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Health Information Exchange

Executive Summary

Background

Health information exchange (HIE) is the sharing of electronic clinical data across organizations.[1] The idea that records should follow patients wherever they receive care has been promoted as a cornerstone of efforts to improve the coordination, efficiency, and effectiveness of health services. The underlying belief is that ultimately patients would benefit if all relevant information were available to the various health care providers involved in treating them and working to maintain their health. However, realizing this vision is challenging because health care is currently provided by a diversity of organizations and providers with disparate information systems. A substantial investment of resources is needed to develop an environment that allows health care information to follow the patient.

Governments at all levels, as well as health systems and individual organizations, have and are continuing to make the significant investment of time and resources to achieve the goals of HIE. For example, in the United States, the Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act of 2009, is providing up to $29 billion in incentive funding for the adoption and "meaningful use" of electronic health records by hospitals and health professionals. The HITECH Act designated an additional $564 million for investment by States or State-designated entities to establish HIE capability among health care providers and hospitals in their jurisdictions.

Evidence-based Practice Program

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

The full report and this summary are available at www.effectivehealthcare.ahrq.gov/reports/final.cfm.

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Evidence-Based Practice

Health Information Technology

Understandably, all stakeholders are interested in assuring that there is a return on this investment. These efforts have resulted in substantial growth of HIE across the United States.[2]

The purpose of this review was to identify, summarize, and synthesize the available research about HIE. The scope of the review was purposely broad and includes studies about four topics: (1) effectiveness, (2) use of HIE, (3) usability and barriers and facilitators to use, and (4) implementation and sustainability.

Methods

This review was completed by the Pacific Northwest Evidence-based Practice Center in fulfillment of a contract from the Agency for Healthcare Research and Quality through the Effective Health Care Program. We used the Program's standard methods and procedures,3 which are similar to those established by the Institute of Medicine for systematic reviews.[4] A detailed description of the methods is available in the review protocol and in the full report, both available at www.effectivehealthcare.ahrq.gov.

After finalizing the Key Questions to be considered in our review, we looked for reports of research on HIE. We searched several bibliographic citation databases (e.g., MEDLINE®) with support from two specialized reference librarians, and we searched Web sites and tables of contents of publications that are not indexed in citation databases. Studies identified through these searches were reviewed for eligibility by two investigators. We included any study with data about an actual HIE designed to be used for clinical or public health decisionmaking. We included many different types of studies in order to provide a comprehensive review of research on HIE effectiveness, use, usability, implementation, and sustainability. Given this broad scope, the included studies varied widely in design and quality. We did not include studies of exchanges of data for research only, or studies about hypothetical or future HIEs. Data from included studies were abstracted from the articles, and this information was summarized in tables and narratives.

Results

Overview

The major results are summarized in Table A and described in this section.

Table A. Summary of evidence

Topic	Number and Type of Included Studies	Main Findings	Primary Limitations of the Evidence
Effectiveness	34 total: 20 retrospective cohort 3 RCT 2 cross-sectional 2 case series 8 survey (1 survey study was an RCT)	Low-quality evidence somewhat supports the value of HIE for reducing duplicative laboratory and radiology test ordering, lowering ED costs, reducing hospital admissions (less so for readmissions), improving public health reporting, increasing ambulatory quality of care, and improving disability claims processing. No studies of harm were reported.	Studies were of a small number of the functioning HIE implementations, with similarity to unstudied ones unknown, possibly limiting generalizability. Studies looked at limited outcomes, considering the intended scope of the impact of HIE.
Use	58 total: 25 survey 13 audit log 9 retrospective database 7 mixed methods 2 focus groups 1 time-motion 1 geocoding	The proportion of hospitals and ambulatory care practices that have adopted HIE is increasing. Currently, rates of HIE use within organizations with HIE are generally low.	While there are relatively high-quality national and regional surveys and reports that track the expansion of HIE among health care organizations, there is not a corresponding comprehensive effort to track changes in rates of use within organizations.

Table A. Summary of evidence (continued)			
Topic	Number and Type of Included Studies	Main Findings	Primary Limitations of the Evidence
Usability and factors affecting use	22 total: 9 multiple-site case study 11 cross-sectional 2 before-after	The most commonly cited barriers to HIE use were lack of critical mass electronically exchanging data (8 studies); inefficient workflow (10 studies); poorly designed interface and update features (7 studies).	Studies of usability did not relate it to effectiveness and do not permit comparisons across settings or types of HIE. Studies had limitations, such as incomplete description of the functionality and architecture of the systems, making comparison by type difficult.
Implementation and sustainability	52 total: 26 cross-sectional 17 multiple-site case study 2 before-after 3 retrospective cohort 2 prospective cohort 2 time series	Most facilitators of implementation cited in research were characteristics of HIE projects or the internal environment of the organizations implementing HIE, such as leadership. Most of the identified barriers to implementation were external environmental factors, such as concerns about competition. Factors related to sustainability were similar to those identified for implementation.	The research has not been designed to allow ranking or comparisons of the relative impact of different barriers and facilitators. The definition and appropriate measures of sustainability of HIE are not yet agreed upon, and the majority of projects are relatively recent.

ED = emergency department; HIE = health information exchange; RCT = randomized controlled trial

We reviewed 5,211 abstracts and 849 full-text articles. Of these, we included 136 studies that addressed one or more of our Key Questions. The data in the following sections come from a body of literature in which studies of 12 different HIE implementations are the most frequent even though they represent a small proportion of the HIEs functioning in the United States. Fewer studies were based on national surveys/datasets, and a comparatively small number of studies were conducted in other countries. Most of this literature has been published since 2006. Most studies were retrospective cohort studies (analysis of existing data comparing a certain outcome with and without HIE) or cross-sectional studies. We included several multisite case studies that consisted of qualitative analysis of data from several sources, including responses from interviews, questionnaires, or focus groups. Other less common research designs included before-and-after studies and time-series studies, which looked at what happened before and after HIE implementation. Only two randomized trials (in 3 publications) were identified. In general, the risk of bias for these studies was high, with some rated as moderate, although not all study designs were rated, and the overall strength of evidence was assessed as low or insufficient for most outcomes.

Effectiveness

We identified 34 studies that associated HIE with various outcomes, with 26 assessing the impact of HIE on resource use and 8 reporting on user perceptions of HIE impact. Studies that examined whether HIE improved resource use defined this as: (1) reduced ordering of laboratory tests, radiology exams, and costs, especially in the emergency department (ED); (2) reduced hospital admissions, hospital readmissions, and consultations; (3) successful public health use; or (4) improvement in quality of care or service delivery. The overall strength of evidence was low, as most studies were retrospective and reported on narrow questions, such as reduction in test ordering or consultations, and not larger overall clinical and financial impacts. Furthermore, the retrospective design of most of the studies raised the potential for confounding factors impacting their conclusions.

Studies of reduced laboratory tests, radiology exams, and costs showed the most consistent associated benefits. Four U.S. studies found reductions in ED orders of lab tests and radiology exams,[5-8] and three more found reductions in radiology alone.[9-11] A United States–based ambulatory study found a reduced rate of increase in laboratory testing

and no impact on imaging,[12] while a Finland-based study found that orders for lab tests increased while orders for imaging decreased.[13] Two studies found that HIE reduced overall ED costs.[5,6]

The studies of admissions and readmissions had inconsistent findings, with some reporting that HIE reduced admissions[6,7,14-16] or readmissions,[17] while others reported no effect.[18-21] Similarly, the findings related to consultations or referrals were mixed, with one study reporting fewer consultations and cost savings[7] and another reporting an increase in referrals by both primary care physicians and specialists.[13] We did not pool the results using meta-analysis, as the patient populations differed across studies.

Studies of other resource-use outcomes more consistently identified benefits. Studies of quality of care found that physicians providing preventive services who used HIE performed better on quality measures.[22,23] Studies also reported that HIE could help identify frequent ED users[24] but did not lead to improvement of medication adherence.[25] One study found that HIE reduced the time needed to evaluate Social Security claims.[26] Another found a positive association between general patient satisfaction in hospitals and whether the hospital had implemented HIE.[27]

In studies that asked users of HIE to report on their perception of its impact, all found at least some benefit, although some uncovered negative aspects as well. Physicians were more satisfied with electronic than paper lab reports;[28] more physicians preferred HIE that pushed data to them than HIE that required them to pull the data with a query;[29] and physicians believed electronic reports of ED use improved followup[30,31] and that HIE improved ambulatory care practice efficiency.[32,33] However, physicians in one study responded that having HIE provide pharmacy information in the ED improved knowledge but did not reduce time spent to provide service and was not worth the cost.[34] Patients reported that they preferred having records transferred via HIE over transferring paper records themselves.[35]

Although most studies of the effectiveness of HIE reported positive results, the literature as a whole was not comprehensive and few studies were of high quality. HIE is usually broad based and designed to affect practice and numerous outcomes; however, evaluation studies have focused on only one or a small number of uses or potential effects. Additionally, even in cases in which the results were positive, the effect sizes were not large or able to be assessed given the information provided. For example, ED savings are hard to evaluate if the overall budget for the ED is not known. (See evidence tables in Appendix F of the full report for detailed results.) Additionally, many studies employed simple study designs that impede risk-of-bias assessment (thus lowering our confidence in the study results). Given these limitations, it is not possible to conclude with any certainty that HIE has consistently been effective in improving health outcomes.

Use of Health Information Exchange

We identified 58 studies that described either the level of use of HIE or the primary uses of HIE. Of these, 15 studies evaluated HIE use nationally in the United States and 2 studies evaluated HIE use across integrated delivery systems. About half (30 studies) of these studies analyzed the extent to which HIE was implemented in a State or across a region, but these were concentrated in New York (10 studies), Texas (5 studies), and Tennessee (5 studies). Six studies evaluated HIE in other countries and three in multiple countries, two of which included the United States.

Nationwide surveys in the United States suggest that HIE use has risen substantially among hospitals since 2008. Use of HIE was reported by 11 percent of hospitals in 2009,[36] while more current estimates range from 30 to 58 percent.[37-39] Recent data from the Office of the National Coordinator for Health Information Technology (ONC) suggest that more than three-quarters (76%) of non-Federal acute care hospitals electronically exchanged laboratory results, radiology reports, clinical care summaries, and/or medication lists with an outside provider.[2] This represents an 85-percent increase since 2008 and a 23-percent increase since 2013. Close to 7 in 10 hospitals (69%) electronically exchanged health information with ambulatory providers outside of their organization, representing a 92-percent increase since 2008 and a 21-percent increase since 2013. Results from the National Ambulatory Medical Care Survey (2013) concluded that 39 percent of office-based physicians reported having HIE capability with other providers or hospitals.40 Limited data suggest that use of technology in general and HIE specifically is very low (> 1%) in long-term care settings.[41,42]

Between 2004 and 2009, *regional health information organization (RHIO)* was the term used to describe HIE organizations; several of the included studies used this term. All RHIOs are involved in HIE by definition, but both their reach and composition vary. In 2008 and 2009, RHIOs included 14 percent of U.S. hospitals and 3 percent of ambulatory care practices.[43] A study of public health departments found that 36 percent had no RHIO in their jurisdiction and 12 percent had no relationship with the

RHIO in their area.[44] Of those with a RHIO in their area, 40 percent were actually exchanging information.44 In RHIOs, the entities most commonly providing data are hospitals (83%), followed by ambulatory settings (60%); the entities most commonly receiving data are ambulatory settings (95%), followed by hospitals (83%), public health departments (50%), and payers (44%).[45]

Studies of HIE in integrated delivery systems included exchanges among the Department of Defense, Department of Veterans Affairs (VA), and the private sector. In an initial test in one city, 73 percent of patients could be located across the system and exchanges were executed two to three times a week.[46] A larger 12-site expansion experiment resolved some issues in matching patients but reported that the VA received information from private organizations for 9 percent of the matched patients.[47]

While organizational involvement and capacity for HIE are increasing, the data about actual use of HIE when it is possible were limited and suggested that HIE is still not integrated into usual care. For example, studies from the MidSouth e-Health Alliance suggested low use of HIE overall (from 2.6% to 9.5% of visits in 2008 and 2009),[48] with higher use for ED visits (15%) and return clinic visits (19%).[49] In another example, data collected in the Central Texas HIE from 2006 to 2011, HIE use was low—used in only 2.3 percent of encounters.[50]

Usability and Other Barriers and Facilitators to Use

We reviewed 22 studies that examined either usability or other barriers and facilitators to actual HIE use. The evidence was insufficient to compare usability by type of HIE function (query-based, or pull, vs. directed, or push, exchange) or by type of architecture (centralized or not).

We found five surveys on HIE usability, and most defined usability as it relates to function and/or measured satisfaction with exchanging health information.[29,32,51-53] Perceptions of usability were related to actual use. One study reported higher scores on a measure of satisfaction with user interface related to more frequent use,[52] and another reported that users endorsing statements that the HIE was useful and easy to learn to operate had higher levels of weekly HIE use.[54] Providers who used HIE also reported increased satisfaction and improved relationships with care partners.[53,55]A related negative finding was that providers had high expectations for HIE before implementation and reported some ongoing unmet needs once HIE was operational.[53]

Barriers and facilitators to use of HIE were identified using cross-sectional and multiple-site case studies that drew on data from several sources (e.g., interviews, focus groups, and observations). Barriers and facilitators identified fell under three broad topics: lack of critical mass electronically exchanging data, workflow, and interface. Several facilitators showed promise in promoting electronic health data exchange: obtaining more complete patient information; thoughtful implementation and workflow; and well-designed user interface and data presentation.

Lack of critical mass was a key issue: if providers do not find useful data from HIE, they are less likely to use HIE in the future. Data were incomplete because of issues of incomplete patient information that related to the setting (more complete in an ED and less in a homeless center) or challenges in matching patients across systems.[46,47,56-61] Privacy, legal concerns, and requirements that patients opt in or opt out to sharing data all reduced the completeness of data, and approaches to address these factors could lead to more comprehensive data and increased use. Differences in how HIE was incorporated into workflow and daily operations also affected use.[32,47,49,51,53,54,56,60-62] Studies found that when proxy nonphysician users accessed the system and provided relevant information to the doctors, the system was used more frequently.[48,49] Studies based on observations found that different providers used the exchange differently, with nurses seeking information on hospital admissions or other care mentioned by the patients, while physicians also used the exchange to complete their understanding of the patient history and to facilitate decisionmaking.[63] The interface and features of the systems were also cited as encouraging or hindering use. User opinions differed in terms of whether they wanted more or less information, based both on desire for more content61 and on interface issues, such as the need to scroll or click through multiple pages.[54,56,60] In addition, users reported that the systems slowed down as data were expanded to include more patients and information or that new information was not added to centralized systems quickly enough (so that going to records in separate systems was quicker).[54]

Implementation and Sustainability

We identified 52 studies that aimed to identify factors that affect implementation and sustainability. Forty-five studies identified facilitators to implementation (which we grouped into 8 categories) and barriers (which we grouped into[7] categories). While fewer studies (17 studies) considered sustainability, we sorted the positive and negative influences on sustainability so that they overlapped with our categories of facilitators and barriers to implementation. Studies were not designed to rank factors and did not provide enough data to allow us to assess the comparative impact of different factors on implementation and sustainability.

Facilitators for implementation focused predominately on the characteristics of the implementing organization or of the HIE system the organizations were planning to implement. The most frequently cited category we labeled *General Structure* of the organizations implementing HIE, and included specifics such as leadership[26,64-66] and prior experience with or readiness for information technology (IT) projects.[53,67] Another category that facilitated implementation, *HIE-Specific Structures*, included governance[26] and participatory approaches.[23,68-71] Organizations implementing HIE shifted their mission or focus (category labeled *Orientation Shift*) toward collaboration[72] and continuity of care,[73] and those that were successful were able to shift from piloting minimal HIE functions to a robust system quickly.[74] Organizations successful in implementing HIE also provided support for the implementation, such as training,[75,76] and focused on selected outcomes, such as meeting a community need.[77] *Key Functions* is our category of facilitators that included HIE designs that reflected workflow,[69] and functions that could be integrated into care processes[47,76,78,79] were also considered facilitators for implementation. The one type of external factor cited as a facilitator was policy in the form of Federal and State laws and mandates,[78,80] as well as grants from Federal and State governments that supported preliminary HIE activities and subsidized participating organizations.[67]

Barriers to implementation overlapped with facilitators but included more categories of external factors. *External Policy* included laws and grants that were identified as barriers when their timelines or changes in requirements imposed burdens on organizations that could mitigate the support they provided for implementation.[65,81] The most frequently cited category of barriers was *Disincentives*, including the issue of financial viability[67,75,78,82,83] and the mismatch between those who invest in HIE and those who benefit.[67,84,85] The *Technology Environment* was another category; characteristics that hindered implementation included lack of standards[44,86] and limited interoperability across organizations.[78,87,88] Three categories of barriers were related to the organization and its efforts to establish HIE: the *Lack of Necessary Components*, such as physician engagement;[72] the Fit between the goals and timeline of the organization and HIE projects;[89,90] and the need for resources to address complex problems with *User Interface and Functionality*.[47]

Fewer studies considered sustainability. Positive influences included factors identified as being associated with both implementation and sustainability, such as leadership by a health information organization[91] and provision of direct financial benefit to HIE participants.[84,92] The most commonly cited negative influences on sustainability were competition and the difficulty in making the business case for HIE.[93-96] Other hindrances to sustainability identified were structural factors, such as a mismatch between the geographic coverage of the HIE and the service area,[96] governance issues and lack of trust,[96,97] and lack of engagement of participating organizations and their providers.[77] One study documented that most HIE projects have overly optimistic timelines and that the lack of time and missed deadlines worked against sustainability.[74]

Implications

HIE represents a significant component of health care reform efforts. HIE is one of the major applications of health IT and requires significant resources. Thus it is not surprising that numerous studies have been published about HIE. However, this body of literature is limited in several ways. Most of the studies are not designed to sufficiently control for risk of bias, and they focus on relatively narrow outcomes when assessing the impact of a broad-based, complex, systemic intervention such as HIE. While the studies of use, usability, implementation, and sustainability provide information on context and allow some insight into trends, in general they do not permit any comparative assessment or ranking of the importance of different barriers or facilitators. Additionally these studies do not provide sufficient technical detail to compare HIE systems by function or architecture.

Although it may not be the purview of research to decide if HIE should be funded as infrastructure (as with a utility) or as a part of business operations, the notion that HIE should improve efficiency and quality of care, including clinical and economic benefits, is not overwhelmingly supported by the available evidence. Positive findings are encouraging, but both the level of the impact and some inconsistencies in results preclude any definitive conclusion.

Additionally, while surveys suggest that use of HIE is spreading, the scope of use within organizations is still limited, implementation is slow, and sustainability seems less than assured. Exactly what is needed for HIE to be effective is also difficult to discern from a body of literature that does not include many comparative studies and that does not seem to build on prior results to create a succession of increasingly relevant studies. We hope that this will improve as HIE implementations become more mature and more robust study designs are used. Future research should consist of prospective studies, carried out in mature HIE settings, assessing patients who are likely to benefit from HIE and comparing appropriate outcomes for the use or nonuse of HIE. The prospective collection of data from diverse settings where HIE is

used, classified by a detailed taxonomy of research type, system implementation, and usage type, could allow for prospective cohort studies that could identify aspects of HIE associated with beneficial outcomes.

Despite these concerns, expansion of HIE seems likely, and research could better serve this effort by developing and pursuing a more deliberate research agenda designed to capture the full potential impact of HIE and identify the comparative role of specific factors related to use, usability, implementation, and ultimately, sustainability.

Conclusions

The full impact of HIE on clinical outcomes and potential harms is inadequately studied, although evidence provides some support for benefit in reducing use of some specific resources and improving quality-of-care measures. Use of HIE has risen over time, and is highest in hospitals and lowest in long-term care settings. However, use of HIE within organizations that offer it is still low. Barriers to HIE use include lack of critical mass exchanging data, inefficient workflow, and poorly designed interface and update features. Factors we identified as facilitating HIE implementation included general characteristics of the organization and specific characteristics of the HIE system. Barriers focused more on the external environment, and disincentives made up the largest category of barriers. Sustainability was less frequently studied; the most frequently cited negative influences were competition and the lack of a business case for HIE.

To advance our understanding of HIE, future studies need to address comprehensive questions, use more rigorous designs, and be part of a coordinated systematic approach to studying HIE.

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Full Report

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