CHAPTER 14

The Evidence Base for Health Information Exchange

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INTRODUCTION

Over the last decade, there has been substantial growth in the adoption of the electronic health record (EHR) systems in ambulatory and hospital settings across the United States, fueled largely by incentive funding provided by the Health Information Technology for Economic and Clinical Health (HITECH) Act. As a result of HITECH, 94% of nonfederal hospitals [1], 78% of hospital-based physicians [2], 84% of emergency departments, and 73% of hospital outpatient departments in the United States have adopted EHR systems [3]. The motivation to increase the adoption of EHR systems is grounded in evidence that health information technology (HIT) can improve the quality, safety, efficiency, and satisfaction with care, as has been reported in a series of systematic reviews [4–7].

A major challenge to effective use of HIT, however, is that most patients in the United States, especially those with multiple conditions, receive care across a number of settings [8,9]. To enable data to follow patients wherever they receive care, attention has recently focused on health information exchange (HIE), defined as the reliable and interoperable electronic sharing of clinical information among physicians, nurses, pharmacists, other health care providers, and patients across the boundaries of health care institutions, health data repositories, states, and other entities who are not within a single organization or among affiliated providers [10]. The HITECH Act recognized that EHR adoption alone was insufficient to realize the full promise of HIT, allocating $563 million for states or state-designated entities to establish HIE capability among health care providers and hospitals [11]. As a result of HITECH funding, HIE adoption has grown in a parallel though somewhat smaller manner. By 2014, 76% of US hospitals had engaged in some form of HIE [12]. An annual survey of organizations engaged in HIE found 135 in the United States in 2014 [13].

Evaluating the effectiveness of HIE (and HIT generally) has been challenging [14]. HIE is a technology that is intermediate to improving care delivery, allowing clinicians and others’ improved access to patient data to inform decisions and facilitate appropriate use of testing and treatment. HIE is not specific to any health issue or diagnosis. HIE implementations have often been supported by one-time start-up funding, without long-term support to sustain the programs long enough for evaluation.

There are three previously published systematic reviews that focus exclusively on HIE [15–17]. One of these reviews is almost a half-decade old [15], another focused only on US-based and clinical-only (ie, not public health) activities [16], and a third assessed only care outcomes and not larger issues of facilitators, barriers, and sustainability [17]. This chapter reports on a systematic review of HIE that updated the previous ones and categorized results based on (1) effectiveness of HIE in improving clinical, economic, population, and intermediate outcomes; (2) use of HIE; (3) usability and facilitators and barriers to use of HIE; and (4) HIE implementation and sustainability. A technical report further describes the methods and includes search strategies and additional information [18].

METHODS

As is done in a typical systematic review, a research librarian conducted electronic database searches identifying relevant articles published between January 1990 and February 2015 in MEDLINE (Ovid), PsycINFO, CINAHL, and the Cochrane Library databases. Searches were peer-reviewed by another librarian and supplemented by references identified from additional sources, including reference lists, table of contents of journals not indexed in databases.
searched, gray literature sources, and experts. English language studies of HIE that reported on outcomes related to our key questions were included. We included comparative studies of effectiveness and other designs for more qualitative outcomes. Two investigators independently evaluated each study to determine inclusion eligibility. Disagreement was resolved by consensus with a third investigator making the final decision as needed.

Details of included studies were extracted by one investigator and reviewed for accuracy and completeness by a second. Investigators rated the quality (risk of bias) of the individual effectiveness studies and strength of the body of evidence based on preestablished criteria. The strength of evidence consisted of four major categories: high, moderate, low, or insufficient based on the methodological limitations of studies; consistency across studies; precision of estimates; and directness of effect. Ratings were reviewed by a second investigator, and disagreements were resolved by consensus or involvement of a third investigator if necessary.

Data could not be combined in a quantitative meta-analysis because of heterogeneity in the interventions, the outcomes measured, and the way data were reported. Therefore, we combined studies qualitatively based on similarity of the type of HIE, the implementation of the HIE, outcomes measured, and results reported. Where studies were not similar in these areas, we provided results of the individual studies without grouping them.

RESULTS

Out of 5211 potentially relevant citations identified in our literature searches, 850 articles were selected for full-text review and 136 studies were ultimately included. Search and selection results are summarized in Fig. 14.1. Of the 136 studies included, two randomized controlled trials (RCTs) described in three papers and 32 observational and survey studies addressed clinical, economic, population, and intermediate outcomes. Most were conducted in the United States, although eight were from Europe, Canada, Israel, and South Korea. These studies reported clinical or public health process, economic, or population outcomes, while no studies reported harms of HIE. The majority were assessed to be of low risk of bias (ie, good internal validity) but also contained mostly retrospective observational evidence. We identified 58 studies that addressed the use of HIE. The majority were conducted in the United States and were low risk of bias or used study designs that were not amenable to rating. Twenty-two studies were identified that addressed usability and facilitators and barriers to use. Most were assessed to be of moderate risk of bias and were conducted in the United States, Austria, and Australia. A total of 52 studies addressed HIE implementation and sustainability. These studies used varying types of qualitative methods that we did rate for risk of bias or used study designs that were not amenable to rating.

Improving Clinical, Economic, Population, and Intermediate Outcomes

Of 34 studies, 26 reported clinical (intermediate), economic, or population outcomes, while eight were found to report on perceptions of outcomes. No studies evaluated primary clinical outcomes from HIE (eg, mortality and morbidity) nor explicitly assessed harms. We list the study designs and geographic locations in Table 14.1.

The most common study design for assessing outcomes was retrospective cohort, typically with HIE use associated with a specific outcome factor (Table 14.1). The next most common design was survey, which was usually focused on perception of outcomes. Two studies were RCTs, one of a particular directed information exchange (two published papers,
one on clinical outcomes and the other on perceptions) and the other of a clinical decision support intervention using data from an HIE implementation. Two studies used cross-sectional analyses of large databases to compare those having access to HIE with those without access. Two other studies used a case series methodology, one of which involved asking clinicians if HIE access avoided undesirable resource use and then calculating the costs saved and the other that retrospectively analyzed data to determine duplicative testing averted. For additional information on study designs, refer to chapter “Measuring the Value of Health Information Exchange” which describes how to evaluate HIE.

The identified studies were performed mostly in the United States, but we identified eight studies from five other countries. Of the 26 US studies, two assessed multiple HIE implementations across the entire United States, one assessed multiple HIE...
implementations in two states (California and Florida), and the remaining 23 studies were conducted in 13 states. Most studies used retrospective designs, usually with an approach examining the association of HIE use with one or more clinical variables. All of these studies focused on the direct effect of HIE, usually in reducing resource use or costs, without determining its larger impact (eg, overall total or proportion of spending in an emergency department (ED) vs the total dollar amounts that HIE appeared to save). None of the studies analyzed individual episodes of care to determine clinical appropriateness of possible changes brought about by HIE use.

The prospective studies also had limitations. The RCTs were focused on highly specific uses of HIE, namely directed exchange of ED reports in one and pharmacotherapy clinical decision support in another. Of note, however, was that neither study showed benefit of HIE. The other prospective study was limited by methodology of physicians self-reporting of resources not utilized when HIE was used, with no follow-up or validation of their decisions or analysis of more holistic views of clinical outcomes or costs.

Most of these studies had reasonable but not strong internal validity. As the HIE intervention was only one of many potential influences on clinical outcome (ie, many more factors go into clinical outcomes than the decision to consult an HIE on a patient), there was possible confounding. As a result, most studies with appropriate retrospective methods are listed as having low or moderate risk of bias.

Due mainly to the study designs and performance or reporting limitations, the lack of ability to combine results, and other factors, the strength of this body of evidence was rated as low, meaning that future studies have the potential to alter these findings in magnitude or direction. In addition, the number of studies and their locations in the United States represent a small fraction of those reporting to be operational, sustainable, or innovating according to the eHealth Initiative Annual Data Exchange Survey, which reported a total of 84 such HIE implementations in 2013 [53] and 106 in 2014 [13]. In other words, while a substantial number of HIE implementations exist in the

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<td>Wisconsin (2)</td>
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United States, only a small number have been subject to evaluation. This low number of studies relative to HIE efforts also makes it difficult to generalize factors about aspects of them, such as location, HIE type, and setting, with results of research.

Improving Resource Use

Most of the studies of HIE effectiveness focused on resource use. We categorized these as follows (Table 14.2): laboratory testing, radiology testing, hospital admissions, hospital readmissions, referrals and consultations, ED costs, public health reporting, quality of care, and other aspects of HIE. Although the risk of bias in most studies was low, the resulting evidence from them was mostly of low strength due to retrospective designs. This low-strength evidence mostly favored the value of HIE in reducing resource use and costs, especially in the ED, but used a very narrow cost perspective and did not account for how HIE was used or its impact on the overall care of the patient beyond the immediate setting where it was used.

Perceptions

Eight studies evaluated clinician or patient perceptions of outcomes from HIE, with all showing partial or complete perception of HIE leading to improved outcomes. Clinician perceptions of the value of HIE, where studied, were generally positive. How such perceptions translate into improved care is unknown. This body of evidence was rated as low strength.

Factors Associated With Outcomes

To determine whether effectiveness of HIE varied by study type, health care setting, location, or HIE type, we categorized these factors by whether HIE was found to have some beneficial effect or not. As shown in Table 14.3, the preponderance of studies showed that HIE use for different functions, in various settings, and of varying types was mostly positive. While the number of positive versus negative studies was not an indicator of the overall direction of the evidence, we did note that for each “negative” study, there was at least one “positive” one. For “Type of HIE,” there was no clear pattern of findings to suggest that one type is clearly better than another, even indirectly. The two RCTs we found were described in three papers. Two of these reported outcomes, one for each RCT, both of which showed no benefit for the HIE intervention [45,46]. A perceptions study of one of the RCTs found impressions of improved patient outcomes and their management [47]. These were in contrast with the observational study designs where almost all found beneficial effects of HIE. For HIE setting, only ambulatory and ED had enough studies to evaluate patterns, with outpatient settings less likely to find beneficial results compared with studies in ED settings, but again based on indirect comparisons only. The sparseness of studies across geographic settings did not allow for identification of patterns, although across most studies in the United States, the findings were positive.

Use of HIE

Fifty-eight studies described either level of use or primary uses of HIE. Many of these were at low risk of bias. Fifteen nationwide surveys conducted in the United States suggested that the proportion of hospitals using HIE has risen substantially in recent years, from 11% (2009) [54] to between 30% and 58% till date [55–57]. Data from the Office of the National Coordinator for Health Information Technology (ONC) from 2014 suggested that more than three-quarters (76%) of nonfederal acute care hospitals electronically exchanged laboratory results, radiology reports, clinical care summaries, and/or medication lists with any outside providers [12]. In ambulatory care settings, 38% of office-based physicians reported exchanging information with other providers or hospitals [58]. Characteristics of higher HIE use were larger
IV. THE VALUE OF HEALTH INFORMATION EXCHANGE

At least 50% of these organizations have reached an advanced stage of use of core functionalities, with many supporting health care reform initiatives and advanced analytics [13,53]. Use varied by type of health care professional, with higher use by nurses and clerks compared with physicians [60,61]. Limited data from residential care settings suggested that use of HIE in this setting is very low (<1%) [62,63], with the consistent pattern of nonprofits having wider use than for-profit entities. An additional 30 studies analyzed the extent to which HIE was

<table>
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<th>Category (Number)</th>
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<td>Laboratory testing (6)</td>
<td>Six studies demonstrated a benefit for HIE in reducing overall tests, although estimates of impact on cost were mixed [20,27,30,32,50,51]. Four of these studies took place in the ED setting, all showing some aspect of reduced testing and cost savings [20,32,50,51]. Two studies were conducted in ambulatory settings, with one showing an increase [27] and the other showing a reduction in the increased overall rate of testing [30].</td>
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<tr>
<td>Radiology testing (9)</td>
<td>Seven studies carried out in the ED setting showing reduced testing [20,22,23,32,49–51]. Two studies were conducted in ambulatory settings, with one showing a decrease [27] and the other showing no change in rate of testing [30].</td>
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<td>Hospital admissions (8)</td>
<td>2 studies found a reduction in hospital admissions and lower costs using methods previously described [20,50]. Three other studies also measured some benefit for HIE use in reducing hospital admissions [24,36,52], although three additional studies found no such reduction [33,34,45].</td>
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<td>Hospital readmissions (2)</td>
<td>For reducing hospital readmissions, one study showed benefit for HIE [35] but the other did not [48].</td>
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<tr>
<td>Referrals and consultations (2)</td>
<td>Two studies, described previously, assessed HIE for reducing referrals and/or consultations, with conflicting results [27,50].</td>
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<td>ED costs (2)</td>
<td>Two studies found reduced overall ED costs per patient when HIE was available [20,32]. Neither study reported overall ED expenditures, making it unknown what proportion of overall ED spending was impacted by HIE.</td>
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<td>Public health reporting (3)</td>
<td>Three studies assessed HIE in public health settings, all of which were conducted in the United States and reported improved automated laboratory reporting [29], improved completeness of reporting for notifiable diseases [25], and improved identification of HIV patients for follow-up care [28].</td>
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<td>Quality of care in ambulatory settings (3)</td>
<td>Two retrospective studies found HIE associated with improved quality of care [21,26], while an RCT focused on medication reconciliation found increased ability to detect medication adherence problems but was unable to show improvement in adherence after it was identified and address by providers [46].</td>
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<td>Other aspects of HIE (3)</td>
<td>Three studies assessed other aspects of HIE, including reduction in time for processing of social security disability claims [19], increased ability to identify frequent ED users [31], and associated of HIE implementation with improved patient satisfaction scores in hospitals [44].</td>
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ED, emergency department; HIE, health information exchange; HIV, human immunodeficiency virus; RCT, randomized controlled trial.
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^aOne survey study was also a randomized controlled trial.
implemented in a state or across a region. These studies evaluated inpatient, outpatient, community clinic, and ED use, but few regions provided data. Results suggested that actual use of HIE is still not well integrated into clinical care, being used in fewer than 10% of visits in both Tennessee [60] and Texas [64], with higher use for ED visits (15%) [61]. Results from nine international or multinational studies suggested the same finding of low to moderate use [65].

Usability and Facilitators and Barriers to Use

Twenty-two cross-sectional multiple site case studies and before–after studies provided descriptive and qualitative data on usability as well as barriers and facilitators to electronically exchanging health data. The main sources of evidence from 17 US studies included survey data from 225 clinician and 174 health professional HIE users, interview transcripts and focus group transcripts of 177 clinician users, and 118 health professional users [37,60,61,66–79]. Five international studies provided survey data that included responses from more than 11,000 clinicians from 31 European countries [38,80–82] and Australia [83]. The most frequent users rated usability higher than infrequent users. Comparison of usability by type of HIE function (directed exchange or push vs query-based or pull) and architecture (eg, whether the query-based system used a centralized or federated model) was difficult as the authors described HIE differently and there was no standard classification. Additionally, users reported barriers to HIE centered on three main themes: lack of critical mass (eg, limited participation in HIE limiting availability of data needed by providers); inefficient workflow; and poorly designed interface.

Implementation and Sustainability

A relatively large number of studies identified in this review assessed factors that impact the implementation (45 studies) and/or sustainability (17 studies) of HIE [19–21,55,66,67,79,80,84–127]. Adopting and then supporting ongoing HIE are organizational decisions, and the research provides insight into what organizations experience as barriers and facilitators. Implementation and sustainability are linked (ie, organizations consider sustainability potential when deciding whether to implement a new technology), but sustainability has been the subject of fewer studies likely because HIE is still a comparatively new innovation (refer to chapter: Managing the Business of Health Information Exchange: Toward Sustainability). Across these studies the most commonly cited implementation facilitators were general organizational characteristics such as leadership and IT readiness. The most frequently cited barriers to implementation were factors viewed as disincentives including competition, costs, limited return on investment, and concerns about data misuse and privacy. Positive influences identified for sustainability were desire for the expected outcomes from HIE and the selection of HIE functions most likely to have financial benefit. The most frequently cited negative influence was competition that limited the collaboration necessary to support HIE. A major limitation of this body of evidence is that the studies have not been designed to directly compare the relative impact of these factors or to prioritize what should be addressed in order to promote the implementation and sustainability of HIE.

CONCLUSIONS

The findings of this systematic review are summarized in Table 14.4. We conclude that a collection of low-quality evidence on HIE suggests value for reducing duplicative laboratory and radiology test ordering, lowering ED costs, reducing hospital admissions (less so for readmissions), improving public health reporting,
TABLE 14.4 Summary of Evidence

<table>
<thead>
<tr>
<th>Topic</th>
<th>Number of Included Studies and Its Type</th>
<th>Main Findings</th>
<th>Primary Limitations of the Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness</td>
<td>34</td>
<td>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 evidence of harms was reported.</td>
<td>Studies were from a small number of the functioning HIE implementations, with similarity to unstudied ones unknown, possibly limiting generalizability. Studies looked at limited outcomes compared with the intended scope of the impact of HIE.</td>
</tr>
<tr>
<td>Use</td>
<td>58</td>
<td>Proportion of hospitals and ambulatory care practices that have adopted HIE is increasing. Currently, proportion of clinicians using HIE and proportion of patients or episodes associated with HIE use are generally low.</td>
<td>While there are relatively high-quality national and regional surveys and reports that are tracking the expansion of HIE among health care organizations, there is not a corresponding comprehensive effort to track changes in rates of use within organizations.</td>
</tr>
<tr>
<td>Usability and other factors affecting use</td>
<td>22;</td>
<td>Three most commonly cited barriers to HIE use were: incomplete patient information (eight studies); inefficient workflow (six studies); poorly designed interface and update features (six studies).</td>
<td>Studies of usability did not relate it to effectiveness and do not permit comparisons across settings or type of HIE. Studies had limitations such as incomplete reporting on sampling, low response rates or selection of a narrow setting or patient population which minimize applicability.</td>
</tr>
<tr>
<td>Implementation and sustainability</td>
<td>52</td>
<td>Most facilitators of implementation are characteristics of the HIE or the internal organizational environment. Many barriers to implementation are external, environmental factors. Factors related to sustainability overlap with those identified for implementation.</td>
<td>Studies do not allow comparison of the impact of different barrier and facilitators. The definition and appropriate measure of sustainability are not yet clear.</td>
</tr>
</tbody>
</table>

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

increasing ambulatory quality of care, and improving disability claims processing. The evidence is low-quality, because the retrospective nature of the studies and limited scope of the questions they address reduce their applicability. It is unlikely that additional studies of the kind included in this review will substantially alter the overall conclusion that HIE can reduce
laboratory and imaging tests associated with episodes of care without broadening their scope and using more rigorous designs. Though the preponderance of evidence supports positive effects in terms of reduced resource use and improved quality of care, it is entirely possible that focused studies with stronger study designs and more comprehensive assessment of utilization or clinical outcomes might reach a different conclusion.

**Comparison With Other Reviews**

The present systematic review of HIE can be compared with two other systematic reviews of HIE: one by Rudin et al. [16] and another by Rahurkar et al. [17]. All three systematic reviews used generally similar approaches, with similar definitions of HIE and focus on studies of HIE impact, excluding system descriptions and simple case studies. The three reviews differed, however, in their scope and inclusiveness. Our review was the broadest in scope and the most inclusive in the search for evidence. In addition to patient and population health outcomes, economic, utilization process outcomes, and barriers and facilitators to implementation and use, our review also included studies concerned with use and usability of HIE. We also included studies beyond the United States and those reporting on public health and surveillance as well as exchange of administrative and financial information. The overall result is that we examined a more diverse and more inclusive collection of evidence, especially with respect to usability and use as well as assessing public health settings, although we came to largely similar conclusions. Rahurkar et al. performed a multivariate analysis that found study design was the only characteristic associated with finding a beneficial effect, with the most rigorous studies being less likely to report benefits of HIE [17].

**Applicability**

One of the concerns of our results is how applicable they might be under “real-world” conditions in health systems, hospitals, and clinics in the United States. One concern has been that the bulk of the evidence about HIT impact has arisen out of a relatively small number of leading HIT centers [4]. These centers have been referred to as such because they are typically large academic medical centers with internally developed HIT systems, implemented incrementally, and refined over a long period of time. In the present review of HIE the concentration of evidence phenomenon is also present, with large numbers of published studies emanating from relatively few areas. Yet this time, it is regional implementation programs rather than academic health centers, such as those in Indiana, New York, and Tennessee, for which we observe a concentration of the evidence. Related to the “HIT leader,” concern is the issue of systems evaluated by their developers, also observed in other aspects of HIT [128] such as clinical decision support that tend to achieve more positive outcomes from their evaluation than external evaluators.

**Future Research Needs**

Given the limited conclusions that can be reached after review of so much published literature on the effects, use, sustainability, and barriers to implementation and use of HIE, what are the implications for future research? Researchers of HIE should work to develop greater focus and clarity about the level at which interventions are operating as well as the types and levels at which outcomes are measured. The outcomes of interest and the factors influencing them may be quite different at different levels of analysis, from specific systems or functionalities of HIE; to individual patients, providers, or episodes of care; to health care
units such as the ED, primary care practice, or hospital ward; to institutions such as hospitals; to aggregates such as health systems; or broader regional multiorganization entities or regions.

What types of studies should be performed? RCTs are impractical for technologies with wide-ranging purposes like HIE. Yet, retrospective studies associating HIE versus nonuse for outcomes such as test ordering and hospital admissions limit the conclusions that can be drawn. Research is also challenging because many of the important clinical outcomes that could benefit from HIE have many other potential contributing and confounding factors relating to the patient, his or her clinicians, the quality of care delivered, the EHR system, and other HIT used, the nature of the health care delivery system, the regulatory environment, and many more.

Future studies should be prospective, carried out in mature HIE settings, assessing patients who are likely to benefit from HIE and comparing appropriate outcomes for the use or non-use of HIE. The prospective collection of data from diverse settings where HIE is used could allow for prospective cohort studies that could identify aspects of HIE associated with beneficial outcomes. This will likely require an effort comparable in scope to national data collection efforts, such as the Patient-Centered Outcomes Research Institute Clinical Data Research Network initiative [129]. Ideally, such an undertaking could be synergistic with these other large-scale efforts.

The full impact of HIE on clinical outcomes and potential harms is insufficiently studied, although evidence provides some support for benefit in reducing use of some specific resources and achieving improvements in quality of care measures. Use of HIE has increased over time and is the highest in hospitals and the lowest in residential care settings. However, use of HIE within organizations that offer it is still low. Barriers to HIE use include incomplete patient information, inefficient workflow, and poorly designed interface and update features, but factors affecting implementation and sustainability remain unclear. 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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IV. THE VALUE OF HEALTH INFORMATION EXCHANGE


