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Transforming Health Data to Actionable Information: Recent Progress and Future Opportunities in Health Information Exchange

Indra Neil Sarkar[1,2*]
[1] Brown University, Providence, RI, USA
[2] Rhode Island Quality Institute, Providence, RI, USA

Summary

Objectives: Provide a systematic review of literature pertaining to health information exchange (HIE) since 2018. Summarize HIE-associated literature for most frequently occurring topics, as well as within the context of the COVID-19 pandemic and health equity. Finally, provide recommendations for how HIE can advance the vision of a digital healthcare ecosystem.

Methods: A computer program was developed to mediate a literature search of primary literature indexed in MEDLINE that was: (1) indexed with "Health Information Exchange" MeSH descriptor as a major topic; and (2) published between January 2018 and December 2021. Frequency of MeSH descriptors was then used to identify and to rank topics associated with the retrieved literature. COVID-19 literature was identified using the general COVID-19 PubMed Clinical Query filter. Health equity literature was identified using additional MeSH descriptor-based searches. The retrieved literature was then reviewed and summarized.

Results: A total of 256 articles were retrieved and reviewed for this survey. The major thematic areas summarized were: (1) Information Dissemination; (2) Delivery of Health Care; (3) Hospitals; (4) Hospital Emergency Service; (5) COVID-19; (6) Health Disparities; and (7) Computer Security and Confidentiality. A common theme across all areas examined for this survey was the maturity of HIE to support data-driven healthcare delivery. Recommendations were developed based on opportunities identified across the reviewed literature.

Conclusions: HIE is an essential advance in next generation healthcare delivery. The review of the recent literature (2018-2021) indicates that successful HIE improves healthcare delivery, often resulting in improved health outcomes. There remain major opportunities for expanded use of HIE, including the active engagement of clinical and patient stakeholders. The maturity of HIE reflects the maturity of the biomedical informatics and health data science fields.

Keywords

Health information exchange; health information interoperability; helivery of health care; COVID-19; health disparities

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1 Introduction

Fundamental to effective healthcare delivery is the transmission and availability of data to support information needs of clinicians, patients, and payers. For clinicians, reliable access to accurate and comprehensive health information is foundational to clinical decision making. For patients, health information is the basis for engagement in health care. For payers, health information forms the basis for supporting reimbursement models and ensuring care coordination. Collectively, health information is needed to support efficient, effective, and high-quality healthcare delivery across the entirety of the healthcare ecosystem. Systematic approaches to support the generation, transmission, and receiving of health information are a major motivation for the use of commonly templated medical charts [1, 2]. Structured electronic medical charts, or "Electronic Health Records" (EHRs), enable health data access across "islands" of healthcare delivery [1]. This promise has increasingly led to the deployment and availability of EHRs globally, through a range of national programs across the Organisation for Economic Co-operation and Development nations as well as global health initiatives for lower and middle income countries [3-5]. The increased availability of EHRs presents the opportunity to leverage digital technologies and communications infrastructure for ensuring the highest quality of care by enabling access to needed information to "the right person at the right time." An enabling feature of this tenet is an EHR's ability to share information – and thus be "interoperable" – with other electronic health systems. In health information technology vernacular, this ability is commonly referred to as "Health Information Exchange" (HIE).

As a concept, HIE is either a verb (the act of health information transmission) or a noun (an entity that supports the transmission of health information, oftentimes referred to as a "Regional Health Information Organization" or a "Health Information Organization"). HIE is the basis for health and healthcare data interoperability, canonically organized into four levels [6, 7]: (1) Foundational – the technical connection between health data sharing partners; (2) Structural – the defined format and syntax for transmission of health data; (3) Semantic – the representation of the transmitted health data into interpretable and meaningful structures for either human or machine use; and (4) Organizational – the sociolegal and policy frameworks to enable the use of the transmitted health data for use in treatment, payment, or operational decision making. Most of the prior reviews have outlined the major facets of HIE generally as well as their application in different contexts, focusing largely on aspects at these four levels.

HIE has increasingly become a major topic reported in biomedical literature, following a similar trend as for EHRs. The increased availability and usage of EHRs has increased the potential for HIE as well as establishment of government or industry endorsed health information organizations that advance the vision to enable the availability of crucial health information data wherever and whenever needed. The Medical Subject Heading (MeSH) descriptor "Health Information Exchange" was created in 2015 with the scope of being an "Organizational framework for the dissemination of electronic healthcare information or clinical data, across health-related institutions and systems. Its overall purpose is to enhance patient care" [8]. Of the 26 systematic reviews indexed in MEDLINE with HIE as a major topic to date [9-34] (retrieved using the search "health information exchange"[majr] AND systematic[sab]), some used "Health Information Exchange" as a search term; however, none explicitly used the MeSH descriptor in their search strategy, as determined from a structured search query (("Health Information Exchange"[majr] or "Health Information Exchange"[mh]) NOT Editorial[pt] NOT Letter[pt]).

This review of the HIE literature presents the results from the first direct analysis of biomedical literature indexed in MEDLINE with the HIE MeSH descriptor. The search strategy did not have any inclusion/exclusion criteria pertaining to country of focus; however, most articles reviewed for this survey focused on HIE in the United States of America. In addition to presenting a summary of the top five topics discussed in the literature since 2018, a summary is provided on HIE studies done within the context of COVID-19 and the 2022 IMIA Yearbook theme ("Inclusive Digital Health: Addressing Equity, Literacy, and Bias for Resilient Health Systems").

2 Objectives

The main objectives of this survey are to:

- Provide a systematic survey of HIE-relevant literature published since 2018;
- Identify and summarize the top five categories of HIE studies done since 2018;
- Summarize HIE studies done of relevance to COVID-19 to date;
- Summarize HIE studies done of relevance to the 2022 IMIA Yearbook thematic area; and,
- Provide recommendations on how HIE can advance the vision of an integrated digital healthcare ecosystem.

3 Methods

A computer program written in Julia (v1.7) [35] was developed and used to search MEDLINE using the Entrez programming utilities. The searches were restricted to those articles written in English (using the English[language] tag) that were published between January 1, 2018 and December 1, 2021. The search strategy explicitly excluded reviews, editorials, and letters. The LitCGeneral PubMed Clinical Query filter was used to identify COVID-19-related articles. The primary search used the following query: ((("health information exchange"[mh]) AND English[language] NOT Editorial[pt] NOT Letter[pt]) NOT LitCGeneral[filter] NOT (Systematic[sb] OR Review[pt]) AND (2018/01/01:2021/12/01[pdat])). The MeSH descriptors were tabulated for the articles retrieved from the primary search, excluding the following MeSH descriptors: Humans; Female; Male; Adult; Middle Aged; United States; Young Adult; Aged, 80 and Over; Adolescent; Medical Informatics; Japan; Aged; Health Information Exchange; Internet; Surveys and Questionnaires; Qualitative Research; Interviews as a Topic; Retrospective Studies; Cross-Sectional Studies; Medical Record Systems; Computerized; Reproducibility of Results; and Child. The top five occurring MeSH descriptors were used to retrieve (using the [mh:noexp] PubMed search tag) articles by combining them individually with the primary search. The COVID-19 specific search was done by toggling the LitCGeneral PubMed Clinical Query filter: ((("health information exchange"[majr]) AND English[language] NOT Editorial[pt] NOT Letter[pt]) AND LitCGeneral[filter] NOT (Systematic[sb] OR Review[pt]) AND (2018/01/01:2021/12/01[pdat])). The following query was used to identify relevant articles that included concepts pertaining to health knowledge and health disparities: ((("health information exchange"[majr]) AND English[language] NOT Editorial[pt] NOT Letter[pt]) NOT LitCGeneral[filter] NOT (Systematic[sb] OR Review[pt]) AND (2018/01/01:2021/12/01[pdat])) AND ("Health Knowledge, Attitudes, Practice"[mh] or health disparities[sb]). The articles for each of the top five HIE categories were manually reviewed and summarized, as well as for COVID-19 and health disparities. The source code for the computer program used for mediating the searches and MEDLINE record retrieval is available on GitHub (https://github.com/INSARKAR/imiayb_hie_2022).

4 Findings and Analysis

The primary search yielded 235 articles indexed in MEDLINE with the "Health Information Exchange" MeSH descriptor as a major index term. Most of these articles focused on HIE within the United States of America (U.S.), which reflects differences in EHR deployment strategies globally. Specifically, in 2009 legislation was passed in the U.S. to promote and encourage the implementation of EHRs [36]. Subsequent legislation in 2016 aimed to further improve the flow and exchange of electronic health information across the U.S. [37]. Nearly all the articles reflect public policy implications either to encourage HIE or be guided by the benefits of HIE globally [3-5]. A total of 15 MeSH descriptors were found to occur across nine or more articles, which were used to identify the top ten MeSH descriptors for this review (shown in Table 1). Articles associated with the six MeSH descriptors that reflected the five most common MeSH descriptors in the retrieved article set (accounting for one tie) formed the basis of the summaries presented here. Additionally, summaries were done for HIE articles retrieved that pertained to COVID-19 (11 articles) or the 2022 IMIA Yearbook theme (10 articles). The presentation of the summaries is ordered from general to specific topical areas, followed by those topics that are cross-cutting.

4.1 Information Dissemination

At the core of HIE is the development and use of technology to support the transmission of health information for healthcare treatment, management, and coordination. The second most frequent MeSH descriptor associated with the primary search was "Information Dissemination," which is defined as the "circulation or wide dispersal of information" [38]. Characteristics of HIE have been captured using national surveys, which provide consistent evidence of nationwide desires to develop national HIE networks that span clinical and political boundaries [39, 40]. However, in the U.S. there remain major concerns about "information blocking," based on federal government regulations enumerating requirements for data sharing

Table 1 Top Ten Ranked MeSH Descriptors. Grey-highlighted rows are the top five MeSH descriptors (including one tie) that formed the basis for this survey.

Rank	Articles	MeSH Descriptor
1	26	Hospitals
2	25	Information Dissemination
3	21	Computer Security
3	21	Confidentiality
4	19	Delivery of Health Care
5	14	Emergency Service, Hospital
6	13	Health Information Interoperability
6	13	Attitude of Health Personnel
7	12	Health Personnel
7	12	Telemedicine
8	11	Referral and Consultation
8	11	Continuity of Patient Care
9	10	Social Media
10	9	Health Information Systems
10	9	Primary Health Care

and exchange where data may not be shared due to non-care delivery reasons (e.g., business or political) [41, 42]. Similarly, there is a need for health information to be shared with non-clinical members of a healthcare team [43]. Ultimately, the effectiveness of HIE will depend on community understanding of the role of HIE and overcoming barriers to support sharing of health data for enabling effective healthcare delivery [3, 4, 39, 44].

HIE has been shown to improve care, through the availability of health information at critical times of need [45, 46]. HIE enables critical information to be disseminated, supporting smooth transitions of care from acute events, such as stroke [47]. Health payment reform also depends on HIEs to enable the potential impacts of bundled payment models [48]. Major challenges with the acceptance and use of HIEs are linked to sociotechnical issues that can be addressed [49, 50]. The sharing of information through HIEs enables improvement in care efficiencies that are based on effective means for disseminating relevant information to all members of a healthcare team [51-53]. Successful information dissemination across care sites improves the patient experience [54] and improves the potential to measure the quality of care and ensure patient safety [46]. HIEs support information dissemination for providers and payers, effectively serving as the underpinning healthcare data highway needed to facilitate the vision of a continuously improving healthcare system.

While not strictly *clinical* HIE, *consumer* HIE is an important aspect to support patients or their caregivers being informed members of the healthcare team. Consumer-facing resources are increasingly noted as an important complement to clinical data to inform healthcare delivery decisions [55]. This might include sharing of medically relevant videos [56, 57], and may require clear guidelines to define the veracity of information being shared [56]. The sharing of information about complex health conditions, such as schizophrenia, may be done through social media (e.g., Twitter [58]). The development of HIE-integrated consumer-facing tools has been shown to improve nationwide HIE initiatives that may have stalled due to lack of community interest in HIE (e.g., in France [59]). Such engagement is essential to address patient concerns about HIE (largely pertaining to potential security or confidentiality issues) and explicitly demonstrate the clinical benefits [60, 61]. The use of contemporary privacy preserving protocols (e.g., blockchain [62]) may therefore be essential for ubiquitous acceptance of HIEs in their use for ongoing monitoring applications.

4.2 Delivery of Health Care

Amidst the global interest in digital health and HIE, there remain notable challenges in leveraging HIE to support healthcare delivery. The fourth most occurring MeSH descriptor in the retrieved article set was "Delivery of Health Care," which is defined as "The concept concerned with all aspects of providing and distributing health services to a patient population" [63]. With respect to HIE, it is essential to understand the barriers and enablers for clinician use of HIE systems [64]. Challenges can be linked to how healthcare systems are configured and how respective policy frameworks structure sharing of health information [65]. An underpinning key to the success of HIE is the availability of interoperable-ready EHRs. EHR adoption may be increased with country-specific incentives [66] or by linking with population-level payment models that are focused on care of individuals ("bundled payment") [48]. Similarly, effective HIE is built around a common set of standards, such that they can be enforced across care environments using common vendor systems [67]. Alternatively, contemporary technologies like blockchain can support performant HIE across healthcare systems when implementation considers the architecture of the data being exchanged [68].

For health data made available by HIE to be rendered useful, the data must be clinically useful and interpretable. Effective HIE is positioned to support nurses, administrators, and researchers by providing otherwise challenging to locate clinical data that can impact clinical decisions, understanding of costs, or guide research inquiries [69]. HIE can also support availability of more complete information, such as medications [70]. Clinical decisions can also benefit from the availability of social care information as a component of HIE [71]. HIE enables the development of early detection systems, which can be highly impactful for conditions such as depression [72]. Enabling population analyses can be done through the use of graph-based query languages in combination with the growing adoption of the Fast Healthcare Interoperability Resources (FHIR) standard [73]. Timeliness in clinical interpretation of complex data available in

HIE can be supported through improved visualizations, which can be impactful in emergency settings [74].

Patient engagement remains a major challenge in supporting effective delivery of care [75]. In contrast to concerns often reflected by providers or developers, patients themselves have limited concerns about HIE [76]. HIEs can support common patient tasks, such as appointment scheduling [77], which has been shown to drive HIE adoption more generally [59, 78]. Improvements in clinical data entry interfaces improve patient access to their health data, and thus improve overall patient engagement [79, 80]. The studies included in this survey demonstrate how HIE enables a healthcare ecosystem that fosters meaningful connections between patients and their healthcare team.

4.3 Hospitals

Historically, providers (including hospitals, health systems, and their clinicians) have been a major potential beneficiary of HIE services [65]. The most frequent MeSH descriptor in the primary article set was "Hospitals," which are defined as "Institutions with an organized medical staff which provide medical care to patients" [81]. There have been limited studies to date that have directly aimed to assess the impact on hospitals. Recent studies provide an important insight to how HIE provides many benefits to hospitals, including improvement in hospital efficiency [82], as well as overall positive impacts on healthcare outcomes [40, 45, 51, 83-85]. Of note, these benefits were shown regardless of which paradigm of HIE is used (i.e., query-based versus direct-access HIE) [52]. Query-based HIE is a federated approach of healthcare data sharing partners that agree to provide health data for a given patient as needed. Direct-access HIE is a centralized approach where healthcare data sharing partners provide health data as they are available into a commonly accessible system. Query-based HIE provides immediate access to timely health information and requires less centralized infrastructure. By contrast, direct-access HIE enables the development of longitudinal histories for patients. Hospitals that engaged in HIE were shown to have reduced rates of re-admission [67], reduction in information loss during care transitions from outpatient [86] or specialty (e.g., psychiatric [87]) settings to acute care hospitals. Ultimately, these studies demonstrate how increased availability and use of HIE in hospital settings have had a markedly positive impact on improving healthcare delivery.

Hospital types can range from specialty focused to general acute care centers to community hospitals, often necessitating the transition of patients across hospital settings. HIE has been shown to be a catalyst to encourage patients to be shared across multiple clinical sites; however, sharing of patient populations may lead to concerns of potential clinical competition between hospitals [54, 88]. Functional HIE enables access to critical decision-driving data, such as laboratory findings and test results [89]. Acknowledging the breadth of hospital types and clinical catchment area demographics, studies have shown that the type of hospital can impact the quality of HIE [53, 90]. Specifically, hospitals that have the resources to invest in health information technology to support HIE are more efficient than those that do not. One study examined the potential of a game-theoretic approach (aiming to achieve Nash equilibrium) to predict the potential benefits of HIE in a range of hospital types [91]. Through this approach, it was found that hospitals with fewer resources may be less inclined to participate in HIE, due to market pressures regardless of any financial incentives. Thus, while successful implementation of HIE may improve healthcare delivery across multiple care sites, it is imperative to consider the financial implications for hospitals that may be consequential to increased market competition.

Alongside enabling their use in healthcare delivery, HIE can unleash the analytic potential of electronic health data for biomedical research, epidemiological, or surveillance uses. To support the use of electronic health data for advanced analytical modeling, such as for studies in critical care medicine [92], requires adherence to policy and legal requirements. Exchange of comprehensive health data sets can enable population-level patient monitoring, disease surveillance, or adverse event detection [93-95]. HIE data can also be used to examine the potential impact of alternative payment models, which accommodate care across multiple care sites [48, 96].

Health data are only actionable if they consist of the right data that are made available in appropriate clinical workflows in the right format and at the right time [97]. Successful HIE is predicated on the use of healthcare team members who motivate both the use and improvement of electronic health data to support clinical decision making. HIE improvements and implementation can be driven by general practitioners to improve care transitions between ambulatory and hospital settings [98]. Nurses and primary care providers can furthermore motivate the use and adoption of HIEs across care settings [99, 100]. The perceived benefits of HIE systems will depend on usability studies, which take into account planned actions relative to clinical decision making [101].

4.4 Hospital Emergency Service

Commonly referred to as the "Emergency Department" (ED), this hospital department is a major beneficiary of, and health data generator for, HIEs. The fifth most common MeSH descriptor associated with the retrieved article set was "Emergency Service, Hospital," which is defined as "Hospital department responsible for the administration and provision of immediate medical or surgical care to the emergency patient" [102]. There are strong desires to connect HIEs into ED EHR systems and clinical workflows. However, there are challenges globally with this integration in a way that can be clinically actionable, largely due to limited consideration of ED workflows [44, 74, 99].

HIEs provide a comprehensive view to the use of healthcare services. With respect to ED utilization, HIEs can be a major source for studying utilization [103], causes for return visits [104], and the impact of social determinants of health on ED visits [105]. HIE-based interventions can be used to also identify causes for repeat-ED visits and provide approaches for their reduction [106, 107]. Clinical trials can also be constructed to examine the value of HIEs across population-specific (e.g., veteran versus civilian hospitals) care settings [108]. The holistic view provided by HIEs for patients in ED settings poses opportunities to enable the study of disorders that involve multiple clinical sites (e.g., as associated with substance use [109]).

The value of HIEs in hospital emergency service contexts is dependent on the availability of necessary health data. There are some notable missing data types (e.g., imaging [110]) that can be critical for decision making. However, success has been demonstrated with exchange of poison information [111], as well as medication information [112]. The exchange of information between EDs and other care settings (e.g., nursing homes) can also have a major impact on better coordination of care [113].

4.5 COVID-19

The emergence and spread of Severe Acute Respiratory Syndrome Corona Virus 2 (SARS-CoV-2) resulted in the COVID-19 pandemic, which has challenged healthcare systems globally since the beginning of 2020. Ten articles were retrieved using the LitCGeneral PubMed Clinical Query with HIE as a major MeSH descriptor. The COVID-19 pandemic served as a focal point for several discussions around the relevance and need for digital health strategies [114, 115]. Predictive modeling approaches have shown merit in the use of HIE-based data to enable prediction of healthcare resource utilization [116]. HIE has been leveraged to support population-level analyses, including those that may be correlated with sociodemographic, behavioral, or clinical data [117]. Harnessing HIE data for research studies also has underscored the importance of ensuring privacy of health data while meeting short-term information needs for research and healthcare delivery [118].

The COVID-19 pandemic has exposed numerous challenges in the healthcare infrastructure, including those pertaining to HIE. The lack of robust and uniform HIE has resulted in the need to develop *ad hoc* solutions to meet public health data needs [119, 120]. Where there was no robust HIE system for supporting public health updates globally, social media has been leveraged as a mechanism to share real-time public health updates [121]. Some of the challenges are rooted in challenges with EHR interfaces, which necessitated reversion to paper records and devising systems for digital conversion of handwriting and markings [122]. Finally, the lack of digital HIE systems between nursing homes and acute care facilities required the development of new digital approaches for electronic document exchange [123]. Collectively, there is an increased acknowledgement of the need for digital approaches for HIE that will be an essential component of next generation public health infrastructures that will be informed by these studies.

4.6 Health Disparities

The overall health of populations is predicated on equal access to healthcare delivery and overall community literacy about health concepts. HIE provides the opportunity for unbiased exchange of health data and knowledge to support population health. For this survey, ten articles were retrieved pertaining to health literacy and equity within the context of HIE. A core tenet of impactful health care is engagement of patients. Patient engagement through online systems, such as patient portals, has been shown to improve overall healthcare outcomes [124, 125]. It is important to also understand information needs of patients or their caregivers, who may rely on general consumer search engines (e.g., Google [126]). Health literacy is an essential facet of patient engagement, which can take the form of either an online forum [127] or public health knowledge campaigns [128]. In addition to digital systems, the use of community members has been shown as an effective peer-to-peer approach to improve health literacy [129]. In the context of patient engagement, HIE is more focused on the dissemination of knowledge in culturally congruent ways.

The use of HIE for exchange of clinical data among healthcare providers and public health agencies has been shown to improve overall population health [130]. HIE-based analysis of population trends (e.g., ED utilization) has been shown to be more accurate than using administrative data [109]. However, engagement in HIE can be challenged by differences in perception of the benefit across racial groups [131] or technical barriers found in rural settings [132]. The promise of HIE as a tangible benefit for populations will only be realized when these major challenges are addressed. The challenges faced in the implementation and use of HIE across populations are reflective of the challenges faced by biomedical informatics and health data science more generally.

4.7 Computer Security & Confidentiality

As with all health information technology, HIE requires clear principles to ensure security in the transmission of protected health information between trusted parties. Tied for the third most common MeSH descriptor in the retrieved article set for this survey were “Computer Security” and “Confidentiality”. “Computer Security” is defined as “Protective measures against unauthorized access to or interference with computer operating systems, telecommunications, or accompanying data; especially the modification, deletion, destruction, or release of data in computers. It includes methods of forestalling interference by computer viruses or computer hackers aiming to compromise stored data” [133]. “Confidentiality” is defined as “The privacy of information and its protection against unauthorized disclosure” [134]. The underpinning principle in HIE is that data are shared securely, which serves as a foundation for supporting the development of interoperable systems that serve communities [135-138]. Attention to security in HIE is especially important in sensitive clinical contexts, such as sharing information associated with organ donors [139] or supporting monitoring of conditions like diabetes mellitus [140]. Secure data sharing must account for public concerns for privacy [76, 141, 142], preservation of anonymity [143], and be trusted by the patient community [125]. In the U.S., the 21st Century Cures Act explicitly addresses these concerns through the use of contemporary HIE technologies, namely FHIR and

SMART-on-FHIR [144]. The transmission of protected health information (PHI) through HIE requires confidence that confidentiality will be ensured. There is a need for patient understanding of their control of PHI [145], which accounts for the balancing of public concerns about privacy, security, and confidentiality, while still providing the benefits of HIE in healthcare delivery [141, 146, 147]. Oftentimes, these concerns must consider political boundaries or legal issues [148, 149].

HIE within and between healthcare delivery sites can occur in multiple ways. There is a need to acknowledge the respective benefits of multiple approaches to HIE, which together can provide the most robust and secure approach to support healthcare delivery [150]. HIE can support secure messaging protocols, which require consideration of secure and reliable transmission of PHI [151]. Medical images also have very specific security requirements that must be considered when transmitted [93, 152]. A variety of approaches have been examined for supporting secure exchange of medical record data across systems, including cryptographic approaches [153], use of secure keys [154, 155], multi-factorial authentication [156], and use of blockchain techniques [62, 68, 157-160].

Challenges in ensuring confidentiality can be especially difficult when considering large volumes of complex data, such as medical images [152], as well as clinical or research contexts [92, 139, 161]. The consideration of confidentiality in HIE requires the consideration of racial or ethnic biases [162, 163], which also necessitates the need to be culturally sensitive [131].

HIEs can leverage a range of technical approaches to ensure confidentiality. These approaches can include the use of authentication keys [154, 155], cryptography, and privacy preserving algorithms [137, 153]. Contemporary techniques, such as blockchain, also show promise in supporting confidentiality without impacting usability of PHI across HIE [157, 159]. Simpler techniques, like three-factor authentication, have also shown promise [156]. The choice of technique or algorithm used to ensure confidentiality across HIE requires consideration of efficiency [143]. The choice of approach needs to be made known to the public to allay concerns about potential privacy breaches with HIE. Gaining public trust is essential for the adoption and ultimate success of HIE [142].

5 Recommendations

The complexity of healthcare delivery requires a reliable and robust healthcare data infrastructure, such as enabled by HIE. The landscape of digital health technologies is rapidly expanding and presents a panoply of opportunities that will usher in a new era of data-driven health care. The importance of HIE in enabling this vision cannot be understated. As the first survey of literature indexed in MEDLINE with the "Health Information Exchange" MeSH descriptor for HIE, this review presents a positive outlook for HIE and describes the challenges in the successful use of HIE to improve care. Considering the topics examined here, three recommendations are offered based on common themes that emerged. These recommendations move beyond the benefit of EHRs in isolated healthcare delivery settings to HIE ecosystems of EHR-based data. It is important to emphasize that these recommendations are not novel, but instead further underscore fundamentals about HIE that have been discussed previously [25, 164-168]. The full impact of HIE will depend on national public policies that support the availability and use of electronic health data across multiple healthcare settings [169-171]. HIE is not uniform across the globe and its implementation is hindered by notable barriers, such as costs and market share concerns that impact the potential for sustainability [172, 173]. In the U.S., the recently (2022) announced Trusted Exchange Framework and Common Agreement (TEFCA [174]) aims to provide a foundational step towards universal interoperability for one nation by providing a common minimum set of infrastructural and technical standards across the variety of networks associated with healthcare data interchange across the country [39]. The recommendations presented here also therefore form the basis for national public policies (e.g., TEFCA) to support HIE.

5.1 Recommendation 1: Get the Basics Right

HIE endeavors often aim to collect, exchange, and transport all available health and healthcare information with equal importance. This can be challenging from a technical perspective and may result in limited benefit to stakeholders [169, 175, 176]. The need for trustworthy and secure technology and standards for HIE are well documented and provide a foundation for enabling robust sharing of health information [175, 177-181]. Policies should support the expansion of organizations that enable HIE to be considered a component of public infrastructure, much like electricity or water delivery, to support healthcare delivery. Prioritization of data and formats should thus adhere to meet use cases that have clinical or public health impact [3, 4, 39, 44, 182, 183]. National standards for interoperability should be prioritized by government designated entities. In the U.S., TEFCA identifies the United States Core Data for Interoperability (USCDI) as a standardized set of health data classes and constituent data elements for nationwide, interoperable HIE updated and maintained through the Interoperability Standard Advisory process from the Office of the National Coordinator for Health Information Technology [39]. In cases where national standards do not exist, stakeholder groups should generate accepted sets of data types to meet specific clinical or public health use cases. The choice of standards should first be driven by clinical needs (e.g., the problem list, allergies, medications, and immunizations) and patient specific aspects (e.g., social determinants of health). Policies should be explicit about the core data types and acceptable standards that form the core of HIE. This core needs not replicate the full content of an EHR, but should include those data that are essential during the transitions of care across healthcare delivery sites and home.

5.2 Recommendation 2: Focus on Complementing, not Competing

Digital health technologies continue to emerge and fulfill many clinical and public health needs. HIE endeavors should be seen as a major partner in these endeavors, supporting their use and adoption [172, 182, 184]. HIE activities should provide clear demonstration of value to patients, healthcare providers, governments, and public health agencies [64, 182, 185]. There are many gaps in health data that need to be addressed. Partnerships between HIE initiatives will be crucial for addressing these gaps in meaningful and sustainable ways [48, 66, 69]. Healthcare delivery depends on reliable, robust, and trustworthy infrastructure, which is predicated on successful HIE working in concert with healthcare teams [66, 67, 70]. National policies should be developed that expand beyond large or medium sized healthcare delivery systems and provide clear incentives for smaller clinical sites that also provide safeguards from loss of clinical market share.

5.3 Recommendation 3: Respect Patients and Providers

Health care is comprised of a menagerie of stakeholders that have a range of often conflicting needs. Effective HIE is where patient and provider needs are met effortlessly [21, 169, 170, 186]. Attention needs to be given to how health data are delivered, and not be redundant or overwhelming. Acknowledging clinical workflow is paramount to identify what data are presented and how [79, 80, 187, 188]. Supporting patients and their caregivers with tools that enable their engagement and membership in healthcare teams can be catalyzed through HIE [75, 109, 124, 125]. HIE alone is not a panacea for health care, but its adoption by patients and providers is essential for effective clinical decision making [76, 77, 130, 186, 189-191]. Research, often on a local basis, is needed to understand stakeholder needs and identify what types of data are needed as part of HIE. National policies should include clear benchmarks for success that include patient (e.g., satisfaction) and provider (e.g., reduction of burnout) metrics alongside overall healthcare improvement outcomes.

6 Limitations

As the first systematic survey using the MeSH descriptor for HIE, there are some limitations of note. The use of MeSH descriptors enabled the design of a systematic approach that could be encoded into a computer program for supporting reproducibility; however, this did limit the potential to identify additional relevant articles that may have been identified through a hand search. It is important to also acknowledge that the indexing of biomedical literature with a given MeSH descriptor does not necessarily include the full universe of relevant articles that may have been found through a scoping review. Additionally, because MeSH descriptors are applied as an artifact of the MEDLINE-indexing process, MeSH descriptors may not necessarily reflect the original intention of the authors for a given article. The identification of topics for this survey were based on frequency of MeSH descriptors, not necessarily importance or quality. Future reviews may consider a citation-based approach to identify articles describing topics as a proxy for importance. The choice of frequency of co-occurring MeSH descriptors also may have limited detailed examination of known reoccurring topics of interest in HIE (e.g., technical architecture or governance [149, 170, 192]). Another major limitation of this review is that most articles focused on HIE in the U.S. This is likely an artifact of TEFCA and related discussions in the U.S. in recent years.

7 Conclusion

Healthcare delivery relies on the availability of necessary data for supporting clinical and public health decision making. HIE provides the foundation for making these data available to meet information needs for the multiple stakeholders in health care. The thematic areas examined for this survey reveal the major advances in HIE as well as opportunities for future enhancements. The importance of HIE in the future of healthcare delivery can be expected to increase and serves as a guiding example for how biomedical informatics and health data science positively impact patient care. The future of health care will undeniably depend on effective HIE.

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Correspondence to:
Indra Neil Sarkar, PhD, MLIS, FACMI, ACHIP
Brown University
Box G-R
Providence, RI 02912
USA
Tel: +1 401 863 2428
E-mail: neil_sarkar@brown.edu