would be valuable as HIEs represent an opportunity to engage non-traditional health care provider research partners.

1. Objective

The adoption of electronic health record (EHR) technology by physicians, hospitals, and other health care providers has exploded over the last few years largely as a result of federal investment and policies. In February 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act established the

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Medicare and Medicaid EHR Incentive Programs [1]. Since 2011, eligible health professionals and hospitals have received incentive payments for implementing new, or upgrading existing, EHR technology in a meaningful manner to improve the care of patients with Medicare or Medicaid benefits or coverage. With the establishment of this program, adoption of EHR technology has spread so broadly that implementation is no longer limited to large institutions or technologically sophisticated providers. According to the Department of Health and Human Services, as of May 2013, 80% of all eligible hospitals and over half of physicians and other health professionals have implemented the necessary EHR technology to receive incentive payments for meeting the Stage 1 expectations of the EHR Incentive Programs [2].

The goal of the EHR Incentive Programs is to ensure that providers are using the capabilities of their EHR systems for more than just recording information, ultimately leading to improved patient care [1]. This effort is commonly referred to as Meaningful Use, as providers are being incentivized to demonstrate that they are using their EHR systems in a meaningful manner. Providers submit reports of specific information from EHRs to the federal government to validate that they are using the EHR technology in a meaningful manner thus requiring EHR vendors to incorporate into their systems the ability to share information. Each stage of Meaningful Use has increasing requirements for the use of certified EHR technology, with Stage 1 requirements emphasizing basic expectations for providers who have recently implemented an EHR system. Many providers are currently working towards meeting Stage 2 which requires participation in Stage 1 for at least two years, and the electronic exchange of structured care summaries among providers using various EHR technologies. Stage 3 requirements are anticipated to emphasize the ability to exchange clinical information securely across institutions and providers [1]. The emphasis on interoperability and sharing among EHR systems has promoted the use of standards such as HL7, LOINC, and SNOMED CT—which facilitate sharing information across institutions and EHR technologies—and has fostered creation of mechanisms to share clinical information electronically between providers including the development of health information exchange (HIE) organizations.

While some HIEs predate the HITECH Act, this federal investment and enhanced provider interest in EHR systems provides the foundation for extensive HIE growth. The HITECH Act defines the HIE as "an organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards" [3]. HIEs manage data collection, mapping, patient matching, and other processes required for exchanging clinical information electronically across disparate EHR technologies. Stage 3 of the EHR Incentive Program is anticipated to increase providers' engagement with HIEs. Adler-Milstein found in a 2012 national survey that 30% of hospitals and 10% of ambulatory clinics participate in an HIE [4], and anecdotal evidence suggests continued growth in the number of participating hospitals and ambulatory clinics.

The widespread adoption of EHR technology, the requirements of Meaningful Use, and the establishment of HIEs create new potential for clinical research. Researchers are beginning to evaluate the evolving systems to determine whether the information collected and shared through HIEs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research activities. For this scoping review, the authors sought information on the use of HIEs to support and conduct clinical or epidemiological research. The objective of this study was to identify published studies that describe the use of HIEs as a data source for the conduct of clinical research specific to one or more of the following 3 areas: (1) clinical or epidemiological research including randomized clinical trials or observational epidemiological studies, (2) financial or cost evaluations of HIE use, including changes in administrative efficiencies, or (3) utilization of health services, including the evaluation of care-seeking patterns.

1.1. Materials and methods

The authors used a scoping study methodological framework as described by Arksey and O'Malley [5]. While similar to a systematic review, there are important differences in that scoping reviews address broader questions with less defined parameters, and therefore do not typically address specific research questions or evaluate the quality of included studies.

1.2. Literature search criteria

The authors conducted a search of both Medline and ISI Web of Science, to identify US-based research studies that relied on HIE data. The initial Medline search strategy used a broad approach to identify relevant articles because the terminology related to HIEs and the electronic exchange of health information has changed substantially over the last 10 years. The search terms used were "health information exchange," HIE, HIO, RHIO, "data exchange," "health information organization" and MeSH terms "health information systems" and "medical informatics applications." The search also included the following HIEs: "Indiana Network for Patient Care" which is part of the Indiana Health Information Exchange (IHIE), "Integrated Care Collaboration of Central Texas," "MidSouth e-Health Alliance," "New York Clinical Information Exchange," and "Wisconsin Health Information Exchange." These HIEs were mentioned in at least one article identified in the search process prior to abstract review. The authors accessed ISI Web of Science to identify "gray literature" such as meeting abstracts not appearing in Medline, and reviewed the content of 33 issues of the Journal of the American Medical Informatics Association (published between July 2011 and March 2014). This journal was chosen because it was the only journal that had published several of the articles identified in the initial search. Finally, the authors reviewed the citations in the identified articles for other potentially relevant articles.

1.3. Study eligibility

Eligible studies were limited to original research studies that used data from an HIE. HIE organizations were defined broadly to include organizations that facilitate exchange of health information within a closed network of care or health system, to organizations that facilitate exchange across multiple independent institutions. We chose to be most inclusive to capture as many of the organizations self-identifying as HIEs as possible. We did not restrict eligibility based on organizational structure, so included both for profit and non-profit, government-based, or health care provider-based HIEs. We also did not restrict our definition of HIEs based on their technology such as maintaining a centralized data repository or master patient index. It is possible for HIEs to participate in research without maintaining a centralized data repository as they could provide data to a clinical researcher real-time which the clinical researcher maintains for later analysis. For example, a researcher studying the impact of a clinical intervention on diabetics could partner with an HIE to send copies of A1C test results for patients enrolled in the study to the researcher as well as the ordering physician.

We excluded networks of health care providers who partnered specifically to share EHR data for research rather than to support the delivery of healthcare. Two such examples of excluded organizations include the Primary (Care) Practices Research Network (PPRNET) managed out of the Medical University of South Carolina (creates multi-provider data sets that members can use to conduct