THE USE OF HEALTH INFORMATION EXCHANGE ORGANIZATIONS IN CLINICAL RESEARCH: CURRENT STATUS, CHALLENGES AND OPPORTUNITIES

By

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ABSTRACT

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Significant federal investment has led to the increased use of electronic health record (EHR) technology and electronic exchange of health information across health care providers. Health information exchange organizations (HIOs) are organizations that provide technology and infrastructure to enable electronic health information to be exchanged across disparate EHR technologies and between different health care provider organizations. While designed to support patient care delivery, this technology has the potential to support clinical research and improve efficiencies for data collection including patient identification and data monitoring.

This study sought to determine whether HIOs have the necessary infrastructure, technological capacity and agreements among participating providers to support research using exchanged clinical data; if HIOs facilitate the development of multi-institutional datasets that can be used for research; and whether the application of HIO data (Indiana Network for Patient Care, INPC) resulted in an accurate, representative, and comprehensive foundation for a specific research question (transitions of care in intracerebral hemorrhage, ICH, patients). Our scoping review to identify published studies that used HIOs as data sources for clinical research found that, outside of the evaluation of HIOs themselves, HIO data were being used to a limited extent in clinical research studies, with only a limited number of specific HIOs involved in generating the

majority of the published research. We then used data from a national survey of HIOs to determine the extent HIOs report supporting research by allowing exchanged patient data to be aggregated and used for clinical, health services or epidemiologic research. We found that most HIOs reported supporting, or planning to support research, and that support for research is closely aligned with advanced technological infrastructure and functionality.

This study culminated in the use of data from one HIO, the INPC, to study transitions of care for ICH patients. We found that the HIO's ability to provide sufficient data to study transitions of care was hindered by two problems: 1) missing clinical data among providers that share data with the INPC and the lack of participation in the INPC for several important post-acute care settings. Most notably, the INPC data did not include encounter information from hospice providers, free-standing acute rehabilitation facilities, skilled nursing facilities (nursing home), home health, or long term care hospitals. For some of these settings (e.g. skilled nursing facilities and home health), this is in part due to the slow implementation of electronic health record and exchange technologies. In addition, we found that encounters are collapsed into broad categories (inpatient, outpatient and emergency) that do not reflect the variety of clinical interactions in a way most useful to researchers and other analysts of healthcare delivery.

As the rapid expansion in EHR use and health information exchange are relatively recent, HIO support for research is still developing. While we found limited utility of HIO data to study transitions of care for ICH patients, we only used data from one specific HIO. Additional research is required to determine whether HIOs are viable partners for research outside of the evaluation of HIOs themselves.

To Christine and Jonathon – my world is a brighter place because of you.
In memory of my best friend, Michael J. Ayers, 1964-2016

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KEY TO ABBREVIATIONS

ACO	Accountable Care Organization
BRDPI	Biomedical Research and Development Price Index
CDS	Clinical Decision Support
CHMIS	Community Health Management Information Systems
CHIN	Community Health Information Networks
CMS	Center for Medicare and Medicaid Services
CPOE	Computerized Provider Order Entry
CTSA ACT	Clinical and Translational Science Awards Accrual to Clinical Trials
EHR	Electronic Health Record
eRx	Electronic Prescribing
GLHIE	Great Lakes Health Information Exchange
HIE	Health Information Exchange
HIMSS	Health Information Management Systems Society
HIO	Health Information Exchange Organization
HITECH	Health Information Technology for Economic and Clinical Health Act
HL7	Health Level Seven
ICH	Intracerebral Hemorrhage
ICD-9	International Classification of Diseases, Ninth Revision
IHIE	Indiana Health Information Exchange
INPC	Indiana Network for Patient Care

IRB	Institutional Review Board
LOINC	Logical Observation Identifiers Names and Codes
LTCH	Long-Term Acute Care Hospital
MIPS	Merit-Based Incentive Payment System
MPI	Master Patient Index
MRSA	Methicillin-resistant Staphylococcus Aureus
ONC	Office of the National Coordinator
PCMH	Patient Centered Medical Home
PCORI	Patient-Centered Outcomes Research Institute
PQRI	Physician Quality Reporting Initiative
RHIO	Regional Health Information Exchange Organization
SNOMED CT	Systematized Nomenclature of Medicine – Clinical Terms
VM	Value-based Modifier

CHAPTER 1: INTRODUCTION

As clinical researchers face stagnating and even declining National Institutes of Health (NIH) funding budgets, the costs of conducting biomedical research continues to increase rapidly.[1] According to the Bureau of Economic Analysis in the US Department of Commerce, the Biomedical Research and Development Price Index (BRDPI) has increased over 15 times since 1950 when it was first measured, while the Price Index for the Gross Domestic Product increased by just over 6 times since 1960. The BRDPI is used by the National Institutes for Health to evaluate the ability of their annual budget to maintain a consistent level of purchasing power.[2] Reduced NIH funding and increased costs combined with the increased pressure to identify the underlying causes for major diseases and identify best health care practices encourage efforts to reduce costs of conducting clinical research. Adoption of electronic health record (EHR) technology in health care provider organizations and their connection to health information exchange organizations (HIO) represent an important opportunity to incorporate clinical research as a secondary use of the health information gathered during patient encounters.

History of health information exchange

Efforts to develop mechanisms to share clinical information electronically began in the early 1990s with grants by the Hartford Foundation to form community health management information systems (CHMISs) that centered on a shared data repository for community health assessment, billing and patient eligibility information.[3] Community health information networks (CHINs) followed in the mid to late 1990s, and emphasized cost savings by improving the efficiency of moving information between providers and used a decentralized model in which

data was maintained by individual providers.[3] Although the CHMIS and CHIN efforts had limited sustainability, they highlighted several important concepts including providing participating organizations with return on investment at a level similar to their investment in the HIO, resolving conflicts inherent to partnering competing organizations, and addressing patient privacy and security concerns.[3] In 2004, President George Bush issued an Executive Order that established the position of the National Health Information Technology Coordinator responsible for developing a nationwide interoperable health information technology infrastructure to improve health care quality, reduce medical errors and reduce health care costs.[4] The Executive Order required the National Coordinator to report within 90 days of operation on a strategic plan to guide implementation of a nationwide interoperable health information system across the public and private sectors. [5] Consequently, $2.3 million in funding was provided in 2004 by the US Health Resources and Services Administration and the Foundation for eHealth Initiative to support the Connecting Communities for Better Health Program to implement health information exchanges.[6] In March 2010, the Office of the National Coordinator (ONC) awarded State Health Information Exchange Cooperative Agreements grants to 56 states, territories and State Designated Entities "to rapidly build capacity for exchanging health information across the health care system both within and across states."[7]

Definitions

Health information exchange as the phrase is used today is defined as "the electronic movement of health-related information among organizations according to nationally recognized standards."[8] Health information exchange originated from a widespread interest in providing health care providers with access to clinical data across disparate electronic health

record (EHR) systems in order for health care providers to provide timely, safe, and effective care while reducing inefficiencies and redundancies.[9] Exchange is facilitated and governed by multiple different types of organizations including independent, non-profit organizations; state governments; state Medicaid agencies; healthcare delivery organizations; EHR vendors; and, academic institutions.

Health care providers such as hospitals, physician practices, and post-acute care providers, participate in health information exchange through a multitude of different strategies. Directed exchange is when information is sent and received securely between EHR systems through one of the following three most common strategies or mechanisms: an interfaced connection between two disparate electronic health record systems, ONC's Direct protocol (similar to secure e-mail), or participation in an health exchange organization (HIO).[9] Directed exchange works similarly to the US postal system in that an electronic message is delivered to an addressed party (i.e. lab results are delivered to the ordering physician). Directed exchange requires accurate identification and location of the health care provider that should receive the exchanged clinical information, labeled sufficiently to allow the receiving system to accurately identify the patient, transmitted according to recognized industry standards (regardless of the sending and receiving EHR technology), and secured with appropriate safeguards for the privacy and security of the protected health information throughout the process.

Query-based exchange enables health care providers to query other providers to determine whether they have clinical information that is important to the care of a shared patient.[9] This type of exchange is often only available using the services of an HIO and requires HIOs to

uniquely identify each patient and attribute clinical information to the appropriate patient, authenticate providers querying the system and monitor access of the system to protect the privacy and security of the patients, transmit and receive clinical information according to recognized industry standards (regardless of the sending and receiving EHR technology), and maintain a central data repository or mechanism to query multiple systems.

Growth of health information exchange

Health information exchange development and growth has been tightly tied to the expansion of EHR capabilities and implementation. The adoption of electronic health record (EHR) technology by physicians, hospitals, and other health care providers has exploded over the last few years largely as a result of federal investment and policies. In February 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act established the Medicare and Medicaid EHR Incentive Programs.[10] Since 2011, eligible health professionals and hospitals have received incentive payments for implementing new, or upgrading existing, EHR technology in a meaningful manner to improve the care of patients with Medicare or Medicaid benefits or coverage. With the establishment of the EHR Incentive Program, adoption of EHR technology has spread so broadly that implementation is no longer limited to large institutions or technologically sophisticated providers. According to the Department of Health and Human Services, as of April 2015, 95% of all eligible hospitals and over half of office-based physicians have implemented the necessary EHR technology to receive incentive payments from the Medicare and Medicaid EHR Incentive Programs.[11,12]

The goal of the EHR Incentive Programs is to ensure that providers are using the capabilities of their EHR systems for more than just recording information, ultimately leading to improved patient care.[10] This effort is commonly referred to as Meaningful Use, as providers are being incentivized to demonstrate that they are using their EHR systems in a meaningful manner. Providers submit reports of specific information from EHRs to the federal government to validate that they are using the EHR technology in a meaningful manner thus requiring EHR vendors to incorporate into their systems the ability to share information. Each stage of Meaningful Use has increasing requirements for the use of certified EHR technology, with Stage 1 requirements emphasizing basic expectations for providers who have recently implemented an EHR system. Many providers are currently working towards meeting Stage 2 Meaningful Use which requires participation in Stage 1 for at least two years, and the electronic exchange of structured care summaries among providers using various EHR technologies.[10] Beginning in 2018, all eligible providers and hospitals will be expected to satisfy the requirements, objectives, and measures of Stage 3 regardless of whether they progressed through the prior stages of Meaningful Use to receive incentive payments. For Stage 3, the objectives and measures align with eight key policy areas of which only one is specifically related to health information exchange and the other seven involve interoperability of EHR systems.[13] (See **Table 1.1**) The emphasis of the EHR Incentive Programs on interoperability and sharing among EHR systems has promoted the use of standards such as HL7, LOINC, and SNOMED CT—which facilitate sharing information across institutions and EHR technologies—and has fostered creation of mechanisms to share clinical information electronically between providers including the development of (HIO).

After a speech by CMS Acting Administrator (the head of CMS) Andy Slavitt in January 2016, it was widely reported that Meaningful Use is ending.[14-17] While Meaningful Use as a separate program is ending, program requirements and associated incentive/penalties are being incorporated into the new Merit-Based Incentive Payment System (MIPS) along with Physician Quality Reporting Initiative (PQRI) and the Value-based Modifier (VM) program. MIPS, which will begin in 2019, will incentivize health care providers (physicians, physician assistants, nurse practitioners and others) based on four categories performance measures: quality, resource use, clinical practice improvement activities, and meaningful use of certified EHR technology.[18] This development further reinforces the government's intention related to the use of technology to support the effective delivery of health care. In fact, within the introduction to the Medicare Access and CHIP Reauthorization Act of 2015 which creates the new MIPS program, Congress "Declares it a national objective to achieve widespread exchange of health information through interoperable certified electronic health records (EHR) technology nationwide by December 31, 2018."[18]

While some HIOs predate the HITECH Act, this federal investment and enhanced provider interest in EHR systems provides the foundation for extensive HIO growth. Provider participation in health information exchange has steadily grown since passage of the HITECH Act with 10.7% of hospitals reporting participating in health information exchange with unaffiliated providers in 2011[19] to 30% in 2014.[20]

EHR adoption and medical institutions' partnerships with HIOs are lagging for long-term and post-acute care institutions compared to those that qualify for Medicare and Medicaid EHR

incentive programs established by the HITECH Act.[10] A 2013 report by the Office of the National Coordinator for Health Information Technology notes that while no national data were available about long-term and post-acute care institutions, they estimated that EHR adoption rates lag behind those of acute care hospitals, by as much as 50%.[21] A survey of New York State long-term and post-acute care providers found that less than half had adopted an EHR, and less than a third participated in health information exchange with a HIO.[22] Similarly, a report by the Minnesota Department of Health found that less than half of the acute care hospitals exchanged health information with nursing homes or other long-term post-acute care facilities, and even fewer did so with home health care providers.[23] Although adoption of EHR and health information exchange technology by long-term care and post-acute care providers is slower than adoption by acute hospitals, the number of institutions that do participate is substantial: one-third to one-half of surveyed hospitals reported exchanging data with these providers.

Motivations for providers and institutions not eligible for incentive payments to participate in health information exchange are similar to those of providers and institutions that do qualify: to improve access to relevant clinical information in a timely way to inform quality patient care and to increase efficiency in the care process. Without access to the incentive payments, these providers and institutions must bear the full implementation costs which can be substantial depending on their local HIO's business model and the costs of building technical interfaces between their EHR and the HIO as well as annual maintenance of the interfaces and participation fees in the HIO. In addition, some of the EHR systems that target post-acute care providers do not readily enable electronic exchange of clinical information as they are not required to be certified electronic health record technology[24] for purposes of the Meaningful

Use program and are therefore not required to provide the functionality necessary to meet Meaningful Use requirements including the ability to electronically exchange clinical information.

Potential for research

The explosion of EHR implementation and growth of HIOs creates opportunities for aggregating patient data to support research. Much research has been published with EHR data as the primary data source and researchers continue their efforts to evaluate the use of EHR data for research and to develop tools and methodologies to address its limitations.[25-28] HIOs have an opportunity to complement promising efforts in development to make EHR data available for research such as the Clinical and Translational Science Awards Accrual to Clinical Trials (CTSA ACT) program and PCORnet. CTSA ACT is a National Institutes of Health funded, medical research institution-based network of funded Clinical Translational Science Award Centers created to share EHR data as a mechanism to improve recruitment for clinical research studies.[29] Similarly, Patient-Centered Outcomes Research Institute (PCORI) created the PCORnet to combine data available in EHRs with patient generated data to support clinical research.[30]

Research is currently ongoing to determine whether the information collected and shared through HIOs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research activities.[31-37] With appropriate measures in place to ensure patient privacy and informed consent, the use of data from HIOs for research purposes has the potential to greatly expand the number and types of health care organizations contributing to

health research including community-based hospitals, private physician practices, urgent care centers, home health agencies, and nursing homes thereby increasing the generalizability of the findings.

Of further note, the mission of the HIO, as defined by the ONC oversight body, does not directly refer to research or any research-related activities.[38] The ONC is a division within the U.S. Department of Health and Human Services tasked with supporting the meaningful use of EHRs and the development of a nationwide health information system. Given the ONC's role as policymaker and distributor of federal grant funds, their description of HIO is widely referenced. As a result, HIOs have largely developed the ability to support research using exchange data with the intention that this service contributes financially to the HIO or meets the needs of participating organizations that include research in their organizational mission. The implications are that HIOs may decide to restrict access to their participating organizations; and, if the HIOs allow access to outside researchers, the researchers will likely have to pay for the use of the data exchanged through the HIO.

Specific aims/Objectives

Extensive public and private investment in EHR implementation and health information exchange compels us to strategize how to maximize the utility of these resources. While the federal government and health care providers invested in this technology to support direct patient care delivery, I propose this technology has the potential to support conducting clinical research and improve efficiencies for data collection and patient identification/monitoring required for clinical research. To this end, I identified several outstanding research questions:

Do researchers currently have access to clinical information exchanged through an HIO? Do HIOs have the necessary infrastructure, technological capacity, and agreements among participating providers to support research using exchanged clinical data? Do HIOs facilitate the development of a multi-institution dataset? Does the information collected and shared through an HIO result in an accurate, representative, and comprehensive foundation to assess transitions of care? The following chapters inform these issues and point to additional work needed in the future.

Chapters 2-4 represent three articles that have either recently been published in a peer reviewed journal or are in the process of submission for publication. Chapter 2 provides the results of a scoping review to determine the extent of HIO involvement in published clinical research. The objective of this study was to identify published studies that describe the use of HIOs as a data source for the conduct of clinical research specific to one or more of the following 3 areas: 1) clinical or epidemiological research including randomized clinical trials or observational epidemiological studies, 2) financial or cost evaluations of HIO use, including changes in administrative efficiencies, or 3) utilization of health services, including the evaluation of care-seeking patterns. This paper was published in the International Journal of Medical Informatics, March 2016.

In follow-up to the scoping review, we investigated the extent to which HIOs report supporting research by allowing the patient data that they exchange to be aggregated and used for clinical, health services or epidemiologic research. We use data from the fifth and most recent version of an ongoing national survey of organizations engaged in health information exchange[39-42] to

determine the proportion of HIOs that are or plan to support research, and to describe the characteristics that differentiate them from HIOs that do not support research. We also evaluate select characteristics of these research-engaged HIOs to describe how they differ in activities, functionality or organizational structure from HIOs not so engaged. These results are presented in Chapter 3. This paper has been submitted for publication but is pending review.

For the last of the three studies (Chapter 4), we sought to use HIO data in a clinical research study that would highlight the potential utility of HIO data for clinical research. We partnered with the Indiana University School of Medicine and the Indiana Network for Patient Care (INPC) to link patient level hemorrhagic stroke cases discharged from two major medical centers in Indianapolis with a regional HIO (INPC). We sought to determine whether HIO data can be used to study transitions of care in patients experiencing an intracerebral hemorrhage (ICH) over the year following hospital discharge. We operationalized our research questions as follows:

- Are the HIO encounter data sufficient to describe accurately the health care utilization patterns among various health care settings following discharge for a first ICH (index admission)? The primary "exposure" of interest was the discharge disposition. Outcomes of interest were patients' care patterns after discharge (number, timing, and care setting) and use of rehabilitative services.

- What information of interest is not available from the HIO?

- What changes in network size and diversity of participating health care providers, administrative and technological infrastructure, and data availability are required to support research in transitions of care?

These studies build upon each other. The scoping review (Chapter 2) informs us of the current published research with HIOs as partners and the results were used to inform the questions included in the national survey (Chapter 3) to determine the proportion of HIOs that are or plan to support research, and to describe the characteristics that differentiate them from HIOs that do not support research. The transitions of care study in Chapter 4 tested whether researchers could obtain and use HIO data to study a topic that should highlight the advantage of an HIO partner as a source of relevant, cross-institutional clinical information.

TABLE 1.1 – OBJECTIVES AND MEASURES FOR MEANINGFUL USE IN 2017 AND SUBSEQUENT YEARS

Program Goal/Objective	HIO Implication
Protect Patient Health Information	Requires a security analysis
Electronic Prescribing (eRx)	Supporting role - Several systems already in place and used by majority of physicians to provide electronic exchange of information related to prescriptions such as Surescripts.
Clinical Decision Support (CDS)	Supporting role - This is largely an EHR-level function although additional information available through an HIO connection could support more accurate and timely receipt of clinically relevant information.
Computerized Provider Order Entry (CPOE)	Supporting role - Orders outside of organizational boundaries would require HIO functionality.
Patient Electronic Access to Health Information	Supporting role - Initially most providers will meet this requirement through an EHR-supported patient portal. HIOs offer an opportunity to patients to access their health information through a single portal rather than through each health care provider's EHR provided portal.
Coordination of Care through Patient Engagement	Supporting role - HIOs could provide the secure messaging functionality or community-wide patient portal.
Health Information Exchange (HIE)	Integral role – HIOs facilitate the sharing of clinical information to support transitions of care and referrals and have systems to support reconciliation of the medical information provided by different health care providers.
Public Health and Clinical Data Registry Reporting	Supporting role – Dependent on the public health agency and registry requirements. HIOs are one option for transmitting this information. HIOs provide real-time data submission that would facilitate a public health agency's efforts to monitor the health of the population.

CHAPTER 2: HEALTH INFORMATION EXCHANGES – UNFULFILLED PROMISE AS A DATA SOURCE FOR CLINICAL RESEARCH

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Introduction to the Chapter

The following chapter uses a scoping review methodology. Arksey and O'Malley published a framework for conducting scoping studies in 2005 to suggest consistent terminology and methods.[43] The authors proposed four common reasons for conducting a scoping review including the examination of current research activity, determination of whether there is additional value for undertaking a full systematic review, summarization and dissemination of findings, and identification of gaps in literature. While similar in process to a systematic review, scoping review methodology differs from conducting a systematic review in important ways. Scoping reviews do not have highly focused research questions but seek to identify all relevant literature without regards to study design. Once researchers have a better understanding of existing literature, they may wish to narrow the parameters but their initial searches are broad and comprehensive. In addition, scoping reviews do not aggregate findings from different studies and therefore do not assess quality of identified studies or the generalizability of their findings.[43]

Abstract

Objective –To determine the use of health information exchange organizations (HIEs)[1] to support and conduct clinical research.

Materials and Methods – This scoping review included US-based studies published between January 2003 and March 2014 that used data from an HIE to address at least one of three categories of research: clinical or epidemiological research, financial evaluation, or utilization of health services. Eligibility was not restricted to research on HIEs. Studies with research questions outside of the evaluation of HIEs themselves were sought.

Results – Eighteen articles met final study inclusion criteria from an initial list of 847 hits. Fifteen studies addressed a clinical or epidemiological research question, 6 addressed a financial consideration, and 8 addressed a utilization issue. Considerable overlap was found among the research categories: 13 articles addressed more than one category. Of the eighteen included studies, only two used HIE data to answer a research objective that was NOT specific to HIE use. Research designs were varied and ranged from observational studies, such as cohort and cross-sectional studies, to randomized trials. The 18 articles represent the involvement of a small number of HIEs; 7 of the studies were from a single HIE.

Discussion – This review demonstrates that HIE-provided information is available and used to answer clinical or epidemiological, financial, or utilization-based research questions; however, the majority of the studies using HIE data are done with the primary goal of evaluating the use and impact of HIEs on health care delivery and outcomes. As HIEs mature and become

[1] Publisher required the use of HIE to represent Health Information Exchange Organizations.

integrated parts of the health care industry, the authors anticipate that fewer studies will be published that describe or validate the role of HIEs, and more will use HIEs as multi-institutional data sources for conducting clinical research and improving health services and clinical outcomes.

Conclusion – Articles identified in this review indicate the limited extent that HIE data are being used for clinical research outside of the evaluation of HIEs themselves, as well as the limited number of specific HIEs that are involved in generating published research. Significant barriers exist that prevent HIEs from developing into an invaluable resource for clinical research including technological infrastructure limitations, business processes limiting secondary use of data, and lack of participating provider support. Research to better understand challenges to developing the necessary infrastructure and policies to foster HIE engagement in research would be valuable as HIEs represent an opportunity to engage non-traditional health care provider research partners.

Objective

The adoption of electronic health record (EHR) technology by physicians, hospitals, and other health care providers has exploded over the last few years largely as a result of federal investment and policies. In February 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act established the Medicare and Medicaid EHR Incentive Programs.[10] Since 2011, eligible health professionals and hospitals have received incentive payments for implementing new, or upgrading existing, EHR technology in a meaningful manner to improve the care of patients with Medicare or Medicaid benefits or coverage. With the establishment of this program, adoption of EHR technology has spread so broadly that implementation is no longer limited to large institutions or technologically sophisticated providers. According to the Department of Health and Human Services, as of May 2013, 80% of all eligible hospitals and over half of physicians and other health professionals have implemented the necessary EHR technology to receive incentive payments for meeting the Stage 1 expectations of the EHR Incentive Programs.[44]

The goal of the EHR Incentive Programs is to ensure that providers are using the capabilities of their EHR systems for more than just recording information, ultimately leading to improved patient care.[10] This effort is commonly referred to as Meaningful Use, as providers are being incentivized to demonstrate that they are using their EHR systems in a meaningful manner. Providers submit reports of specific information from EHRs to the federal government to validate that they are using the EHR technology in a meaningful manner thus requiring EHR vendors to incorporate into their systems the ability to share information. Each stage of Meaningful Use has increasing requirements for the use of certified EHR technology, with Stage

1 requirements emphasizing basic expectations for providers who have recently implemented an EHR system. Many providers are currently working towards meeting Stage 2 which requires participation in Stage 1 for at least two years, and the electronic exchange of structured care summaries among providers using various EHR technologies. Stage 3 requirements are anticipated to emphasize the ability to exchange clinical information securely across institutions and providers.[10] The emphasis on interoperability and sharing among EHR systems has promoted the use of standards such as HL7, LOINC, and SNOMED CT—which facilitate sharing information across institutions and EHR technologies—and has fostered creation of mechanisms to share clinical information electronically between providers including the development of health information exchange (HIE) organizations.

While some HIEs predate the HITECH Act, this federal investment and enhanced provider interest in EHR systems provides the foundation for extensive HIE growth. The HITECH Act defines the HIE as "an organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards."[38] HIEs manage data collection, mapping, patient matching, and other processes required for exchanging clinical information electronically across disparate EHR technologies. Stage 3 of the EHR Incentive Program is anticipated to increase providers' engagement with HIEs. Adler-Milstein found in a 2012 national survey that 30% of hospitals and 10% of ambulatory clinics participate in an HIE,[40] and anecdotal evidence suggests continued growth in the number of participating hospitals and ambulatory clinics.

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

Materials and Methods

The authors used a scoping study methodological framework as described by Arksey and O'Malley.[43] While similar to a systematic review, there are important differences in that scoping reviews address broader questions with less defined parameters, and therefore do not typically address specific research questions or evaluate the quality of included studies.

Literature Search Criteria

The authors conducted a search of both Medline and ISI Web of Science, to identify US-based research studies that relied on HIE data. The initial Medline search strategy used a broad approach to identify relevant articles because the terminology related to HIEs and the

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

Study eligibility

Eligible studies were limited to original research studies that used data from an HIE. HIE organizations were defined broadly to include organizations that facilitate exchange of health information within a closed network of care or health system, to organizations that facilitate exchange across multiple independent institutions. We chose to be most inclusive to capture as many of the organizations self-identifying as HIEs as possible. We did not restrict eligibility based on organizational structure, so included both for profit and non-profit, government-based, or health care provider-based HIEs. We also did not restrict our definition of HIEs based

on their technology such as maintaining a centralized data repository or master patient index. It is possible for HIEs to participate in research without maintaining a centralized data repository as they could provide data to a clinical researcher real-time which the clinical researcher maintains for later analysis. For example, a researcher studying the impact of a clinical intervention on diabetics could partner with an HIE to send copies of A1C test results for patients enrolled in the study to the researcher as well as the ordering physician.

We excluded networks of health care providers who partnered specifically to share EHR data for research rather than to support the delivery of healthcare. Two such examples of excluded organizations include the Primary (Care) Practices Research Network (PPRNET) managed out of the Medical University of South Carolina (creates multi-provider data sets that members can use to conduct clinical research)[45] and the National Institutes of Health funded Clinical and Translational Science Awards Accrual to Clinical Trials (CTSA ACT) program (facilitates the identification and recruitment of clinical trial participants using EHR data).[29]

We restricted specific studies that used HIE data for 1) clinical or epidemiological research including randomized clinical trials or observational epidemiological studies; 2) financial or cost evaluations of HIE use, including assessment or changes in the cost of health care or changed administrative efficiencies, or 3) utilization of health services, including the evaluation of patient care-seeking patterns. Eligibility was not restricted to research HIEs. Included studies could have addressed any broad research topic or question or they could have been done with the primary purpose of evaluating the use and impact of HIEs such as whether HIEs improved care, changed outcomes, improved costs, or changed the amount or type of care received.

Studies with research questions outside of the evaluation of HIEs themselves were sought. Research objectives explicitly focused on the evaluation of HIEs are categorized as HIE-specific research objectives and labeled as such in **Table 2.1**. The review included articles published during the 10 year period January 2003 to March 2014, thereby ensuring we identified publications that covered the initial development years of HIEs while recognizing that much of the HIE expansion has occurred in the recent past due to significant federal investment.

Studies were excluded if their primary purpose was to describe how or why an HIE should be implemented. This resulted in a large number of studies being excluded for any of the following four reasons: 1) implementation related topics (e.g., how HIEs are developing, their current status, and justification for establishing HIEs); 2) the validity of HIEs for managing or sharing clinical information; 3) physicians' or providers' support and awareness of HIEs, or 4) consumers' support and engagement in HIEs. Articles published prior to 2003, in a language other than English, conducted outside of the United States, or lacking an abstract were also excluded. Initial inclusion criteria were tested by a second reviewer (MJR) and iterative changes made until the reviewers agreed upon a final set of criteria. Two abstractors (CP, MJR) then independently reviewed studies for relevance. The final list meeting inclusion criteria was determined after a consensus meeting.

Each article that met eligibility criteria was categorized according to the type of research (clinical or epidemiological research, financial/cost evaluation, or utilization of health services), and research design (quasi-experimental, retrospective or prospective cohort, cross-sectional,

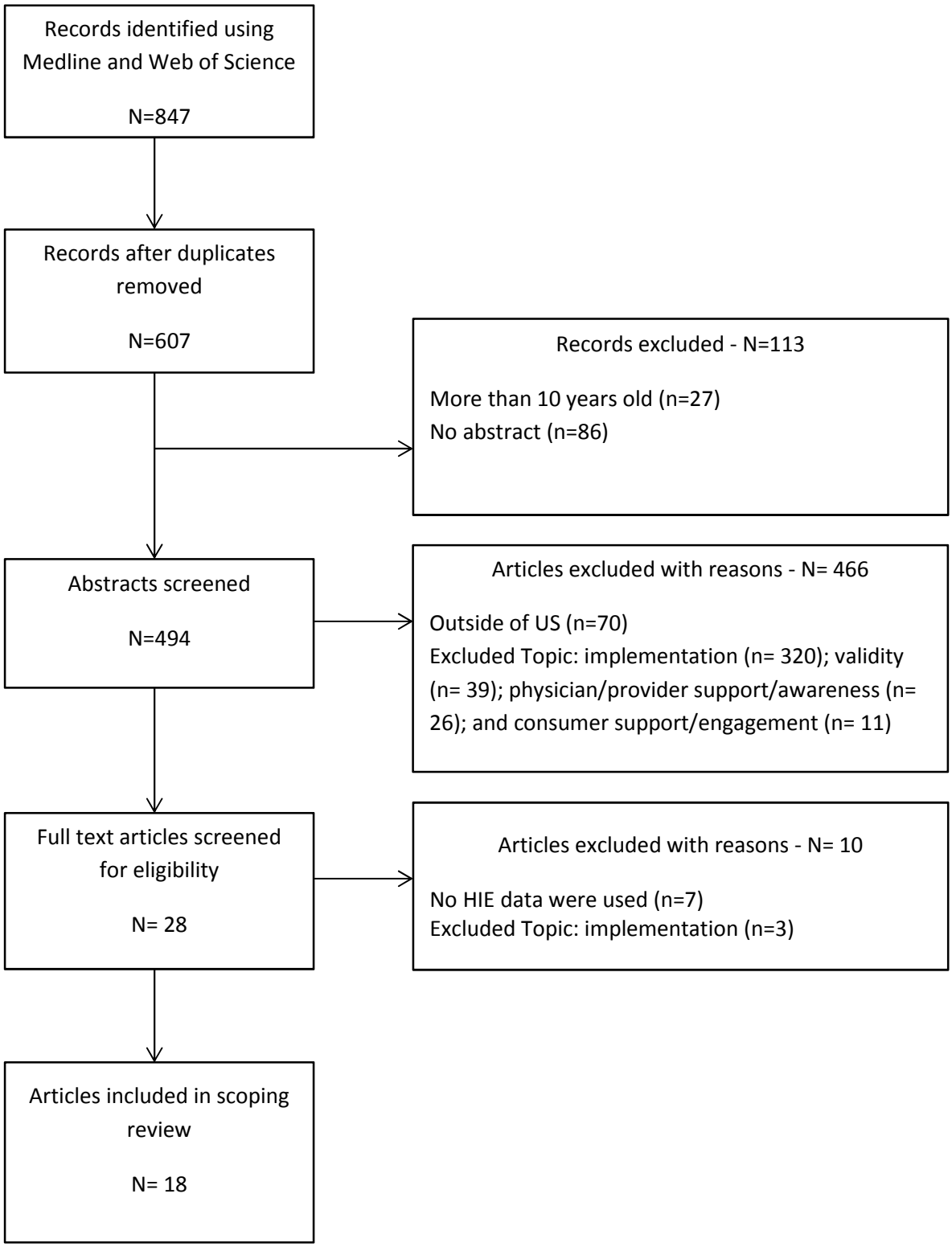
case-cohort, or randomized control trial). HIE-specific research objectives and conclusions were reported by article.

Results

The search resulted in 847 initial matches (**Figure 2.1**). Removing duplicate entries reduced the number to 607. Next, removing articles without an abstract, or published prior to 2003, reduced the number to 494. Upon review of the 494 abstracts, the authors excluded 466 articles because they were either conducted outside the United States (n= 70) or addressed a topic that was excluded from this review: these were implementation-related topics (n= 320), the validity of HIEs for managing or sharing clinical information (n=39), physicians' or providers' support and awareness (n= 26), and consumers' support and engagement (n= 11). The authors screened the full text of the remaining 28 articles and excluded an additional 10 articles because they did not include data from an HIE (n= 7), or they met at least one exclusion criterion, such as addressing an implementation topic. The remaining 18 articles were deemed the final eligible articles and are summarized in **Table 2.1**. As noted earlier in the Materials and Methods section, we did not evaluate the quality and methodology of the included studies. We also did not evaluate their findings or conclusions. As such, research objectives and conclusions presented in **Table 2.1** are based on those published in the original manuscripts.

Of particular interest to the authors was to assess whether HIE data was being used for research unrelated to the evaluation of the use and impact of HIEs. Of the eighteen included articles, only two met our inclusion criteria as clinical or epidemiological research, financial or cost evaluations, or utilization of health services using HIE data without a research objective

FIGURE 2.1: SUMMARY OF SEARCH PROCESS



specific to HIE use. [31,33] The remaining 16 articles met the criteria within the context of evaluating the use and impact of HIEs such as whether HIEs improved care, changed outcomes, improved costs, or changed the amount or type of care received.

There was considerable overlap among the 18 articles in terms of the three research categories that they addressed: 15 studies addressed a clinical or epidemiological research question, 6 addressed a financial consideration, and 8 addressed a utilization issue. In **Table 2.1**, articles are presented by category in the following order: 1) clinical or epidemiological research only (n=5); 2) clinical or epidemiological, and utilization (n=7); 3) clinical or epidemiological, utilization, and financial considerations (n=5); and 4) financial and utilization (n=1). No articles were categorized in the three remaining possible categories: financial only, utilization only and clinical or epidemiological and financial. Within each grouping, articles are organized with the most recent publication first and then alphabetically for publications within the same publication year. As noted previously, study research objectives that addressed HIE use and its impact were categorized as HIE-specific objectives and labeled as such in **Table 2.1**. Similarly, study conclusions that were specifically related to HIE use are included in the last column of **Table 2.1**, titled HIE-Specific Conclusions.

The included articles represent partnerships with a limited number of HIEs, primarily the IHIE through its Indiana Network for Patient Care, which serves as the HIE partner for 7 of the 18 studies.[31,33,35-37,46,47] New York Clinical Information Exchange[32,48,49] and MidSouth e-Health Alliance[50-52] were both the HIE partner for three articles. The remaining HIE partners were Louisiana Public Health Information Exchange,[53] Carolina e-Health Alliance,[54,55] Integrated Care

Collaboration of Central Texas[56] and Wisconsin Health Information Exchange.[47] Finally, one article used health information exchange (HIE) participation information from the Health Information Management Systems Society (HIMSS).[57]

Among the 5 articles that used HIE data to study a clinical or epidemiological research question only,[31,35-37,46] one study validated an automated search method that could be used to identify adverse events resulting from the implantation of a medical device.[35] Two others focused on methicillin-resistant *Staphylococcus aureus* (MRSA) and evaluated whether infected patients seek care at multiple hospitals[46] and whether a MRSA prevention strategy was effective (one of two studies without HIE-specific research objectives).[31] The remaining two studies examined whether an HIE is a valid data source for health outcomes and clinical effectiveness research; one study specifically addressed whether HIE data was sufficient to determine medication adherence;[36] the other looked at statin use and control of cholesterol using HIE data.[36,37] Although additional efforts are needed to ensure that HIE data are appropriately coded and structured for clinical research, these studies confirmed the validity of the data source and described the limitations of using HIE data for identifying target populations,[37,46] tracking outcomes,[35] and establishing interventions.[36]

Thirteen of the studies addressed multiple research categories. Seven articles addressed clinical or epidemiological and utilization components[32,33,48,49,53,54,56] by determining whether using HIE data changed how providers deliver health care or improved clinical outcomes or the impact on utilization of health services. One article calculated utilization rates for implantable cardioverter-defibrillators using an HIE as one of its data sources.[33] This study did not have an

HIE-specific research question although it did highlight limitations of using HIE data to calculate utilization rates.[33] Three of these articles explored utilization in terms of patients' care-seeking behavior;[32,48,49] two other studies examined the impact of HIEs on quality measures or clinical outcomes such as hospital readmissions.[33,53,54] The seventh article examined whether the availability of clinical information in an HIE was associated with fewer unnecessary emergency department visits and hospitalizations.[56] These studies addressed a wide array of topics including the utility of HIEs for supporting patient engagement[53] and the role of HIE data in improving reports of infectious diseases.[48] They also confirmed the hypothesis that patients frequently seek care from multiple providers and institutions,[49] and that HIEs can be useful resources for supporting efforts to reduce unnecessary utilization.[32] Finally, although one article found no impact on clinical outcomes,[54] another determined that providers are more likely to access HIEs when caring for more complex patients.[56] This latter phenomenon could introduce the problem of confounding by indication when assessing the value of HIE data to reduce unnecessary care.

Five articles addressed all three categories: clinical or epidemiological, financial, and utilization. Three studies[52,55,57] evaluated whether the use of an HIE resulted in cost savings by reducing admissions, consultations, or diagnostic testing in an emergency department. The two other articles[50,51] assessed whether the use of an HIE reduced unnecessary imaging and the associated costs in emergency departments and whether they also improved adherence to clinical guidelines. Specific findings include reduced diagnostic imaging,[50,51] improved adherence to clinical guidelines,[51] reduced consultations and diagnostic testing[55] and fewer readmissions.[52,55]

The final article combined analysis of financial considerations and utilization of health care services to describe an analytic framework for estimating financial consequences of an HIE and demonstrating its use in developing pricing policies. The authors used HIE data to create their model which concluded that all HIE participating providers had achieved financial gains through reductions in unnecessary hospitalizations and repeat emergency department visits.[47]

Discussion

This scoping review found that clinical information electronically exchanged through HIEs is being used to a limited extent to support clinical research. Although the number of studies meeting the review's inclusion criteria was small, these studies demonstrate the potential of HIEs as a data source for clinical and health services research. The findings of this review illustrate the diversity of studies that are possible with data generated from HIEs, including focus on various research questions (clinical or epidemiological research topics, financial or cost components, and utilization of health care services) and the use of a variety of research designs to meet their objectives.

Our search strategy demonstrated that the majority of published studies about HIEs are limited to the discussion of implementation, such as describing how HIEs are developing, their current status, and justification for establishing HIEs. The review also demonstrated that much of the existing literature addresses the validity of HIEs for managing and sharing clinical information. This category of reports typically addresses whether the clinical information shared through an HIE is attributed to the correct patient, delivered to the appropriate provider, and displayed to the receiving provider accurately. Although articles focusing on validity issues were not

included in our review, these studies are important in demonstrating the important and necessary stages in the development of functional HIEs. As HIEs mature and become integrated parts of the health care industry, the authors anticipate that fewer studies will be published that describe or validate the role of HIEs, and more will be focused on how HIEs are used to conduct clinical research and improve health services and clinical outcomes.

Of further note, the mission of the HIE, as discussed by the oversight body, the Office of the National Coordinator for Health Information Technology (ONC), does not refer to research or any research-related activities.[38] The ONC is a division within the U.S. Department of Health and Human Services tasked with supporting the meaningful use of EHRs and the development of a nationwide health information system. Given the ONC's role as policymaker and distributor of federal grant funds, their description of HIEs is widely referenced. It is important to recognize that those organizations that have developed research capabilities have done so under their own initiative without ONC direction, encouragement or funding. In addition, while our scoping review defined HIE organizations broadly to include organizations that facilitate exchange of health information within a closed network of care or health system to organizations that facilitate exchange across multiple independent institutions, we excluded networks of health care providers and/or interested parties who partnered specifically to share EHR data for research rather than to support the delivery of healthcare. While organizations such as the Primary (Care) Practices Research Network (PPRNET) managed out of the Medical University of South Carolina and the National Institutes of Health funded Clinical and Translational Science Awards Accrual to Clinical Trials (CTSA ACT) program are important contributors to the effort to

support clinical research using electronically available health care information, our scoping review focused on HIE organizations created to facilitate the delivery of health care.

Partnerships between HIEs and clinical researchers should be beneficial to both researchers and HIEs. While this paper is focused on the value of HIEs to clinical researchers, the authors hypothesize that the preparation of data for use in clinical research should improve the operation and data integrity of the HIE. The authors propose that for HIEs to succeed they need to offer more services than point-to-point data exchange which many organizations can accomplish through their own electronic health record systems (using for example ONC's Direct protocol or HL7 interfaces). Preparing shared data to support clinical research requires similar efforts as preparing data to evaluate outcomes and health care utilization within and across organization boundaries. This type of analysis is required in order for health care providers to succeed under reimbursement methods emphasizing outcomes and management of care episodes. In addition, data preparation for health care analytics could highlight data issues in need of further quality improvements by the HIE and its participating providers. For example, not all HIEs work with their participating provider organizations to augment data according to established standards or terminologies,[58] such as mapping locally created codes to LOINC codes for diagnostic test results. Appropriate use of standards and terminologies allows for more timely and reliable information retrieval and allows data from different provider data sources to be combined so as to provide a unique resource for both clinical research and clinical care delivery. Standards and terminologies can improve the speed and accuracy of using HIE data in both clinical care and research, and could thereby reduce costs of doing business.[37] Preparing

data for clinical research drives improvements in data quality and comprehensiveness thus benefiting other HIE functions.

A serious potential concern regarding the use of HIE data for research purposes is that HIE data may not have sufficient clinical detail for some research questions and so additional data retrieval from individual EHRs or paper-based records may be required. Some of the studies included in this review have elaborated on this challenge. One study demonstrated important limitations to using clinical information queried from an established HIE, specifically with respect to determining contraindications to medical treatment without a more detailed review of the medical record.[33] They also noted concerns regarding loss to follow-up, although similar challenges exist when using more traditional data collection strategies.[33] Another study undertaken to evaluate the effectiveness of an intervention for prevention of MRSA found that data in the HIE required supplementation with medical-record data, since the HIE data was not coded or structured to allow the needed query to be performed.[31]

Two recent systematic reviews evaluated the use of HIEs and the impact of HIE use on the delivery and quality of health care.[34,59] Both reviews consequently only included research studies that directly addressed the use and impact of HIEs on clinical care. The scope of these two systematic reviews therefore differ from our review which included studies that used HIE data to address a specific research question (i.e., clinical or epidemiological research, financial or cost evaluations, or utilization of health services) unrelated to the evaluation of HIEs per se. However, despite our different focus, the majority of the studies included in our review also included an objective related to the evaluation of the HIEs in terms of their use and impact on

clinical care. Rudin and colleagues[34] noted that few HIEs have been evaluated for their impact on health care outcomes which is consistent with our findings. Their review concluded that HIE use probably reduced emergency department use, but limitations in the data precluded drawing conclusions about care delivered in other settings.[34] Rahurkar and colleagues identified 27 articles that assessed how HIEs affected cost, service use, and quality of health care but because only a few (n=6) studies had strong internal validity they concluded that " little generalizable evidence currently exists regarding benefits attributable to HIEs."[59]

The strengths of this study include the use of a scoping review method. The authors chose to explore the research available on this topic in recognition of the relatively recent developments in HIE implementation. Articles were not evaluated regarding the quality or soundness of research design, methods, findings or conclusions. The results are categorized and presented as originally published. The scoping review approach allows for an open and flexible search process designed to identify as many eligible articles as possible, and so provides a broad understanding of the current state of HIE involvement in clinical research.

We also note some limitations. Although we engaged in a broad and inclusive literature search, we acknowledge that our search might have missed some studies that involved a HIE. For research targeting certain kinds of HIEs, such as those built around an individual health system or a closed network of care, publications may reference the network as the data source without identifying that the providers share data through an HIE. In contrast, community-based HIEs are designed to allow exchange of clinical information among providers across networks and are

therefore more likely to be identified as the data source when research crosses multiple networks.

With respect to future research directions and priorities, more research is required to determine the extent and roles of using information from an HIE for clinical research. Identifying barriers at both the HIE and health care provider level is required to more effectively resolve these challenges. Priority areas for future study are many and include validation of whether the clinical information in an HIE is representative of a definable underlying target population; how providers participating in an HIE are similar to, or different from, providers not participating (i.e., selection bias); whether providers participating in an HIE care for patients in a manner similar to providers not participating; how HIE structure, network, and business practices affect the quality and comprehensiveness of the data; how HIE structure, network, and business practices influence whether and how the data are available to researchers; and whether the HIE is identified as the data source in published research. Finally, this article focuses on challenges unique to HIEs and does not address broader challenges related to the secondary use of health information, where additional research is needed to resolve associated privacy, security, technical, ethical and social challenges.[26,27] Supporting clinical research and providing data to researchers require HIEs to develop appropriate technological and administrative infrastructure, policies, and procedures, including privacy and security protections, business case, partners' support, and mechanisms to manage the research process among the multiple levels of the organization, research partners, and individual staff. For example, HIEs are designed to support clinical care delivery, whereby clinical data are typically accessed one patient at a time. Researchers often want to query data about multiple patients

who meet their inclusion criteria, requiring the HIE to invest in technological enhancements to allow this type of query. In addition, most HIEs do not have the technology to support natural language processing, which is required to extract useful information from the textual data in medical records. Due to the required investments, the articles included in this review represent institutional partnerships with a small number of HIEs; the IHIE through its Indiana Network for Patient Care provided data for 7 of the 18 studies. As noted previously, HIEs that developed a clinical research infrastructure did so at their own initiative and without federal direction or financial support. The authors were unable to identify any published articles that detailed the technological and organizational development required to facilitate the use of HIE data for research purposes. While the authors recognize that a handful of more established HIEs have such an infrastructure, this may not be true for most. The majority appears to have no publicly stated policies or procedures in place related to data access and use of HIE data for clinical research. Our experience is that HIEs' data exchange agreements do not typically address the use of data for clinical research and therefore would require additional accommodations for uses beyond treatment, payment, and clinical operations. The authors' communications with HIEs have indicated that even organizations with some experience in clinical research often require researchers to seek individual provider consent for data use specific to each research project. In addition, the authors have found those HIEs who have the capability to support clinical research also request significant fees for this support.

Providers participating in HIEs require proven technologies and procedures to ensure that clinical data are handled consistently with patients', providers', and government's expectations for privacy and security of protected health information. HIEs prioritize compliance with state

and federal rules and regulations related to the use of patient-identifiable information such as the privacy and security requirements mandated by the Health Insurance Portability and Accountability Act. As a result, they have invested in the necessary expertise and systems to ensure security of health information and protections for patient privacy. Engagement in research will require HIEs to develop expertise and systems for monitoring compliance with rules and regulations specific to human subjects research. Finally, HIEs will need to develop new business partnerships to support their research participation, including honest broker organizations that could provide de-identified data to researchers on behalf of the HIE. Honest broker organizations may also incorporate and maintain linkage codes if patient re-identification is required, and can manage these inquiries to protect patient privacy. Analysis of a national survey of HIEs, the fifth survey by the Adler-Milstein research team that was expanded to include questions related to research capacity and associated barriers, is underway.[40] Although partnerships between HIEs and clinical researchers represent a major opportunity to advance clinical and health services research, much work remains. We recommend that data exchange agreements include reference to the use of the HIE data for research, and facilitate research whenever possible and reasonable.

Conclusion

Given the increasing participation by providers across the health care continuum in HIEs, these entities represent a tremendous opportunity to broaden the involvement of clinical HIE data for research purposes. Although some health care providers participating in HIEs are those that would traditionally participate in clinical research, such as academic medical centers, many are organizations that joined HIEs solely to support their health care delivery roles including

community-based hospitals, private physician practices, urgent care centers, home health agencies, and nursing homes. HIEs therefore represent an opportunity to engage health care providers who traditionally would not have participated in clinical research. While additional efforts to overcome challenges associated with HIE data are required, great potential exists to improve the timeliness and scope of research and to reduce the cost of conducting clinical research through the effective development of infrastructure and policies to facilitate and support research using HIE data.

TABLE 2.1 - SUMMARY OF ELIGIBLE STUDIES AND CONCLUSIONS

First Author, Year	Research Design	Research Category			Research Objective(s) Specific to HIE Use	HIE-Specific Research Objective(s)	HIE-Specific Conclusion(s) as reported by the cited Study Author(s)
		C/E*	U^	F+	Y/N		
Doebbeling 2013[27]	Quasi-experimental	X			N	Study objective was to evaluate a MRSA** prevention strategy.	HIE data required supplementation from participating hospitals as some data was not appropriately coded or structured.
Ballard 2012[31]	Retrospective cohort	X			Y	Determine accuracy of an automated search of HIE data identified surgeries meeting study criteria including those that involved complications.	Automated search method was valid and its use may facilitate tracking device-related adverse events.
Zhu 2011[32]	Retrospective cohort	X			Y	To determine if medication adherence can be assessed using HIE data.	Findings support establishment of interventions to assess medication adherence using HIE data.
Zhu 2010[33]	Retrospective cohort	X			Y	To determine whether HIE data could be used to study the association between patient low-density lipoprotein (LDL) control and statin adherence.	Proportion of medication adherent patients and patients with optimal LDL control were lower in the HIE-identified population, perhaps reflecting "real-world" settings.
Kho 2008[43]	Retrospective cohort	X			Y	To determine whether patients with MRSA** who travel between hospitals are identified as MRSA**-positive.	HIE data could hasten identification of known MRSA** patients in communities with multiple hospitals.
Hoang 2014[29]	Cross-sectional	X	X		N	Study objective was to determine utilization rates for implantable cardioverter-defribillators for primary prevention of sudden cardiac death.	Identified limitations calculating utilization rates from HIE data alone.
Magnus 2012[50]	Case-cohort	X	X		Y	Describe the human immunodeficiency virus (HIV) patients identified by HIE as out of care and assess intervention outcomes.	An HIE informed intervention can facilitate care utilization for HIV-infected persons not in specialty HIV care.

TABLE 2.1 (con't)

Onyile 2011[46]	Retrospective cohort	X	X		Y	Determine the relationship between certain disease conditions and the likelihood of seeking care at more than one provider location using HIE data.	Patients with certain disease conditions (primarily psychiatric or drug/alcohol related) were disproportionately more likely to visit multiple health care delivery sites.
Shapiro 2011[28]	Cross-sectional	X	X		Y	Validate the use of HIE data to measure returns to emergency departments within 72 hours across multiple institutions.	With additional data cleanup, using HIE data allowed more accurate evaluation of emergency department returns within 72 hours across multiple institutions.
Proeschold-Bell 2010[51]	Randomized Control Trial	X	X		Y	Examine the effect of HIE participation between multi-disciplinary HIV care providers on patient health outcomes.	Exchange of relevant clinical information between HIV medical providers and ancillary care providers did not affect clinical outcomes.
Shapiro 2010[45]	Cross-sectional	X	X		Y	Demonstrate the utility of an HIE in documenting care-seeking behavior in New York City during the H1N1 outbreak.	HIE participation improved outbreak reporting with all HIE participating hospitals reporting data for each day of the study.
Vest 2008[53]	Cross-sectional	X	X		Y	Assess whether HIE information access reduces emergency-department visits and hospitalizations for ambulatory care-sensitive conditions among indigent adults.	HIE was significantly more likely to be accessed for higher-risk patients; HIE access was associated with increases in health care utilization.
Carr 2014[52]	Observational, prospective	X	X	X	Y	Estimate savings from avoidance of unnecessary services or diagnostic testing; assess length of stay and quality of care associated with HIE data availability to treating clinicians.	Using the HIE resulted in cost savings from avoided unnecessary services. Providers perceived improvements in quality of care, and time savings. Data were insufficient to evaluate timing of access on length of stay.

TABLE 2.1 (con't)

Lammers 2014[54]	Retrospective cohort	X	X	X	Y	Assess whether use of HIE reduces duplicate imaging in HIE participating emergency departments.	HIE use was associated with reductions in repeat imaging tests in the emergency department.
Bailey 2013[47]	Retrospective cohort	X	X	X	Y	Determine whether accessing HIE data reduces duplicate diagnostic imaging and associated costs in repeated back pain evaluation in emergency departments.	While use of HIE was low, use was associated with reduced duplicate diagnostic imaging. Authors were unable to demonstrate cost savings from reduction in duplicative imaging.
Bailey 2012[48]	Retrospective cohort	X	X	X	Y	Determine whether accessing HIE data reduces potentially unnecessary neuroimaging, decreases costs, and increases evidence-based guidelines adherence in headache evaluation in emergency departments.	Although use of HIE was low, use was associated with reduced diagnostic neuroimaging and increased evidence-based guidelines adherence. Staff use accounted for majority of HIE access and larger cost savings.
Frisse 2012[49]	Retrospective cohort	X	X	X	Y	Examine financial impact of HIE use in emergency departments.	HIE access was associated with a decrease in hospital admissions and the associated costs.
Sridhar 2012[44]	Retrospective cohort		X	X	Y	Describe an analytic framework for estimating financial consequences of an HIE and demonstrating its use in developing pricing policies. The authors used HIE data to create the model.	According to the model, all providers and payers saw financial gains for participating in an HIE especially for providers with more patients insured by health maintenance organizations, largely due to reduced unnecessary hospitalizations and avoided repeat emergency department visits.

*C/E indicates a study that addresses a clinical or epidemiological question.

^U indicates a study that addresses utilization of health services including care seeking patterns.

+F indicates a study that includes financial considerations such as reduction in costs or improved administrative efficiencies.

**MRSA is methicillin-resistant *Staphylococcus aureus*, a bacterium resistant to many antibiotics and that can cause life-threatening bloodstream infections, pneumonia, and surgical-site infections in institutionalized patients. http://www.cdc.gov/mrsa/. Accessed May 29, 2014.

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CHAPTER 3: HEALTH INFORMATION EXCHANGE ORGANIZATIONS AND THEIR SUPPORT FOR RESEARCH – CURRENT STATE AND FUTURE OUTLOOK

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Introduction to the Chapter

The results of the scoping review presented in Chapter 2 quantified the status of HIO involvement in published research and confirmed the usefulness of determining current and planned development of this capacity. As part of the literature review for the scoping review, I contacted researchers with known involvement in the HIO industry including Julia Adler-Milstein (University of Michigan) who offered to include questions in a national survey of HIOs to further explore the characteristics of HIOs supporting research versus those that do not to identify barriers and best practices. The national survey described in this chapter builds upon the results of the scoping review and my experience as the Executive Director for Great Lakes Health Information Exchange (GLHIE). Michigan State University and the University of Michigan, both key member organizations of GLHIE, encouraged the development of the capacity necessary to support research. As the Executive Director, I spent a significant amount of time researching what would be required and started the process to create the necessary infrastructure. My investigation involved discussions with researchers, software vendors and other HIOs. The research-specific questions in the survey are based on my experience and expertise as Executive Director of GLHIE with advice and counsel from the other authors and were designed to add context to the results of the scoping review. We sought to determine the proportion of HIOs that are or plan to support research and describe the characteristics that differentiate them from HIOs that do not support research. The following chapter describes the implementation and results of the national survey.

Abstract

Objective - To identify and describe Health Information Organizations (HIO) that reported current or planned support for research by allowing investigators to use exchanged data.

Background and Significance - Federal investment spurred HIO development, maturation, and third-party approaches to electronic health information exchange across disparate EHR technologies, creating opportunities for aggregating health information from multiple medical institutions to spur research. However, whether HIOs have pursued these opportunities or invested in specific research capabilities is not known.

Methods - Using a 2014 national survey of organizations engaged in health information exchange, we selected the subset self-identified as "health information organization" (N=64) to focus on organizations whose primary mission is data exchange. The survey asked respondents whether they supported research. We compared characteristics of research-supporting HIOs to non-research supporting HIOs and described adopted research-specific infrastructure and policies.

Results - Fifteen (23%) of the 64 HIOs reported supporting research, 30 (47%) planning to support research, and 19 (30%) did not support research. The 45 research-supporting HIOs were more likely than non-research supporting HIOs to offer functionality allowing users to query and retrieve data from multiple sources (93% vs. 72%, p=0.03), provide master patient indices (84% vs. 58%, p=0.08), provide clinical data repositories (82% vs. 47%, p<0.001), or provide data to participating networks and providers for their own analysis (49% vs. 26%,

p=0.09). The infrastructure elements most widely adopted by research-supporting HIOs were the ability to create multi-institution datasets (89%) and de-identified datasets (84%).

Discussion - The majority of HIOs reported investing in support for research, with advanced technological infrastructure and functionalities that can foster healthcare delivery reform. Given current challenges creating comprehensive longitudinal patient data sources for research, HIOs could fill an important niche.

Conclusion - With further study to validate these results, HIOs support for research could potentially promote additional value for third-party approaches to health information exchange.

Background and Significance

In addition to encouraging increased use of electronic health record (EHR) technology, the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act[10] emphasized the ability to exchange health information across health care providers. In March 2010, the Office of the National Coordinator for Health Information Technology (ONC) awarded State Health Information Exchange Cooperative Agreements grants to 56 states, territories and State Designated Entities, "to rapidly build capacity for exchanging health information across the health care system both within and across states."[7] This federal investment spurred the development and maturation of health information exchange organizations (HIOs), which offer third-party approaches to enable electronic health information exchange across disparate EHR technologies. The number of operational HIOs has grown steadily, from 32 in 2007 to 119 in 2012.[40,60] In parallel, medical institutions' participation in exchange has grown, with 11% of hospitals reporting engaging in exchange with unaffiliated providers in 2011[19], increasing to 30% in 2014.[20]

The explosion of EHR implementation and growth of HIOs create opportunities for aggregating clinical data to support research. Much research has been published with EHR data as the primary data source, and researchers continue their efforts to evaluate the use of EHR data for research, develop tools and methods to address their limitations, and create guidance for EHR developers to incorporate necessary functionality for research in EHR systems.[25-28,61] A key challenge with using EHR data for research, however, is that the data needed to track care episodes are often distributed among multiple EHR systems, such that multiple systems need to be accessed to track episodes accurately. In contrast, HIOs can provide a mechanism to

aggregate electronic health information across multiple medical institutions with diverse EHR platforms. Additionally, as institutional providers join HIOs to support direct patient care, HIOs have an opportunity to foster research by supporting functions needed for research and engaging institutions that traditionally would not have provided data to support research, including many community-based hospitals, physicians' private practices, urgent care centers, home health agencies, rehabilitation facilities, and nursing homes.

However, leveraging HIOs for research comes with challenges common to sharing data across distinct institutions, as well as unique issues specific to the use of exchanged data for research. To exchange health information electronically, HIOs must accurately identify the patient and health care provider receiving the information, transmit the information according to recognized industry standards regardless of the sending and receiving EHR technology, and ensure appropriate safeguards for the privacy and security of the protected health information throughout the process. Leveraging HIOs for research requires additional functionality, including the ability to create datasets of multiple patients across multiple institutions with differing data structures; to incorporate data standardization strategies that provide consistent representation of data among institutions; to de-identify health information when requested by data providers; to implement policies assuring appropriate use of data for research; and to create a governance model to review, approve, and monitor research requests. A recent systematic review of HIO research support found that only seven HIOs were involved in published research that used HIO data to address a specific research question.[62] Two other recent systematic reviews that assessed use and impact of HIOs on the delivery and quality of health care found similar results: only a limited number of HIOs supported research beyond the

direct evaluation of the impact of exchanging data on clinical outcomes (e.g., reductions in redundant testing).[34,59] These studies suggest that the research potential of HIOs has yet to be fully realized and points to the importance of ongoing assessment of the research capabilities of HIOs.

An assessment of the degree to which HIOs are willing and able to support research can serve to inform policymakers concerned with the development and sustainability of health information exchange. Promoting research using digital health data is an important policy priority. In addition, HIOs' involvement in research could serve as a pathway to their own sustainability, via the inclusion of important, multi-purpose functionalities that increase the HIOs' value to a diverse array of customers. Insights into how HIOs are supporting research also serve to inform development efforts of other HIOs that are planning to or considering supporting research.

Objectives

The objectives of this study are to assess the extent to which HIOs report supporting research using data from the most recent national survey of HIOs, identify characteristics that differentiate HIOs that report supporting research from those that do not, and describe the specific infrastructure and policies used by HIOs that report supporting research.[39] We defined an HIO as supporting research if it allows exchanged clinical data to be aggregated and used for clinical, health services, or epidemiologic research. Using this definition, we determined the proportion of HIOs that reported that they support, or plan to support, research, and then identify the characteristics that differentiate them from HIOs that reported that they did not

support research and had no plan to do so. We examined three types of characteristics: organizational factors (e.g., duration of operation), functional capabilities (e.g., types of information exchange that they support), and whether and how they support health care system reform (e.g., providing technical infrastructure). Finally, we described among research-supporting HIOs the extent to which they have in place any of 15 types of infrastructure and policies that specifically facilitate research (e.g., data use agreements allowing use of HIO data for research). Although the cross-sectional nature of the survey data does not inform assessment of causality, we hypothesized that HIOs reporting support for research would have advanced technological infrastructure and functionalities as well as more developed organizational infrastructure compared to non-research supporting HIOs.

Methods

We used data from a 2015 national survey of organizations that support clinical data exchange between independent entities. This ongoing national survey has been conducted five times between 2007 and 2015, with a high response rate (80% in the 2015 survey).[40-42] Full methodological details of the most recent (2015) survey, conducted between December 2014 and April 2015, have been described elsewhere.[39] The survey was sent to the Executive Directors of organizations identified as supporting health information exchange, including all organizations from the four previous surveys, through online survey software. New organizations supporting health information exchange that emerged after 2012 were identified using Web searches as well as personal references and contacts. Consistent with previous iterations of the survey, health information exchange networks created by EHR vendors, such as Epic's CareEverywhere[63] and CommonWell Health Alliance[64], were excluded.

The survey instrument included screening questions to ensure that the respondents met the definition of an HIO; inclusion criteria included facilitating or planning to facilitate, the exchange of clinical data among entities with no shared financial or governance structure.[39] The 2015 survey included questions designed to determine how many organizations support health information exchange in the US, how many hospitals and physicians' practices participate in health information exchange, the type of exchange occurring, and challenges to sustainability and development. It also included a new set of questions designed to characterize involvement in research. These questions included introductory text that defined research as "any investigation or analysis to address a specific question regarding patient or population health that is not part of the data exchange mission of the health information exchange effort, and is not used to support treatment/payment/operations/quality improvements." We also provided the following examples of research: "determining the use and effectiveness of a clinical treatment or intervention, or describing disparities and trends in the utilization of health services." For organizations responding that they support or plan to support research, additional questions determined the level of participation in research, existing restrictions related to their participation in research, and capacity to support researchers. Organizations indicating that they do not plan to support research were not asked the questions related to research. Respondents were not required to answer questions related to their support for research in order to proceed with the remainder of the survey.

We pilot tested the instrument with five potential respondents to ensure that the questions were clear, and modified the survey instrument based on their feedback. The survey instrument is available upon request. Non-respondents were contacted and provided with alternate

methods to participate, including a telephone interview or paper-based questionnaire. Respondents received a $50 gift card as an incentive to complete the survey. The survey team attempted follow-up with individual organizations, to correct or clarify any apparent errors or inconsistencies in responses.

Of the 127 organizations that participated in the survey, 64 (50%) classified their organization as a HIO. Respondents were able to select multiple organizational types, including HIO, state government, state Medicaid agency, healthcare delivery organization, and academic institution. We limited our analyses to organizations that self-identified as HIOs, because we were interested in organizations whose primary mission is exchange of health information. We included any respondent that selected HIO regardless of whether it was the sole selection or one of many.

We created a dichotomous outcome variable that combined the HIOs that reported supporting or planning to support research using the exchanged clinical data compared to those HIOs that reported that they did not support research. We then compared 20 characteristics between those HIOs that did (or plan to) support research to those that did not. We selected these 20 characteristics based on the authors' knowledge (CP, JAM, MW) of the resources and functionalities required for an HIO to support research. This knowledge was enhanced by discussions with researchers, software vendors and HIO directors. We grouped measures into three categories: organizational characteristics, functional capabilities, and support for health care delivery system reform (**Table 3.1**). There were four organizational characteristics: business structure (independent, operating within another organization, or other), duration of

operation (fewer than five years, or five or more years), whether they allow competing entities to participate (yes/no), and whether participating organizations cover organizational expenses (yes/no). We hypothesized that five years was a reasonable estimate for organizational maturity and stability that would allow HIOs to pursue more advanced uses of data, including research.

The seven functional capabilities variables were designed to describe the different types of exchange that the HIOs supported such as whether the HIO provides a clinical data repository or supports data level interoperability. The characteristics of support for reforming healthcare delivery were derived from questions that asked about whether efforts to reform health care delivery (e.g., Medicare or commercial accountable care organizations [ACO], Patient Centered Medical Homes [PCMH], or other) were supported and, if so, what types of support were provided (e.g., providing technical infrastructure). Based on these questions, we created eight dichotomous measures. The final measure in this category was whether the HIO can use exchanged data to profile providers on metrics of cost or quality.

For the subset of HIOs supporting or planning to support research using exchanged clinical data, we created a dichotomous variable indicating current vs. planned. We then compared the characteristics of these two groups using 15 measures that describe the infrastructure and policies in place to support research (see **Table 3.2**). We considered responses of "unsure" to be "no."

We first compared the frequencies of the three types of characteristics (organizational demographics, functional capabilities, and support for delivery system reform), between HIOs

currently supporting, or planning to support, research, and HIOs that do not support research or plan to do so, using chi-square tests (given the small sample size of the survey we considered $p \leq 0.1$ to be statistically significant). Similarly, among the subset of research-supporting organizations, we compared the frequencies of the 15 types of research-specific infrastructures and processes using X^2 analysis.

Results

Fifteen (23%) of the HIOs reported currently supporting research, 30 (47%) reported that they do not currently support research but plan to do so in the future, and the remaining 19 HIOs (30%) do not currently support research and have no plans to do so, or are unsure of their future plans regarding research.

Organizational, Functional, and Delivery System Reform Support Characteristics

Table 3.1 displays organizational characteristics, differences in functionality, and support for delivery system reform efforts, for the 64 HIOs based on their involvement in research.

TABLE 3.1 - ORGANIZATIONAL, FUNCTIONAL, AND DELIVERY-SYSTEM REFORM SUPPORT CHARACTERISTICS OF HEALTH INFORMATION ORGANIZATIONS (HIOS)

Characteristic	n	Number (percentage) responding, "Yes"	Supporting research, or planning to do so	Not supporting research	p
Total number of organizations	64	64 (100)	45 (70)	19 (30)	
Organizational Demographics					
Independent Organization	64	53 (83)	38 (84)	15 (79)	0.5943
Multiple competing entities can participate	64	36 (56)	27 (60)	9 (47)	0.3520
Duration of operation ≥5 years	59	35 (59)	23 (56)	12 (67)	0.4500
Participants cover 100% of operating expenses	64	39 (61)	25 (56)	14 (74)	0.1744
Functionalities					
Currently provides master patient index*	64	49 (77)	38 (84)	11 (58)	0.0220
Currently provides clinical data repository*	64	46 (72)	37 (82)	9 (47)	0.0046
Query retrieves data from multiple other sources*	60	52 (87)	39 (93)	13 (72)	0.0312
Unidirectional messaging into electronic health record	60	53 (88)	36 (88)	17 (90)	0.8514
Unidirectional messaging into an inbox outside an electronic health record system	56	56 (100)	39 (91)	17 (90)	0.8805
Supports data level interoperability	63	52 (83)	37 (84)	15 (79)	0.6216
Currently provides provider directory	64	38 (59)	29 (64)	9 (47)	0.2038
Delivery System Reform Support Capacity					
Provides technical infrastructure to support delivery-system reform*	64	31 (48)	25 (56)	6 (32)	0.0795
Provides data to networks or providers for their analysis*	64	27 (42)	22 (49)	5 (26)	0.0948
Supports Accountable Care Organizations	57	40 (70)	29 (74)	11 (61)	0.3095
Supports Patient-Centered Medical Home	55	39 (71)	29 (76)	10 (59)	0.1869
Integrates data from multiple sources	64	36 (56)	26 (58)	10 (53)	0.7046
Performs analytics	64	23 (36)	18 (40)	5 (26)	0.2972
Provides consulting on design or operations	64	20 (31)	15 (33)	5 (26)	0.5800
Incorporates technology and workflow redesign	64	30 (47)	22 (49)	8 (42)	0.6193
Can profile providers about cost or quality metrics	64	24 (38)	15 (33)	9 (47)	0.2893

* $p<0.1$.

The 64 HIOs have similar *organizational characteristics.* Most (83%) are independent organizations, more than half (56%) allow multiple competing entities to participate in the HIO, more than half (59%) have been in operation for at least five years, and almost two-thirds (61%) indicated that their participants collectively cover 100% of their operating expenses.

The two groups demonstrated statistically significant differences in three *functional capabilities,* with research-supporting organizations more likely to provide a master patient index (84% vs. 58%, p=0.02), a clinical data repository (82% vs. 47%, p≤0.001), and the ability to query data from multiple other sources (93% vs. 72%, p=0.03). The remaining four functional capability measures did not differ between the two groups.

HIOs supporting research were also more likely to *support delivery system reform efforts* such as PCMH and ACO, by providing technical infrastructure (56% vs. 32%, p=0.08) and by providing data to networks/providers for their analysis (49% vs. 26%, p=0.09). The remaining seven delivery system reform measures did not differ statistically between the two groups.

Research Infrastructure

When we examined the research-specific infrastructure and policies in place within research-supporting HIOs, we found that some were widely adopted and others were not. **Table 3.2** shows specific policies and technical infrastructure capabilities between the 15 HIOs currently supporting research, compared to 30 HIOs planning to support research but not currently doing so. Between the two groups, the most widely adopted infrastructure element was the ability to create multi-institution datasets (89% total; currently supporting, 80%; and planning to support, 93%, p=0.0702) with HIOs still in the planning phase significantly more likely to report this

TABLE 3.2 - RESEARCH INFRASTRUCTURE FOR HEALTH INFORMATION ORGANIZATIONS (HIOS) SUPPORTING, OR PLANNING TO SUPPORT, RESEARCH

Characteristic	Number (percentage) Responding, "Yes"	Involved in research	Planning to support research	p
Number of HIOs by category (denominator for percentages)	45 (100)	15 (33)	30 (67)	
Creates multi-institution datasets*	40 (89)	12 (80)	28 (93)	0.0702
Creates de-identified datasets	38 (84)	13 (87)	25 (83)	0.7985
Data use agreements allow use for research*	28 (62)	14 (93)	14 (47)	0.0023
Research part of business model, strategic priorities or mission*	28 (62)	12 (80)	16 (53)	0.082
Restricts direct interaction with system to employees of HIO or participating providers	28 (62)	9 (60)	19 (63)	0.4739
Evaluates requests from researchers on case by case basis	28 (62)	9 (60)	19 (63)	0.2835
Policies and procedures in place*	26 (58)	13 (87)	13 (43)	0.0055
Requires written data use agreement	25 (56)	10 (67)	15 (50)	0.2888
Permits data to leave the firewall	24 (53)	10 (67)	14 (47)	0.1156
Creates limited datasets that can be relinked to patients with their consent	23 (51)	9 (60)	14 (47)	0.6112
Requires approval by an Institutional Review Board*	21 (47)	10 (67)	11 (37)	0.0572
Requires approval of research proposal from oversight body*	19 (42)	10 (67)	9 (30)	0.0189
Requires written approval from stakeholders	18 (40)	4 (27)	14 (47)	0.1967
Restricts access to data for research to participating stakeholders	6 (13)	2 (13)	4 (13)	0.2835
Requires approval from a specific, designated Institutional Review Board	4 (8.9)	2 (13)	2 (6.7)	0.4588

* $p<0.1$.

functionality. Creating de-identified datasets (84% total; currently supporting, 87%; and planning to support, 83%, p=0.7985) was second most common and was reported similarly between the two groups. The third most common element was incorporating the use of exchanged data for research in data use agreements (62% total; currently supporting 93%; and

planning to support 47%; p≤0.001) with HIOs currently supporting research significantly more likely to report incorporation into data use agreements.

The least commonly adopted infrastructure and policies were those related to requiring Institutional Review Board (IRB) approval from a specific, previously approved IRB (8.9%), restricting access to exchanged data to participating stakeholders (13%), written approval from stakeholders to use their data for research (40%), and approval from an oversight body to ensure the research protocol is valid and appropriate (42%), although HIOs currently supporting research were much more likely to require approval from an oversight body (67% vs 30%; p=0.02).

Discussion

HIOs can be important partners in research because they are a potential source of clinically relevant, cross-institutional clinical information; yet, there is little systematic data about their research capabilities. In this study, we found that over 70% of HIOs reported that they currently support, or plan to support, research. While less than a quarter (23%) of the 64 HIOs currently support research, a significant number of HIOs plan to support research (47%). While we found that HIOs that support research did not differ from those that do not in terms of general organizational characteristics such as duration of operation and whether the HIO allows competing entities to participate, research-supporting HIOs were more likely to have advanced functional capabilities, as well as efforts to support reform of healthcare delivery such as the development of Accountable Care Organizations and Patient-Centered Medical Homes. Almost all of the HIOs supporting or planning to support research reported the ability to create multi-

institutional and de-identified datasets, both important for research. Other complementary policies and infrastructure were also widely adopted; almost half of HIOs involved in research reported having data use agreements that allow the use of clinical information for research, and have the necessary policies and procedures in place. Taken together, our results indicate that HIOs report being more involved in research than previously thought,[62] and offer advanced capabilities that can create value beyond supporting direct data exchange. Since our cross-sectional data cannot inform conclusions about causality, it is unclear whether an interest in supporting research is prompting HIOs to develop these enhanced capabilities, or whether HIOs that provided these capabilities for other reasons now recognize the opportunity to maximize the use of the capabilities by including support for research.

Supporting research might provide HIOs with a mechanism to create additional value for participating providers and partnering organizations. Health care providers can accomplish point-to-point data exchange through their own EHR systems--using, for example, ONC's Direct protocol, or HL7 interfaces directly connecting to data providers such as hospitals and labs--so HIOs that can differentiate their role from these other options may be best positioned for sustainability. A 2014 systematic review found that measuring value of health information exchange was the fifth most cited barrier to implementation of health information exchange in the published literature.[65] Similarly, prior work based on this national survey found that 64% of respondents identified the "lack of agreement on what HIE [health information exchange] includes" as the most substantial barrier to progress.[39]

Supporting delivery-system reform models such as PCMH and ACO are examples of added value for HIOs. Our survey found that HIOs supporting research also support these reform efforts by providing technical infrastructure, integrating data from multiple sources, providing analytical support, preparing data for networks to analyze themselves, and providing consultation about design or operational approach. PCMHs are certified by The Joint Commission, the accrediting organization for hospitals and health care systems, to signify that ambulatory practices meet "each patient's physical and mental health care needs, including prevention and wellness, acute care and chronic care" and is "coordinated across the broader health care system."[66] ACOs are networks of providers who work together to provide Medicare beneficiaries with coordinated care of high quality.[67] Supporting delivery-system reform models such as PCMH and ACO requires an HIO to have a diverse network of participating institutions that send and receive a significant amount of electronic health information, and maintain a robust technical infrastructure. Consistent with this, we found that HIOs supporting research, and a significant proportion of those planning to support it, can integrate health care data across multiple providers, perform health care analytics such as modeling and predictive analytics, and provide data to participating providers for their own analysis.

Supporting research requires high comfort level among participating providers for sharing their data with researchers. Medical institutions are stewards of their patients' health information, so HIOs must develop trust with and among their customers, to create appropriate exchange. HIOs must demonstrate to their customers that their technologies and procedures ensure that clinical data are handled consistently with respect to federally and state-mandated privacy and security protections for health information. Developing such trust takes time and, once

established, could extend to additional sharing of health care data such as required to support research. Our survey results help to illustrate how this trust can be transformed into policies and infrastructure. Specifically, we found that most HIOs supporting research have invested in the implementation of policies and procedures governing research-related activities, have created data use agreements that allow the use of exchanged data for research, and have established or work with oversight bodies to evaluate research proposals prior to receiving HIO support. This suggests that they are putting in place what is needed to ensure that they can enable research in a way that in turn, helps to ensure customers' trust.

Some results surprised us. For example, we anticipated that 100% of the HIOs currently supporting research would require IRB approval, but only 46% responded that they did, and only 9% indicated that they required documentation from a list of pre-approved IRBs. It is possible that a portion of the HIOs not requiring IRB documentation are at the initial stages of supporting research or limit their support to the provision of IRB-exempt, de-identified datasets of which almost all the HIOs report the capacity to create. Similarly, the supporting and planning-only HIOs differed in terms of whether they required approval from an oversight body, with 67% of supporting, HIOs, and 30% of planning HIOs, having such a requirement in place. Oversight bodies are useful for reassuring provider organizations contributing health information to the HIO that research using their data has a valid foundation and that the researchers have provided plans to protect the safety, confidentiality, and privacy of the research participants. We suspect that this result reflects a learning curve in which planning-only HIOs may not yet realize the value of the use of this institutional mechanism to review requests for data from researchers.

HIOs have an opportunity to complement existing efforts to make EHR data available for research. Research is currently ongoing to determine whether the information collected and shared through HIOs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research activities.[31-37] Even if HIOs are found to be valuable research partners but not sufficient as a primary data source for research, the opportunity to facilitate aggregation of data across providers could address some of the limitations of current partnerships to share EHR data for research. For example, the Clinical and Translational Science Awards (CTSA) program that is funded by the National Institutes of Health and based at medical research institutions created a network of sites called CTSA Accrual to Clinical Trials, to share data and thereby improve recruitment for clinical research studies.[29] Similarly, the Patient-Centered Outcomes Research Institute created the PCORnet, a network that combines data available in EHRs with patient-generated data, to support clinical research.[30] With appropriate measures in place to ensure research participants' confidentiality, privacy, and informed consent, HIOs' participation in these efforts can greatly expand the number and types of health care organizations contributing health care data, and the pool of potential research participants, promoting greater generalizability of their findings.

Our survey has limitations. First, we relied on self-reported data and were not able to verify the accuracy of the responses independently. In addition, this was the first time that the survey included questions about research. Further work is required to understand the reliability and validity to these survey questions. While the same definitions were provided to all respondents, respondents were directors of HIO organizations and may not have had research training or experience. As a result, respondents' interpretations of the questions might have differed. As

example of this might be the question related to the IRB; respondents might have been uncertain about the nature of an IRB, its purpose, or its requirements, which could have contributed to the unexpectedly low number of HIO that reported needing IRB approval. Second, given the cross-sectional design it is not possible to know the direction of the associations identified – thus we do not know whether these attributes lead to an interest in research or vice versa. Third, we used a more liberal definition of statistical significance ($p<0.1$) which in combination with the multiple independent statistical tests could have resulted in an increase in type 1 errors. Fourth, consistent with previous iterations of the survey, health information exchange networks created by EHR vendors, such as Epic's CareEverywhere[63] and CommonWell Health Alliance[64], were excluded. Finally, although the survey team incorporated multiple sources to identify all HIOs in the country, some might have been missed or might not have received the survey. While the survey achieved response of 80%, we do not know whether responders and non-responders differed significantly.

The results of the survey presented in this paper are intended to describe the level of HIO support for research, and identify characteristics and barriers associated with this support. Future iterations of the survey should assess the reliability of the questions (for example test-retest evaluations), conduct further investigation into perceived barriers, and determine the reasons behind the decision of HIOs who do not support research. Engaging HIO Executive Directors in one-on-one interviews or focus-groups could serve as complementary approaches to address these issues. Future research is also needed to confirm that the reported administrative and technological infrastructure in place is functioning. In particular, it would be valuable to validate that a researcher can access HIO data, as well as assess the costs,

restrictions, and limitations. It would also be useful to collect data that speaks to whether an HIO facilitates the development of a multi-institution dataset or if the effort to use an HIO is comparable to securing data from each participating organization separately. Finally, further investigation into whether the information collected and shared through HIOs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research is needed.

Conclusion

In the first systematic effort to collect data on HIOs' support for research, we found that most HIOs reported supporting or planning to support, research. Such support results in additional value created by third-party approaches to health information exchange. Within the group of HIOs that reported support for research, the types of research support that they offer likely vary. This was reflected in their infrastructure preparation and data-use requirements. Policymakers pursuing the development and growth of health information exchange can use the results of this survey to promote HIOs' involvement in research as a mechanism to maximize the federal investment in EHR systems and health information exchange strategies. For those running HIOs, these results may inform the development efforts required to support research and enhance the value provided by the HIO to its customers.

Clinical Relevance Statement

Medical research has transformed, and continues to advance, clinical practice. HIOs can be important partners in research, because they are a potential source of clinically relevant, cross-institutional clinical information. Since HIOs were developed to support the delivery of health

care, information is shared synchronously, potentially decreasing the time and cost of providing clinical information to researchers. In addition, health systems are in the midst of reform by means of models such as Patient-Centered Medical Homes and Accountable Care Organizations, which emphasize coordination of care among health care providers to achieve improved clinical outcomes. HIOs that support, or plan to support, research were found to support delivery-system reform such as Patient-Centered Medical Homes and Accountable Care Organizations.

Conflict of Interest

JAM serves on the advisory board for QPID Health. CP, MR and MW have no conflicts of interest to declare.

Human Subjects Protection

Because the survey described in this manuscript collected data on organizations rather than human subjects, the study was determined to be exempt by the University of Michigan's Institutional Review Board.

CHAPTER 4: EVALUATION OF POST HOSPITAL TRANSITIONS OF CARE IN INTRACEREBRAL HEMORRHAGE PATIENTS USING DATA FROM A HEALTH INFORMATION EXCHANGE ORGANIZATION

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Introduction to the Chapter

Building upon the results of the scoping review (presented in Chapter 2) and national survey (presented in Chapter 3), the following chapter describes the application of my hypothesis that Health Information Exchange Organizations (HIO) could be a source of relevant, cross-institutional clinical information for clinical research. Specifically, we sought to determine whether encounter data exchanged through a health information exchange organization (HIO) could be used to identify and characterize care received in post-acute care institutions following hospitalization for intracerebral hemorrhage (ICH) patients, in the 12 months following hospital discharge. The research question focused on whether HIO data could be used to study transitions of care; hence, we did not request data from institutions not participating in the Indiana Network for Patient Care (INPC). The INPC, founded in 1994 and managed by the Indiana Health Information Exchange, averages half a million clinical transactions every day.[68] With over 130 participating entities, INPC receives clinical information from providers across the state of Indiana and surrounding communities with significant concentration around Indianapolis.[69]

For readers unfamiliar with the technology used in electronic health records and HIOs, I've summarized the technology behind and challenges with identifying patients and linking clinical information received from multiple EHRs in an HIO. Linking patient data in an HIO is the work of the master patient index (MPI). Each patient is uniquely identified in the HIO using a set of demographics (first name, last name, birthdate, sex, address, etc.). The MPI maintains a record of user IDs used by the data provider organizations. Individual patients often have multiple user IDs within the same institution. The MPI connects the user IDs from the data provider

organizations with the unique ID maintained by the HIO so that all patients have only one unique ID in the HIO that links with many different IDs across the data providers.

Some MPIs use a deterministic matching model while others use a probabilistic matching model. There are pros and cons to both. Deterministic matching is sometimes referred to as exact matching in which the data received by the HIO must have the exact same information in the selected fields to match with an existing ID in the MPI. This model prevents false matches but also requires extensive and continuous management to limit the number of unique ids assigned to each patient. Every misspelled name (Diane vs. Dianne), nickname (Bill vs. William), hyphenated name (Parker-Lee vs. Parker Lee), Jr/Sr, switched number (3/24/64 vs 24/3/64), etc. results in an additional record for a patient. Probabilistic matching loosens up the restrictions and accepts a predetermined level of difference for certain variables (such as a phone number is recognized to change but a gender is unlikely to change). The probabilistic matching process slightly increases the risk of false matches but is much less resource intensive and timely.

Abstract

Objective: Evaluation of post discharge transitions of care is becoming increasingly important, especially for readmission reduction efforts. We sought to determine whether encounter data exchanged through a health information exchange organization (HIO) could be used to identify and characterize care received during the 12 months following hospitalization for intracerebral hemorrhage (ICH).

Methods: We used a retrospective cohort of patients with spontaneous ICH (ICD-9 codes 431 and 432.9) admitted to two Indianapolis area hospitals between January 1, 2009 and December 31, 2011. Patient information was abstracted from medical charts and linked to the local HIO (Indiana Network for Patient Care, INPC) to identify medical encounters that occcurred up to one year post discharge. Data from the INPC was limited to participating acute care hospitals and included ER visits, hospital admissions, acute (in-patient) rehabilitation, and hospital-based hospice, as well as hospital-based outpatient visits. No information was available for free-standing acute rehabilitation facilities, sub-acute rehabilitation facilities, skilled nursing facilities or other outpatient visits. Primary outcomes were the patients' care patterns after discharge as determined by the INPC described in terms of the number, type of care setting, and timing of encounters over the one year follow-up period.

Results: Based on medical chart information, of the 468 ICH patients discharged alive, 41% were discharged to acute rehabilitation, 30% to home, 19% to skilled nursing facility, 7% to hospice and 3% to another acute setting. We found that although 235 patients were discharged to an inpatient setting for which the INPC had encounter data (acute rehabilitation, hospital-

based hospice, or other acute hospital acute setting), 131 (44%) did not have an encounter recorded in the INPC for their discharge destination. We also found that 57% of patients discharged home had no encounters within 30 days of discharge, highlighting the inability of current HIO data to track transitions across all outpatient settings or document the lack of encounters. Finally, because encounters in the INPC were collapsed into three categories by their type of care setting (inpatient, outpatient or emergency) we were unable to distinguish which inpatient encounters were readmissions.

Conclusion: While HIOs could be an important source of relevant, cross-institutional encounter information useful to study transitions, the utility of data from this HIO was limited to data provided by participating acute care hospitals. Expanding the network of participating providers, increasing the types of data exchanged through the HIO, and prioritizing data quality improvements is necessary for HIOs to support research on transitions of care.

Background and Significance

Intracerebral hemorrhage (ICH), which represents about 15% of all strokes, requires intense resource utilization in post-acute care settings– most notably rehabilitative care following the index hospital admission.[70] ICHs carry a high risk of mortality—approximately 40% at 30 days[71,72]—and serious long-term disability, with only 20% of affected patients expected to be functionally independent at six months.[73,74] Efforts to reduce unnecessary use of health care services often include stroke as a targeted condition in part due to the intense resource utilization.[75-77] In addition, certification as a Comprehensive Stroke Center by The Joint Commission includes several standardized performance measures that specifically address the quality of care provided as well as coordination of post-discharge care for stroke patients.[78]

Understanding transitions of care for stroke patients, including transitions to a higher level of care (i.e., complex transitions),[79] would support efforts to reduce readmissions and improve patient functional recovery.[80-82] All transitions from the acute inpatient setting begin with the hospital discharge disposition, which indicates the next site of care. Common post-acute and long-term care settings include acute (inpatient) rehabilitation, hospice (either hospital-based or community-based), skilled nursing facilities which include nursing homes and sub-acute rehabilitation units, and long-term care hospitals. Stroke patients discharged home often seek care from out-patient rehabilitation providers, home health agencies, primary care and specialty physicians. Finally, emergency departments care for stroke patients with emergent and serious conditions post-discharge and can be useful indicators of failed transitions of care.

Research has found that most patients with stroke–up to 70% of Medicare beneficiaries—receive some type of post-acute care.[83] In a review of Medicare data, the top four locations of care following discharge for patients with stroke were: home with no services (31%), skilled nursing facilities (30%), inpatient rehabilitation facilities (22%), and home with home health services (14%).[84] Several studies have identified variations in the use of post-acute care for patients with stroke – for example selection of acute rehabilitation versus sub-acute rehabilitation,) – and that these variations are influenced by factors such as age, gender, income, insurance, race/ethnicity, region of the country, type and severity of stroke, and reimbursement policies.[80,85-92] In addition, transitions of care following hospitalization are both targeted by interventions to improve patient outcomes[93-99] and addressed by guidelines and recommendations for stroke care.[100-102]

While researchers continue to investigate factors impacting selection of post-acute facilities and long-term care providers, it is well recognized that reimbursement policies – particularly those from the Centers for Medicare & Medicaid Services are an important driver of post-acute care utilization patterns. For example, reimbursement rules dictate that acute (inpatient) rehabilitation facilities target patients who are likely to return to a community setting but require intensive rehabilitative services (3 hours/day, 5 days/week).[101] Whereas stroke patients unable to handle intensive rehabilitative services but who require daily skilled nursing or rehabilitative care are then typically discharged to skilled nursing facilities for sub-acute rehabilitative services.[103]

Obtaining data from post-acute care facilities and long-term care providers for patients with stroke is particularly important, since care is often fragmented across the transitional period.[81,102,104] Given the fragmentation of the care continuum for stroke patients, transition of care research requires information from a multitude of provider types. However, there are few such data sources and those that do exist were often created for reimbursement purposes resulting in significant delays between the time of data collection and availability to researchers and limitations in the type and amount of clinical information available. This makes stroke a particularly informative condition upon which to test the study of transitions of care using alternative data sources.

The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act[10] invested millions of dollars to encourage increased use of electronic health record (EHR) technology and electronic exchange of health information among health care providers and institutions. With this federal investment came the development and expansion of health information exchange organizations (HIOs), from 32 in 2007 to 119 in 2012.[40,60] HIOs are organizations that provide technology and infrastructure to enable electronic health information exchange across disparate EHR technologies and health care institutions. EHRs and the HIOs that connect them provide unique opportunities for aggregating clinical data to support research among multiple health care institutions and settings; thus, HIOs would seem particularly well suited to document transitions of care across multiple different care settings.

The ability to study transitions of care from an acute hospital to a post-acute provider is particularly important as Medicare implements reforms of post-acute care provider payment

policies. These recent reforms were initiated to ensure utilization of post-acute providers are based on patient care needs and clinical characteristics;[103] the capacity to readily monitor transition patterns and patient outcomes would benefit this effort. Large-scale clinical registries such as Get With The Guidelines-Stroke[105,106] lack information to describe transition patterns post-discharge. If such information were available from HIOs, researchers could identify and evaluate factors affecting clinical outcomes that occur beyond the inpatient setting and organizational boundaries of the discharging hospital. Because of the complexity of the post-discharge care needs of ICH patients, stroke is an excellent condition to assess the capacity of HIOs to elaborate these post-care strategies.

Objectives

The objective of this study was to use data from one HIO to identify and characterize care received in the 12 months following discharge from the index acute hospitalization for patients with ICH.

Methods

Patient Cohort

We used a retrospective cohort of patients with spontaneous ICH (ICD-9 codes 431 and 432.9) admitted to two Indianapolis metropolitan-area hospitals between January 1, 2009 and December 31, 2011. Previous research demonstrated that ICD-9 codes 431 and 432.9 have high sensitivity for identifying patients with ICH (79% for 431 and 72% for 432.9).[107]

The list of potentially eligible patients was created using data from the Indiana Network for Patient Care (INPC), a clinical data repository managed by the Indiana Health Information

Exchange. Potential cases were reviewed by a board certified neurologist (JM) using clinical information abstracted from the hospitals' electronic health record systems (EHR). Patients with any of the following conditions were excluded from the cohort: evidence of traumatic ICH, aneurysm, encephalitis, brain tumor, hemorrhagic transformation of an ischemic infarct; hemorrhage due to venous sinus thrombosis, carotid endarterectomy, or thrombolytic administration for ischemic stroke.

EHR Dataset

Clinical data for all cohort members were abstracted from the hospital EHRs by trained study staff using a standardized chart review process with a defined database instrument. The EHR dataset contained administrative, demographic, and clinical information, including the discharge disposition, which was recoded into: home, rehabilitation, skilled nursing facility, hospital/acute setting, hospice, or unknown. Dispositions of prison, homeless shelter, assisted living, and friends or relatives were recoded as home, to distinguish them from medical institutions with formal care services. Extended care facility or nursing home was recoded as skilled nursing facility.

HIO Data Source – the INPC

We queried the INPC for encounters by the patients in the ICH cohort for a one year period following discharge from the index admission (post-ICH). The INPC, founded in 1994, has encounter information for more than 90% of care delivered in Indianapolis-area hospitals including inpatient admissions and services in hospital-based outpatient departments. Patients were assigned unique identification numbers by the INPC, allowing linkage between INPC institutions as well as between the INPC and hospital-based EHR datasets. New incident ICH

events in confirmed ICH cases were excluded. A Regenstrief Institute data manager with authorized access to INPC data prepared and de-identified the INPC data and completed the linkage between the EHR and INPC datasets.

The INPC dataset included demographic (age, race, ethnicity) and post-discharge encounter information (i.e., the record of services provided to a patient during an appointment, admission or other interaction with a health care provider). Encounter information included the number of days between the date of discharge for the index event and subsequent encounters, length of stay, encounter care setting (inpatient, outpatient and emergency), encounter location (such as the unit or floor for an inpatient visit or a specific hospital emergency room), insurance provider(s), medical provider name, provider specialty, and provider type (such as medical doctor or nurse), and primary and secondary diagnoses including ICD-9 code and description. The INPC also provided date of death which we used to calculate in-hospital, 30-day and one year mortality rates.

The INPC dataset did not include encounter information from independent physician practices, free-standing hospice providers (outside the acute hospital setting), free-standing acute rehabilitation facilities, skilled nursing facilities (that provide sub-acute rehabilitation and long term nursing home care), or long-term acute care hospitals (LTCHs). These provider types either do not participate in the INPC, or do participate but do not allow their data to be used for research. No information on the use of home health services was available.

Encounters in the INPC were classified into three categories by their type of care setting -- inpatient, outpatient or emergency[108] which means that a variety of different patient clinical

interactions were collapsed into each category. Inpatient care settings included admissions to any inpatient facility which, in this dataset, was limited to acute care hospitals and their acute rehabilitation and hospice units. Outpatient care settings were limited to services from hospital-employed physicians and hospital outpatient departments, and could include, for example, occupational therapy, orthopedic services, and primary care outpatient services. Emergency care setting was limited to encounters in a hospital emergency department.

Data Analysis

The primary outcome of interest was the specific care pattern of individual patients after hospital discharge for the index ICH event defined as the timing and type of care setting for first and second encounters.

Analyses were limited to the generation of descriptive statistics. We calculated rates of missing data and provided a summary of the demographic and clinical characteristics of the starting cohort. Discharge disposition frequencies were reported for patients discharged alive from the index admission. We calculated the in-hospital mortality rate for the index admission, 30-day post-discharge mortality rate, and one-year post-discharge mortality rate using death-certificate data. To aid comparability with prior studies, we also calculated the 30-day and one-year mortality rates from the date of admission.

Because the INPC data was limited to inpatient, outpatient or emergency encounters, we could only validate the discharge destination for those ICH patients who were discharged to another inpatient setting (defined as acute rehabilitation, another acute care hospital, or hospital-based hospice). Thus, for patients with a discharge destination of acute rehabilitation, hospice or

hospital/acute setting (i.e., hospital transfer), we defined the first inpatient encounter that occurred within two days of discharge as a 'confirmation encounter', as these encounters confirmed that the patient received care at the type of care setting indicated by their discharge destination. We were not able to confirm discharge destinations for free-standing facilities such as hospice or skilled nursing facilities. We were also not able to validate discharges to home as the INPC had limited encounter information for providers that typically care for stroke patients discharged home including free-standing out-patient rehabilitation providers, home health agencies, and independent primary care and specialty physicians. Available data for the three care settings by discharge destination is summarized in **Table 4.1**, highlighting the limitations of the HIO as a data source.

TABLE 4.1: AVAILABLE INPC DATA BY CARE SETTING THAT CAN BE USED TO VALIDATE DISCHARGE DESTINATION RECORDED IN EHR

Discharge Destination	*Encounter Care Settings*		
	Emergency	*Inpatient**	*Outpatient*
Acute Rehabilitation		✓ for hospital-based**& X for free-standing	
Skilled Nursing Facility		X	
Hospital/Acute Setting Transfer		✓	
Hospice		✓ for hospital-based** X for free-standing	
Home			✓ for hospital-based** X for independent

* ✓ indicates data is available; **X** for missing data.

** Located within a hospital.

*** Not located within a hospital.

We assessed the type and amount of missing encounter data by examining each of the first two encounters that were identified in the INPC data (i.e., inpatient, outpatient and emergency encounters), following the index admission, and compared them to anticipated care patterns. We describe the type of care setting, timing and duration of the first encounter after stratifying according to the discharge disposition that followed the index admission (i.e., acute rehabilitation, home, skilled nursing facility, hospice, other hospital/acute setting). We stratified first encounters by time period (first 30 days versus remainder of the year) and by the discharge disposition following the index hospitalization. For the two time periods (within 30 days and between 31 days and one year from discharge), we provided mean encounter length of stay and mean days between discharge and the first encounter for each care setting within each discharge disposition category. We also reported number of patients alive after 30 days,

by discharge disposition, and number of patients with a first encounter between 31 days and one year and a cumulative proportion of patients who had at least one encounter within the 1 year follow-up period.

Finally, we looked at the pattern of care settings for second encounters using the same stratification structure - by time period and discharge disposition. For the two time periods (within 30 days and between 31 days and one year), we provided mean length of stay and mean days between discharge from the index admission and the second encounters for each care setting within each discharge disposition category.

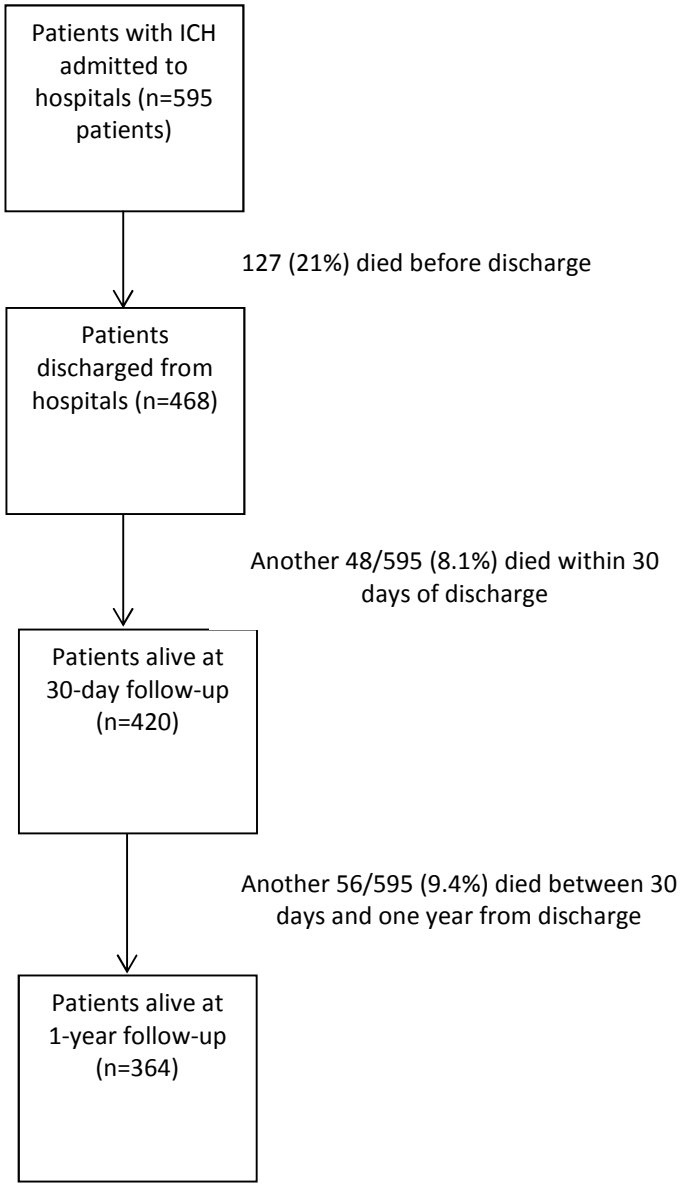
Results

Patient Cohort

Our cohort consisted of 595 patients with confirmed ICH admitted to two Indianapolis metropolitan-area hospitals between January 1, 2009 and December 31, 2011. (**Figure 4.1**) Of these patients, 127 (21%) died before discharge. Additional deaths reduced our cohort at 30 days after ICH discharge to 420 patients, and at one year after ICH to 364. Thirty-day mortality rate from admission was 30.1% and at one-year was 39.0%. The cohort was 70% white and 27% African American. Sex distribution was balanced (53% male), and mean age was 70 years. At ICH admission, one quarter (24%) of the patients were employed, 10% disabled and 66% retired or otherwise unemployed. Almost half (46%) of the patients were married, 20% single, 17% widowed, 11% divorced and 6% living with a partner. Half (48%) of the patients had Medicare coverage, another 9% were dually covered by Medicare and Medicaid, 8% Medicaid alone, 22%

had commercial coverage, and 13% were uninsured. An additional ICH was experienced by 2.3% of the cohort during the one-year follow-up period.

FIGURE 4.1 – COHORT FLOW DIAGRAM



EHR Data

Clinical information was abstracted from the hospitals EHRs to determine whether patients met study inclusion criteria and to provide information on patients' index admission including their discharge disposition. Most data elements had few missing entries (≤2%); however, two variables had substantial levels of missing data: patient site of origin before admission (e.g., home, nursing home, extended care facility) was missing in 39%, and number of days between index admission and prior stroke was missing for 45% of the 184 patients with documentation of a prior stroke (**Table 4.2**).

TABLE 4.2: FREQUENCY OF MISSING DATA ELEMENTS BY DATA SOURCE

Data Variable	*Frequency Missing*
Electronic health record data	
Employment status	0.0%
Insurance categories	2.0%
Length of stay for index admission	0.0%
Discharge disposition	0.4%
Admission through emergency department	2.0%
Transfer between hospitals	0.0%
Admitted to intensive care unit	0.0%
Source of admission	39%
Days between index admission and prior stroke [for patients with evidence of prior stroke (n=184)]	55%
Health information organization data	
Encounter care setting	0.3%
Length of stay for encounters	0.5%
Insurance	9.7%
Site of encounter	43%
Provider profile elements (name, specialty, provider type)	85%

The frequency distribution of discharge disposition is provided in **Table 4.3**. Ninety percent of the 468 patients discharged alive went to one of the following three destinations: acute rehabilitation (41%), home (30%), and skilled nursing facility (19%).

TABLE 4.3: DISCHARGE DISPOSITION FOLLOWING INDEX ADMISSION FOR INTRACEREBRAL HEMORRHAGE (N=468 PATIENTS DISCHARGED ALIVE); SOURCE: HOSPITAL EHRS

	Frequency	*Percentage*
Acute rehabilitation	191	41
Home	141	30
Skilled nursing facility	90	19
Hospice	31	6.6
Hospital/Acute setting	13	2.8
Missing	2	0.4

HIO Data (INPC)

For 468 patients discharged alive from index admission, the INPC provided data on 4,845 different encounters during the year following the index admission. Some variables within each encounter record had substantial amounts of missing data: encounter locations (i.e., unit or floor for inpatient visits or specific hospital emergency departments) were missing in 43% of the encounters, and provider profile elements (including provider name, specialty and provider type) were usually missing (85%) **(Table 4.2).**

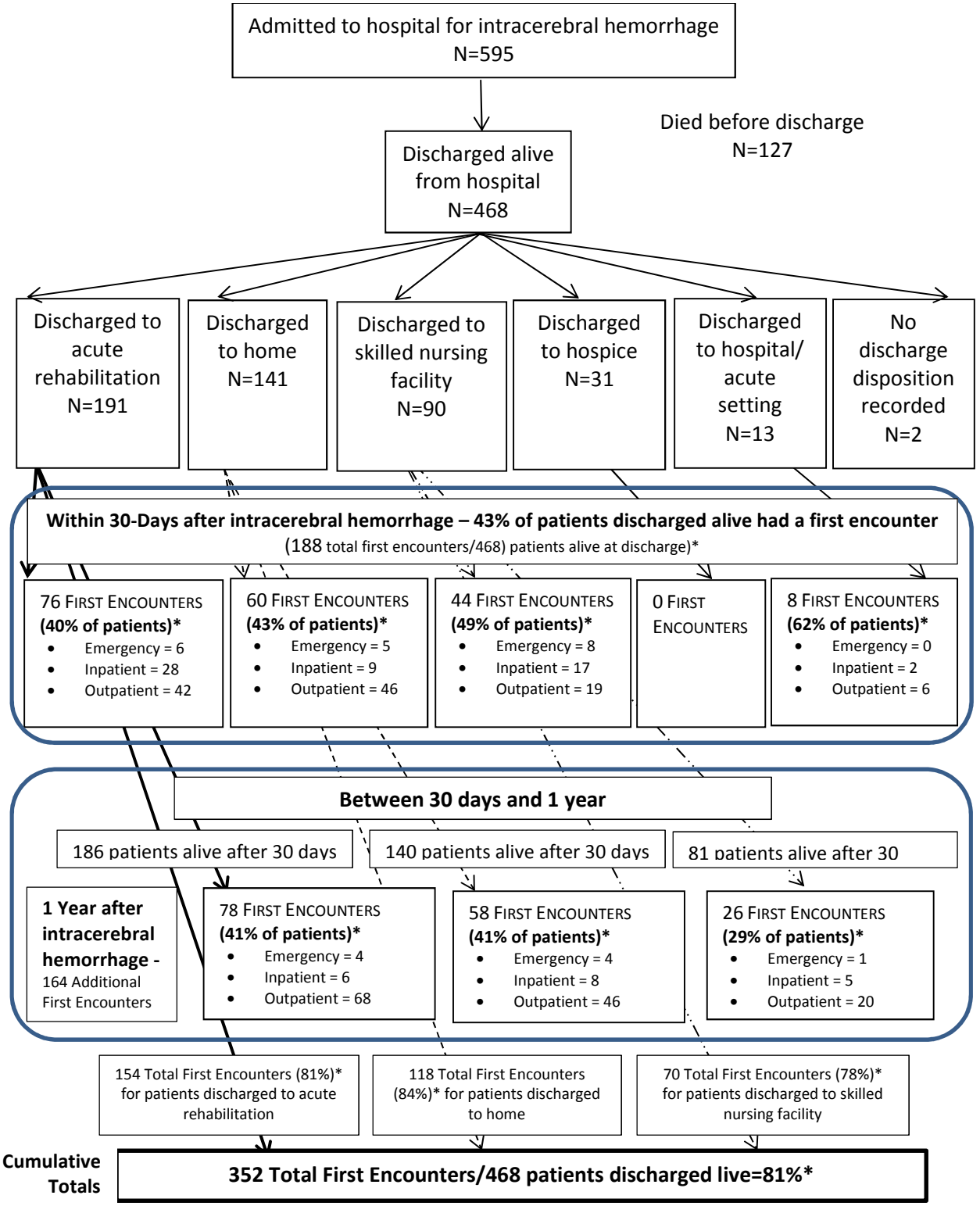
Reported care settings for encounters were categorized by the INPC as outpatient (65% of all encounters), inpatient (23%), and emergency (12%). The proportion of confirmed encounters (encounters confirming patients received care as indicated by their discharge destination) demonstrated the problem of missing encounter data in the HIO dataset. Slightly more than half (56%) of the 235 patients discharged to an inpatient facility for which the INPC had encounter data (acute rehabilitation, hospice, or hospital/acute setting) had a confirming inpatient encounter. Only half of the 191 patients discharged to acute rehabilitation could be confirmed, i.e., had an inpatient encounter in the INPC within two days of discharge from their

index admission. Eight of the 13 patients (62%) transferred to another hospital or acute setting had confirming inpatient encounters within two days of discharge. The most complete set of encounter information was for hospital-based hospice with 90% of the 31 patients with this discharge destination having a confirmed encounter. Lastly, there were four inpatient encounters within two days of discharge for patients discharged to skilled nursing facilities. While these encounters met the criteria for a confirmed encounter, the INPC encounter data did not include encounters from a skilled nursing facility. Therefore, these encounters are likely readmissions and were not included in the proportion of patients discharged to inpatient facilities with confirmed encounters.

First Encounters

Given that patients with ICH have high continuing medical needs after discharge, patients discharged alive from the index admission would be expected to have a first encounter within 30 days. Of the 48 patients who died within 30 days of discharge from the index admission, all but two patients (96%) had at least one post-discharge encounter in the INPC data. **Figure 4.2** illustrates the relationship between discharge disposition, numbers and timing of first encounters, and the numbers of patients without a record of any first encounter.

FIGURE 4.2 – NUMBERS OF FIRST ENCOUNTERS (EXCLUDING CONFIRMING ENCOUNTERS) AT 30 DAYS AND 1 YEAR, BY DISCHARGE DISPOSITION



*Percent calculated by total number of patients discharged alive by discharge disposition

Table 4.4 provides total numbers of first and second post-ICH encounters for the first 30 days and for 31 days to one year by discharge disposition, mean length of stay, and mean number of days between ICH discharge and first and second encounters. Rates were calculated relative to the total number of patients discharged alive by discharge disposition.

More than half (57%) of patients discharged home did not have record of a first encounter within 30-days. Almost two-thirds (60%) of patients discharged to acute rehabilitation and 51% of patients discharged to a skilled nursing facility did not have a first encounter within 30 days.

After accounting for the encounters confirming admission to an inpatient acute rehabilitation unit, almost one-fourth (22%) of the 191 patients discharged to acute rehabilitation had an outpatient encounter as their first encounter within 30 days, 15% had an inpatient encounter which in this case is likely to indicate a hospital readmission, and 3% had an emergency encounter.

Of patients discharged to a skilled nursing facility, 21% had an outpatient encounter, 19% an inpatient encounter (likely indicating a hospital readmission), and 9% an emergency encounter within 30 days following discharge. Recall that INPC did not have encounter information from skilled nursing facilities so we were unable to confirm care received according to their discharge disposition. Almost half (46%) of the 13 patients transferred to another hospital/acute setting had an outpatient encounter and 15% an inpatient encounter during the 30 day period (outside of the eight confirming encounters) (**Table 4.4**). Of the patients with a discharge disposition to home who had a first encounter within 30 days, 77% of those encounters were in an outpatient setting, 15% inpatient encounter (suggesting hospital readmission), and 8% emergency. All 31

hospice patients died before the 30-day follow-up and had no other encounters beyond the confirming inpatient encounter.

First encounters more than 30-days following discharge from the index admission likely indicate patients who had a long stay in an acute or sub-acute setting, delayed seeking care if they were discharged home, or sought care from a non-INPC participating provider such as a skilled nursing facility or free-standing rehabilitation facility. Most (87%) of the patients discharged to 'acute rehabilitation' who had a first encounter recorded in the INPC dataset more than 30 days after discharge from the index admission had their first encounter in an outpatient setting (**Table 4.4**).

We found that 81% of patients eventually had a first encounter other than a confirming encounter within the year after ICH, suggesting that 19% of the patients seek all of their post-acute care with institutions outside the INPC, or with institutions in the INPC that do not allow their data to be shared for research.

TABLE 4.4: TOTAL NUMBER OF FIRST AND SECOND ENCOUNTERS AFTER INTRACEREBRAL HEMORRHAGE (ICH) OVER 1-YEAR FOLLOW-UP BY DISCHARGE DISPOSITION AND CARE SETTING

Encounter Care Setting	*Number of **First** Encounters*	*% of Patients by Discharge Disposition**	*First Encounter Mean Length of Stay*	*Mean Number of Days between ICH Discharge and First Encounter*	*Number of **Second** Encounters*	*% of Patients by Discharge Disposition**	*Second Encounter Mean Length of Stay*	*Mean Number of Days between ICH Discharge and Second Encounter*
Encounters within 30 Days from Discharge from ICH Index Admission								
Acute Rehabilitation (n=191)								
No encounters recorded within 30 days	115	60.2%						
Emergency	6	3.1%	2.5	9.8	2	1.0%	1.5	7.0
Inpatient**	28	14.7%	9.1	11.5	19	9.9%	23.1	11.5
Outpatient	42	22.0%	6.0	15.0	17	8.9%	12.8	21.7
Total within 30 days	76	39.8%			38	19.9%		
Home (n=141)								
No encounters recorded within 30 days	81	57.4%						
Emergency	5	3.5%	1.0	4.0	5	3.5%	1.4	13.8
Inpatient	9	6.4%	10.8	7.2	5	3.5%	16.4	8.2
Outpatient	46	32.6%	3.2	13.8	25	17.7%	5.0	16.9
Total within 30 days	60	42.6%			35	24.8%		
Skilled Nursing Facility (n=90)								
No encounters recorded within 30 days	46	51.1%						
Emergency	8	8.9%	3.3	12.3	1	50.0%	1.0	14.0
Inpatient**	17	18.9%	6.4	13.1	1	50.0%	1.0	12.0
Outpatient	19	21.1%	1.0	14.9	0	0.0%	N/A	N/A
Total within 30 days	44	48.9%			2	2.2%		
Hospital/Acute Setting (n=13)								
No encounters recorded within 30 days	5	38.5%						
Emergency	0	0.0%	N/A	N/A	0	0.0%	N/A	N/A
Inpatient**	2	15.4%	14.5	17.0	1	7.7%	5.0	16.0
Outpatient	6	46.2%	24.3	17.5	2	15.4%	1.0	9.0
Total within 30 days	8	61.5%			3	23.1%		
Total of First and Second Encounters for all Discharge Dispositions within 30 days	188	43.2%			78	17.9%		

TABLE 4.4 (cont'd)

Encounter Care Setting	*Number of **First** Encounters*	*% of Patients by Discharge Disposition**	*First Encounter Mean Length of Stay*	*Mean Number of Days between ICH Discharge and First Encounter*	*Number of **Second** Encounters*	*% of Patients by Discharge Disposition**	*Second Encounter Mean Length of Stay*	*Mean Number of Days between ICH Discharge and Second Encounter*
Encounters 31 Days from Discharge for ICH Index Admission to One Year and Cumulative Totals								
Acute Rehabilitation (n=191)								
No encounters recorded 31 days - 1 year	113	59.2%						
Emergency	4	2.1%	1.3	108.5	4	2.1%	2.8	79.5
Inpatient	6	3.1%	6.8	180.2	19	9.9%	9.1	114.8
Outpatient	68	35.6%	5.6	71.0	68	35.6%	9.0	84.1
Total between 31 days and one year	78	40.8%			91			
Total from discharge to 1 year	154	80.6%						
Home (n=141)								
No encounters recorded 31 days - 1 year	83	58.9%						
Emergency	4	2.8%	1.5	102.3	5	3.5%	1.2	174.0
Inpatient	8	5.7%	2.4	131.1	12	8.5%	4.0	189.0
Outpatient	46	32.6%	1.0	56.7	45	31.9%	2.9	88.3
Total between 31 days and one year	58	41.1%			62			
Total from discharge to 1 year	118	83.7%						
Skilled Nursing Facility (n=90)								
No encounters recorded 31 days - 1 year	64	71.1%						
Emergency	1	1.1%	1.0	199.0	0	0.0%	N/A	N/A
Inpatient	5	5.6%	6.3	92.2	0	0.0%	N/A	N/A
Outpatient	20	22.2%	1.0	44.1	1	1.1%	1.0	34.0
Total between 31 days and one year	26	28.9%			1			
Total from discharge to 1 year	70	77.8%						
Hospital/Acute Setting (n=13)								
No encounters recorded 31 days - 1 year	11	84.6%						
Emergency	1	7.7%	1.0	50.0	1	7.7%	1.0	34.0
Inpatient	0	0.0%	N/A	N/A	0	0.0%	N/A	N/A
Outpatient	1	7.7%	1.0	33.0	1	7.7%	1.0	72.0
Total between 31 days and one year	2	15.4%			2			
Total from discharge to 1 year	10	76.9%						
Total of First and Second Encounters between 31 days and one year	164	37.7%			156	35.9%		
Cumulative Total Number of Encounters	**352**	**80.9%**			**234**	**53.8%**		

* Percentage calculated by dividing the numbers of encounters by care setting by the total number of patients with the specific discharge disposition.

** First encounters exclude inpatient admissions within 2 days of discharge from index admission.

Second Encounters

Second encounters provide further insight into the care trajectory of ICH patients. Just over half (54%) of the patients had a second encounter in the INPC dataset. For patients discharged to acute rehabilitation, half of the second encounters that occurred within 30 days were in inpatient settings (which suggest readmissions), and 45% were outpatient encounters, while acute rehabilitation patients with second encounters between 31 days and one year were largely outpatient (75%). Second encounters for patients discharged home were, as expected, predominately outpatient during both time periods – within 30 days (71% of 35 second encounters) and between 31 days and one year (73% of 62 second encounters). Within 30 days, 14 (9.9%) patients discharged home had an inpatient encounter as their first or second encounter, likely representing readmissions, and within a year it was 34 (24.1%) patients. Patients discharged to skilled nursing facilities and hospital/acute settings had too few second encounters to identify any meaningful trends.

Discussion

We sought to use data from one HIO to identify and characterize care received in the 12 months following discharge from the hospital for patients with ICH. In the following discussion, we compare our findings with existing research, discuss the importance of network size and diversity of participating health care providers on data for research, describe the completeness of the HIO data, outline data challenges, share limitations of our study, and suggest future research directions.

Comparison of Findings with Previously Published Research

Findings from previously published studies with similar outcomes were limited to the examination of mortality rates, discharge disposition, and the number of post-acute encounters. Mortality at 30 days and one year following discharge from the index admission differs from other published studies have found. Our 30 day mortality rate was 30.1% compared to a previous finding of 44.0%.[71] Previous research found a 54% mortality rate for patients with ICH[109] and our cohort had a 39.0% one-year mortality rate. In a review of Medicare data, the top four locations of care following discharge for patients with stroke were: home with no services (31%), skilled nursing facilities (30%), inpatient rehabilitation facilities (22%), and home with home health services (14%).[84] We found that 41% of our cohort was discharged to acute rehabilitation, 31% to home (we did not differentiate between home with or without services), and 19% skilled nursing facilities. We were unable to identify any articles that confirmed discharge disposition with care received or that characterized care settings of first and second encounters post-discharge specific to ICH patients such as our study did.

Finally, a previously published review of Medicare data evaluated the number of sites of post-acute care for a set of conditions with the largest patient groups that use post-acute services (all stroke, hip fractures and lower extremity join replacements). These authors found that 72% of the patients with these conditions used only one site of care during the 30 days following discharge.[84] We found that of the 294 ICH patients discharged to acute rehabilitation, skilled nursing facility or another hospital/acute setting, 128 (43.5%) had at least two encounters within 30 days. Our findings suggest that ICH patients experience more post-acute care

encounters and transitions of care than all stroke, hip fractures and lower extremity join replacements combined.

Network of Providers

Using a HIO to accurately characterize transitions of care requires that they include a network of providers which is sufficiently broad to capture information from across the care continuum. For stroke this would include acute-care hospitals, and their acute rehabilitation and hospice units, free-standing acute (inpatient) rehabilitation facilities, hospice providers, skilled nursing facilities, home health agencies, long-term care hospitals, and non-hospital-based primary care and specialty care physician practices. We selected INPC as our research partner as they are one of the longest running HIOs with the most developed research infrastructure. We found that even a mature HIO with a well-developed research enterprise is hindered by limited partnerships with post-acute providers. The INPC dataset included encounter information from only acute care hospitals and their acute rehabilitation settings, hospice, and outpatient departments, but not the other types of sites providing care to patients discharged after ICH. Given that three of the top five discharge dispositions following ICH admission were acute rehabilitation, skilled nursing facility, and hospice (**Table 4.3**), this incompleteness in representation of the stroke care continuum creates a large gap in information when studying transitions of care, since not all patients seek post-acute services within the hospital setting. Most importantly, we could not follow patterns of post-acute care that may have included multiple visits among post-acute care and primary care settings.

Post-acute provider participation in the INPC is more limited than national trends would suggest. EHR adoption and medical institution partnerships with HIOs are lagging for long-term and post-acute care providers such as skilled nursing facilities, long-term acute hospitals and rehabilitation hospitals compared to acute care hospitals and physicians. This is in part because the latter two groups qualify for Medicare and Medicaid EHR incentive programs established by the HITECH Act.[10] A 2013 report by the Office of the National Coordinator for Health Information Technology notes that while no national data were available across all long-term and post-acute care institutions, they estimated that EHR adoption rates lag behind those of acute care hospitals based on data available for long-term acute care hospitals and rehabilitation hospitals, by as much as 50%.[21]

HIOs interested in supporting transitions of care research must also encourage bi-directional exchange between acute care hospitals and the long-term care and post-acute care providers, to provide a comprehensive picture of patients' interactions with health care providers across the stroke care continuum. This means that long-term and post-acute providers would share encounter information and associated clinical information with the HIOs, rather than just accepting data from referring institutions through the HIO. National-level data about engagement of long-term care and post-acute care providers in bi-directional exchange are limited. A recent national survey of HIOs found that less than half reported participation by long-term care providers, with 40% receiving data from long-term care providers, and 51% providing data to long-term care providers.[39] Long-term and post-acute providers create and maintain extensive amounts of clinical information on their patients, creating value to informing health care delivery as well as research. Efforts to include long-term and post-acute

care providers in health information exchange must also address the need for bi-directional exchange, to ensure a robust set of clinical information.

Completeness of HIO Data

When captured, information for each encounter in the INPC dataset was fairly complete, with most data elements provided at least 90% of the time. However, our assessment found that the capture of encounters was insufficient. Slightly more than half (56%) of the 235 patients discharged to a type of inpatient facility for which the INPC had encounter data (acute rehabilitation, hospice, or hospital/acute setting) had a confirming encounter (i.e., an inpatient encounter within two days of discharge from the index admission). After excluding confirming encounters, of the 468 patients discharged alive from the index admission, we determined that the INPC data showed that less than half (43%) had an encounter in any care setting within 30 days of discharge. This low rate cannot be explained by patients who did not survive long after discharge; we determined that 96% of the patients who died within 30 days had at least one post-discharge encounter. With an average length of stay for acute rehabilitation at 8.9 to 22.2 days depending on the patient's impairment following stroke,[110] we would expect only a minority of the patients discharged to acute rehabilitation to still be in an inpatient facility at 30 days post-discharge. The high rate of patients discharged to acute rehabilitation who did not have an encounter during the first 30 days (60%) therefore suggests that a significant number of encounters are not captured by the INPC data. Similarly, we found that 57% of patients discharged home did not have an encounter within 30 days.

Although these findings are specific to our review of INPC data and ICH-related transitions of care, they indicate challenges that researchers would face when using data from any HIO to study transitions. Expanding the network of providers sharing clinical information and increasing the amount of clinical information that each provider shares would advance the HIO's ability to meet their primary mission to provide timely, clinically relevant data to inform health care delivery.

Data Challenges

As with all datasets created for clinical purposes, HIO data requires adjustments and accommodations to facilitate use by researchers. HL7 standards have resulted in a limited number of care setting categories for encounters (patient class variable).[111] HL7 is the most commonly used set of standards in the world that defines the language, structure and data types for exchanging health information to support clinical management and practice.[112] As a result of the limited number of care setting categories, encounters involving very different types of health care providers are collapsed into a few categories (inpatient, outpatient, and emergency) that do not reflect the variety of clinical interactions in a way most useful to health researchers. For example, records of inpatient encounters in our HIO data included inpatient stays at acute care hospitals, hospital-based hospice units, and hospital-based rehabilitation units. If the INPC were able to make available to researchers encounter information for skilled nursing facilities, free-standing hospice facilities and free-standing rehabilitation facilities, these encounters too would be categorized as inpatient encounters in the INPC dataset. As a result, inpatient encounters in the INPC dataset do not necessarily signify hospital readmissions. Similarly, the outpatient encounter category included encounters with all hospital outpatient

departments, including primary care and specialty physician visits as well as outpatient services such as occupational therapy, speech therapy, outpatient procedures. We were unable to differentiate between encounters within these broad categories, since the data elements that would allow us to determine conclusively the type of service provided during each encounter were largely missing: encounter location was missing for 43% of recorded encounters, while data fields for the provider's name, specialty, and type were all missing 85% of the time.

Limitations

Our study has several limitations. First, this is an analysis of data from one HIO. It is possible that other HIOs have participating provider networks that include more of the post-acute care settings, engaged in bi-directional exchange, that were not available in our data set (such as free-standing acute rehabilitation, free-standing hospice facilities, and skilled nursing facilities). Second, we were unable to obtain geographic distribution of patients at a level more specific than home state to meet the INPC's requirements for protecting the privacy and security of patient information. Third, we have no way to determine whether encounter or other clinical information is missing due to technical issues related to the data feeds between the HIO and its institutional network, as sometimes feeds go down during software upgrades or facilities work. Fourth, de-identification and data formatting were done by a third party on behalf of the INPC, so we did not see the original raw data and were uninvolved in the process to restructure the INPC data for our use. Fifth, the manual abstraction of EHR data could be subject to human data entry error, as was providers' entry of clinical information into EHRs—which is ultimately the source of the HIO data. Sixth, we used an existing dataset and, therefore, did not influence which data elements were selected for abstraction from the EHR. Finally, our analysis of

missing encounter information in the HIO dataset relied on the assumption that patients with ICH will require care within 30 days of discharge. While it is true that ICH patients are at increased risk for death and disability, there are many factors that influence whether a patient seeks and receives health care. Therefore, it is possible that some of the patients without a first encounter within 30 days chose not to seek or were unable to access such post-discharge care.

Future Research Directions

Research to determine whether the clinical information in an HIO is representative of a definable underlying target population (accurate, representative, and sufficiently complete) should continue. Evaluating whether results from studies using HIO data are consistent with published findings from studies that use different data sources such as administrative or EHR data, comparing the populations represented in the HIO with the general population, and assessment of the health care providers sharing data with HIOs across the country are all possible future research questions. Research is also needed to determine strategies to assess, and address the impact of, incomplete encounter information as a result of patients' seeking care at medical institutions that do not partner with a HIO.

Conclusion

Our efforts to use HIO data to study transitions of care for patients experiencing ICH demonstrated the potential and limitations of this data source. Our HIO partner, the Indiana Health Information Exchange, uses one of the longest-running networks—the INPC—with the most developed research infrastructure, and yet its ability to provide data sufficient for research on transitions of care is hindered by an incomplete set of partnerships between post-

acute providers and the HIO, and the ways in which data are represented using nationally recognized standards, specifically the limited categorization of care settings to inpatient, outpatient and emergency. Expanding the network of participating providers, increasing the types of data exchanged through the HIO, and prioritizing data quality improvements such as expanded levels of care setting categorization not only would support HIOs in their efforts to support researchers, but would also support HIOs in ensuring that participating health care institutions are given the timeliest, most complete and accurate picture of healthcare services provided to their patients. While HIOs could be an important source of relevant, cross-institutional encounter information useful to study transitions, the utility of data from this HIO was limited to data provided by participating acute care hospitals.

Clinical Relevance Statement

Intracerebral hemorrhage (ICH), which represents about 15% of all strokes, requires intense resource utilization in post-acute care settings, most notably rehabilitative settings. With a fragmented stroke care continuum, and patients' high risk of death or serious long-term disability, HIOs with robust, complete data could be used to support and study transitions of care in patients with ICH following hospital discharge. However, due to limitations in the current structure and organization of HIOs their capacity to document transition care patterns is very limited.

Conflict of Interest

The authors have no conflicts of interest to declare.

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Human Subjects Protections

This research was approved through Indiana University's Institutional Review Board (protocol number 1205008657R004), and as part of a reciprocity agreement with Michigan State University (protocol number 15-1113R).

CHAPTER 5: CONCLUSION

The desire to improve the quality and efficiency of patient care was the compelling need that led to extensive public and private investment in EHR implementation and the development of health information exchange capabilities. These technologies also have the potential to support the conduct of clinical research by improving efficiencies for data collection and facilitating patient identification and data monitoring across different health care settings. The previous three chapters focused on the following four research questions:

1. Do researchers currently have access to clinical information exchanged through a Health Information Exchange Organization (HIO)? [Chapter 2 – Scoping Review, Chapter 3 – National Survey]

2. Do HIOs have the necessary infrastructure, technological capacity, and agreements among participating providers to support research using exchanged clinical data? [Chapter 3 – National Survey]

3. Do HIOs facilitate the development of a multi-institution dataset? [Chapter 3 – National Survey, Chapter 4 – Transitions of Care]

4. With respect to a given HIO (INPC) used to assess a specific research question (transitions of care in ICH patients), does the information collected and shared through the HIO result in an accurate, representative, and comprehensive foundation to assess transitions of care? [Chapter 4 – Transitions of Care]

Findings from these studies are summarized in the following paragraphs. They are presented in chronological order which reflects the development process culminating in the actual use of HIO data to answer research questions. The scoping review (Chapter 2) informed us of the current published research with HIOs as partners. The results of the scoping review were used to inform the questions included in the national survey (Chapter 3). The transitions of care study in Chapter 4 was to test the ability to obtain and use HIO data to study a topic that would highlight the advantages of an HIO partner as a source of relevant, cross-institutional clinical information.

Chapter 2 provided the results of a scoping review to determine the extent of current HIO involvement in published clinical research. The study objective was to identify published studies that described the use of HIOs as a data source for clinical research specific to one or more of the following three areas: 1) clinical or epidemiological research including randomized clinical trials or observational epidemiological studies, 2) financial or cost evaluations of HIO use, including changes in administrative efficiencies, or 3) utilization of health services, including the evaluation of care-seeking patterns. We found that, outside of the evaluation of HIOs themselves, HIO data were being used to a limited extent for published clinical research with only a limited number of specific HIOs involved in generating the majority of the published research.[62] Of the eighteen articles that met our inclusion criteria, 16 articles met the criteria within the context of evaluating the use and impact of HIOs such as whether HIOs improved care, changed outcomes, improved costs, or changed the amount or type of care received.[32,35-37,46-57] Only two of the articles had research objectives not specific to evaluating the use and impact of HIOs.[31,33]

In follow-up to the scoping review and presented in Chapter 3, we investigated the extent to which HIOs reported supporting research by allowing the patient data that they exchange to be aggregated and used for clinical, health services or epidemiologic research. We used data from the fifth and most recent version of an ongoing national survey of organizations engaged in health information exchange[39-42] to determine the proportion of HIOs that were or were planning to support research, and to describe the characteristics that differentiated them from HIOs that do not support research. We found that the majority of HIOs (70%) reported currently supporting or planning to support research. Fifteen (23%) of the 64 HIOs reported supporting research, 30 (47%) were planning to support research, and 19 (30%) did not support research or indicate plans to do so. Unsurprisingly, we found that the 45 HIOs that were supporting or planning to support research were more likely than non-research supporting HIOs to offer more advanced technology with enhanced functionality including allowing users to query and retrieve data from multiple sources, providing a master patient index, providing a clinical data repository, and providing data to participating networks and providers for their own analysis. We also examined the research-specific infrastructure and policies in place within the 45 research-supporting HIOs and found that some were widely adopted while others were not. The most widely adopted infrastructure elements associated with HIOs that reported supporting research were the ability to create multi-institution datasets (combination of data from multiple health care providers using different EHR systems), capacity to produce de-identified datasets, and the development of data use agreements that allow the use of exchanged data for research. Some infrastructure and policies useful to HIOs that chose to provide research support had minimal adoption by the HIOs. One example was the use of an

oversight body to ensure the research protocol behind a request for data is valid and appropriate, HIOs currently supporting research were much more likely to require approval from an oversight body than HIOs than HIOs who did not support research. Based on survey results, we concluded that the HIOs that reported support for research are at different developmental stages and their higher level of research support was reflected in their infrastructure preparation and data use requirements.

While the majority of HIOs (45 out of 64) reported in response to our national survey that they currently support or were developing the capacity to support research,[113] the scoping review of HIO research support found that only seven HIOs were involved in published research that used HIO data to address a specific research question.[62] Two other recent systematic reviews that assessed use and impact of HIOs on the delivery and quality of health care found similar results: only a limited number of HIOs supported research beyond the direct evaluation of the impact of exchanging data on clinical outcomes (e.g., reductions in redundant testing).[34,59] We propose three possibilities for the apparent discrepancy between self-reported capacity from the national survey of HIO directors and the number of peer-reviewed publications involving HIO data identified in the scoping review. First, a significant portion of HIOs (41%) have been in operation less than five years.[113] Even if an HIO was founded with research as one of its priorities, it takes time to implement the technology, secure a network of health care providers, develop the required interfaces to exchange data and create the necessary administrative infrastructure. The research process - conducting a research project, analyzing data, and writing the article – also takes time so it is possible that studies using HIO data were in process and therefore were not yet published. Thus, the limited number of HIOs mentioned in peer-

reviewed publications may be due to time alone. A second possibility is that researchers that have used HIO data have determined the data is not sufficiently valid to submit the results for publication. Third and final, while the same definitions were provided to all respondents to the national survey, respondents were directors of HIO organizations and may not have had research training or experience. As a result, respondents' interpretations of the survey questions might have differed from those intended by the survey authors. We defined research for respondents as "any investigation or analysis to address a specific question regarding patient or population health that is not part of the data exchange mission of the health information exchange effort, and is not used to support treatment/payment/operations/quality improvements." HIO Directors unfamiliar with conducting research could potentially interpret the concept of support for research to include projects that would not result in publishable findings while they responded to our survey positively.

For Chapter 4, we used HIO data to assess its utility to study transitions of care. We partnered with the Indiana University School of Medicine and the Indiana Network for Patient Care (INPC) to link patient level data manually abstracted from EHRs for intracerebral hemorrhage (ICH) cases discharged from two major medical centers in Indianapolis with INPC encounter and demographic information. We sought to determine whether encounter data exchanged through a HIO could be used to identify and characterize care received during the 12 months following hospitalization for ICH. INPC, our HIO partner, is one of the longest running HIO entities with the most developed research infrastructure. However, we found that its ability to provide sufficient data to study transitions of care was hindered by slow implementation of EHR and health information exchange technology in several post-acute care settings. Most notably,

data from the INPC was limited to participating acute care hospitals and included ER visits, hospital admissions, acute (in-patient) rehabilitation, and hospital-based hospice, as well as hospital-based outpatient visits. No information was available for free-standing acute rehabilitation facilities, sub-acute rehabilitation facilities, skilled nursing facilities (nursing homes) or outpatient visits that occur outside of hospital-owned practices. Given that three of the top five discharge dispositions following ICH admission were acute rehabilitation, skilled nursing facility, and hospice, this incompleteness in representation of the stroke care continuum creates a large gap in information when studying transitions of care, since most patients seek post-acute services outside of the hospital setting. Most importantly, we could not follow patterns of post-acute care that may have included multiple visits among post-acute care and primary care settings. Ensuring a comprehensive network of data sharing health care providers is one of the primary challenges of using HIO data for transitions of care research.

We also identified significant challenges with encounter classifications. HL7 version 2 standards have limited care setting categories for encounters (patient class variable).[111] As a result, encounters with very different types of health care providers are collapsed into categories (inpatient, outpatient, and emergency) that do not reflect the variety of clinical interactions in a way most useful to health services researchers and other analysts of healthcare delivery. We were unable to differentiate between encounters within these broad categories, since the data elements that would allow us to determine conclusively the type of service provided during each encounter were largely missing. Specifically, the encounter's physical location was missing in 43% of encounters, while details of the provider (name, specialty, and type) were missing in 85% of encounters.

Our analysis highlighted the importance of determining the impact of missing encounter information due to either patients seeking care from non-participating INPC health care providers. For example, given that ICH patients are at a high risk of mortality (approximately 40% at 30 days)[71] or serious long term disability (only 20% expected to be functionally independent at 6 months),[73] the majority of patients would be expected to have some type of encounter within 30 days discharge from the index admission. After excluding confirming encounters, of the 468 patients discharged alive from the index admission, we determined that the INPC data showed that less than half (43%) had an encounter in any care setting within 30 days of discharge. This low rate cannot be explained by patients who did not survive long after discharge; we determined that 96% of the patients who died within 30 days had at least one post-discharge encounter. We propose that before using HIO data for research, it is critical to both evaluate the list of providers contributing to the HIO as well as the level of participation within a specific geographic area by provider type. For example, while the INPC dataset included hospital-based acute rehabilitation and hospice encounters, it lacked encounter information from free-standing acute rehabilitation and hospice providers. The analysis we conducted, while descriptive, provided insight into the amount of encounter information that we were potentially missing and the limitations of the HIO data.

Finally, the process to identify an appropriate HIO partner and make the formal request for HIO data was very informative. While we were encouraged by the findings of our national survey (Chapter 3), we found that accessing HIO data for research is challenging and requires persistence, time and resources. Over the course of several months, we had conversations with multiple HIOs and encountered significant barriers to securing data including, HIOs not having

the necessary technology to compile a multi-institutional dataset or de-identify data to protect patient privacy, outright prohibition of the use of exchanged data for research, and excessive administrative burdens such as having to request IRB approval from over 40 institutions. Our ultimate partner for the HIO transitions of care study, the INPC, is the most cited HIO and arguably the most experienced working with researchers. As anticipated, the INPC had an established process for researchers to request and receive data. Nevertheless, the process did require persistence, time and resources. INPC has a formal data request process to ensure balance between protecting the interests of their participating providers and their patients, the needs of researchers, and the INPC's need for sustainability. Researchers requesting data are required to provide a proposal with proof of IRB approval as well as financial assistance to support the cost of employing INPC data managers, who are essential for data preparation and maintenance.

Where do we go from here?

Significant challenges exist that are either delaying or preventing HIOs from reaching their full potential as resources for research. To be effective partners in research, HIOs should have an expansive network of participating health care providers that share a comprehensive set of clinical information through the HIO. Providing data to researchers requires HIOs to develop appropriate technological and administrative infrastructure; policies and procedures, including privacy and security protections when sharing data with researchers; and, a business case for providing research support services. Such a business case would include a detailed outline of the targeted research support services, an analysis of the gaps between current and necessary technological and organizational capacity, analysis of the market for research support services,

justification for developing the capacity to support researchers (how do these services align with the mission and strategic direction), cost-benefit analysis, and an implementation plan that addresses personnel, technology and marketing. Costs beyond existing HIO operations that are associated with developing the capacity to support research are dependent on the technological and organizational capability of the HIO. For example, not all HIO software systems are capable of creating multi-institutional databases. Many of them are structured to access information for one patient at a time as they were created to support clinical care. To support research, the HIO would need to invest in additional software and potentially staff. Another example would be the expertise of personnel. HIOs with staff knowledgeable of research methodology and protocols are better prepared to evaluate the legitimacy of requests for data, interact with researchers to ensure data requests are appropriately filled, and monitor issues that could impact ongoing research projects. Since most HIOs do not employ staff with this type of expertise and experience, the cost for a new employee or consultant to meet these needs should be included in their cost analysis. HIOs must also gain partners' support for secondary use of their data for research and implement mechanisms to manage the research process among the multiple levels of the organization, research partners, and individual staff. Engagement in research additionally requires HIOs to develop expertise and systems for monitoring compliance with rules and regulations specific to human subjects research, an area of expertise not required by their primary mission to deliver clinical information that informs the delivery of health care.

To overcome these challenges requires partnerships between HIOs and interested researchers. Their objectives, while different are complementary. For researchers, HIOs could be important

research partners as they are a potential source of relevant, cross-institutional clinical information. Data from HIOs could greatly expand the number and types of health care organizations contributing health care data and the pool of potential research participants, promoting greater generalizability of research findings. For HIOs, supporting research provides HIOs with a mechanism to create additional value for participating providers and partnering organizations. HIOs that can differentiate their role from other options for point-to-point data exchange such as, ONC's Direct protocol, or HL7 interfaces directly connecting data providers to receiving providers, may be best positioned for sustainability. In addition, preparing shared data to support research requires similar efforts as preparing data to evaluate outcomes and health care utilization within and across organization boundaries and would likely highlight data issues in need of further quality improvements by the HIO and its participating providers. By committing to support researchers, HIOs and their data contributing organizations commit to ongoing efforts to increase the amount of clinical information shared as well as improving the use and adherence to standards such as HL7, LOINC, and SNOMED CT—which facilitate sharing information across institutions and EHR technologies. These commitments also further the mission of HIOs to deliver clinical information that informs the delivery of health care as they promote more clinical information delivered in a more consistent manner.

Future Policy Recommendations

The ONC, as the primary governmental agency responsible for the interoperability of health information systems, has the opportunity to influence federal policy to enable and encourage the development of research capacity by HIOs. First, allowing future HIO funding opportunities to address network and infrastructure development necessary for research would provide an

important avenue for funding, addressing a barrier for HIOs many of which do not have significant cash reserves. It would also incorporate research support into the federal definition of a HIO which is widely referenced and consulted. Second, the ONC could work with their sister agency, Centers for Medicare & Medicaid Services (CMS), to incorporate incentives into payment systems for post-acute care providers to encourage development of health information exchange capacity and participation in HIOs. Third, the ONC could work with CMS to tie existing incentive programs for health care providers to continuous efforts to improve the accuracy and comprehensiveness of the clinical information exchanged through HIOs. This work with CMS would support both the development of research capacity as well as HIOs' primary mission of providing relevant clinical information to providers across organizational boundaries. Fourth, the ONC could work with the primary HIO technology vendors to encourage incorporation of functionality necessary to support research into their products. HIO technology vendors are in a very competitive market and supporting HIO clients in their efforts to secure additional ONC funding or to recruit additional providers, such as post-acute providers, could give the vendors an edge maintaining their existing HIO clientele and attracting new clients. Finally, the ONC could work to modify HL7 standards by ensuring consistent definitions for data variables critical for supporting transitions of care such as 'patient class' which is used to classify location of encounters but has limited categorization of care settings (inpatient, outpatient and emergency).

Future Research Framework

The following framework for future research identifies key areas requiring resolution to maximize the utility of HIOs for research. While the framework is new, research is ongoing in

some areas, particularly looking at the impact of HIO use on clinical care. Examples are provided below each category but are not intended to be exhaustive.

Impact on clinical care

- whether timely access to clinical information from patients' other health care providers informs delivery of care and improves timeliness, effectiveness and efficiency;

- whether the use of HIO data by health care providers facilitates improved patient outcomes;

- how the use of HIO data influences the ordering of tests and imaging;

- whether and how HIOs facilitate transitions of care between health care institutions through improved and timely transfer of clinical information;

Data validation – Is HIO data a sound choice for research projects?

- whether the clinical information in an HIO is representative of a definable underlying target population (accurate, representative, and sufficiently complete);

- how providers participating in an HIO are similar to, or different from, providers not participating whether providers participating in an HIO care for patients in a manner similar to providers not participating (i.e., does the use of HIO data in a research project introduce selection bias?);

- how HIO structure, network, and business practices affect the quality and comprehensiveness of the data;

- how HIO structure, network, and business practices influence whether and how the data are available to researchers;

Functionality of HIOs for research purposes

- understand challenges to developing the necessary infrastructure and policies to foster HIO engagement in research;

- confirm the reported administrative and technological infrastructure in place is functioning;

- determine whether a researcher can access HIO data, the cost-effectiveness of this resource, and associated restrictions and limitations;

- evaluate whether an HIO facilitates the development of a multi-institution dataset or if the amount of effort to use an HIO is equal or more than the effort of securing data from each provider organization separately;

HIO as a data source for clinical research

- determine utility of HIO support for participant identification and recruitment;

- assess whether HIOs can support timely reporting of safety data for participants of clinical studies;

- evaluate the use of HIOs as mechanism for reporting of safety and other data to federal agencies including the Food and Drug Administration (FDA), Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health;[5] and,

- determine the impact of and strategies to address incomplete encounter information as a result of patients seeking care at non-HIO participating health care providers.

Conclusion

As the rapid expansion in the use of EHRs and the growth of health information exchange are relatively recent, HIOs support for research is still developing. While we found limited utility of HIO provided data to study transitions of care for ICH patients, we used data from one specific HIO and other HIOs may have broader participation by providers other than hospitals. Additional research is required to determine whether HIOs are viable partners for research outside of ICH transitions of care and the evaluation of HIOs themselves.

BIBLIOGRAPHY

BIBLIOGRAPHY

1. Boadi K. Erosion of Funding for the National Institutes of Health Threatens US Leadership in Biomedical Research. 2014. https://www.americanprogress.org/issues/economy/report/2014/03/25/86369/erosion-of-funding-for-the-national-institutes-of-health-threatens-u-s-leadership-in-biomedical-research/. Accessed January 21, 2016.

2. National Institutes of Health. Price Indexes. 2015; https://officeofbudget.od.nih.gov/gbiPriceIndexes.html. Accessed January 21, 2016, 2016.

3. Vest J, Gramm L. Health information exchange: persistent challenges and new strategies. *JAMIA.* 2010;17(3):288-294.

4. The Office of the President. Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator. In: President TOot, ed. Vol 692004:2459-24061.

5. Thompson T, Brailer D. The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care. In: Office of the Secretary US DHHS NCfHIT, ed2004.

6. Thompson Launches "Decade of Health Information Technology" [press release]. July 21, 2004 2004.

7. HealthIT.gov. HITECH Programs & Advisory Committees. 2015; http://healthit.gov/policy-researchers-implementers/state-health-information-exchange. Accessed 8/1/2015, 2015.

8. National Alliance for Health Information Technology. *Defining Key Health Information Technology Terms.* 2008.

9. HealthIT.gov. What is HIE? https://www.healthit.gov/providers-professionals/health-information-exchange/what-hie. Accessed January 18, 2016, 2016.

10. Centers for Medicare and Medicaid Services. EHR Incentive Programs. http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/EHRIncentivePrograms/01_Overview.asp. Accessed 06/04/2013, 2013.

11. Office of the National Coordinator for Health Information Technology. Hospitals Participating in the CMS EHR Incentive Programs. In: Technology OotNCfHI, ed. #45 ed. July 20152015.

12. Office of the National Coordinator for Health Information Technology. Health Care Professionals Participating in the CMS EHR Incentive Programs. In: Technology OotNCfHI, ed. #44 ed2015.

13. Centers for Medicare and Medicaid Services. Medicare and Medicaid EHR Incentive Program Basics. https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Basics.html. Accessed 8/1/2015, 2015.

14. Miliard M. Meaningful use will likely end in 2016, CMS chief Andy Slavitt says. *Healthcare IT News*2016.

15. Rapp A. Meaningful use to end in 2016, and more announcements by Andy Slavitt. In: News H, ed2016.

16. Leventhal R. CMS's Andy Slavitt Says Meaningful Use Over in 2016. *Healthcare Informatics*.

17. Mace S. Meaningful Use Program 'Effectively Over,' Says CMS Head. 2016.

18. 114th Congress of the United States. Medicare Access and CHIP Reauthorization Act of 2015 - Public Law 114-10-April 16, 2015. In: Congress U, ed2015.

19. Adler-Milstein J, DesRoches C, Jha A. Health information exchange among US hospitals. *The American journal of managed care.* 2011;17(11):761-768.

20. Adler-Milstein J, Jha A. Health information exchange among U.S. hospitals: who's in, who's out, and why? *Healthcare.* 2014;2:26-32.

21. Office of the National Coordinator for Health Information Technology. *Health IT in Long-term and Post Acute Care Issue Brief.* March 15, 2013 2013.

22. LeadingAge New York. *Electronic Health Record Adoption and Health Information Exchange Among Long Term and Post Acute Care Providers: A Survey of LeadingAge New York Members.* March 2015 2015.

23. Minnesota Department of Health Office of Health Information Technology. *Hospitals: Adoption and Use of EHRs and Exchange of Health Information, 2014.* June 2015 2015.

24. Centers for Medicare and Medicaid Services. Certified Electronic Health Record Technology (CEHRT). https://www.cms.gov/Regulations-and-

Guidance/Legislation/EHRIncentivePrograms/Certification.html. Accessed August 28, 2016.

25. Ouyang L, Apley D, Mehrotra S. A design of experiments approach to validation sampling for logistic regression modeling with error-prone medical records. *J Am Med Inform Assoc.* 2015;0:1-8.

26. Safran C, MD, MS, Boomrosen M, MBA, Hammond WE, PhD, et al. Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper. *Journal of the American Medical Informatics Association.* 2007;14(1).

27. Elger BS, Iavindrasana J, Iacono LL, et al. Strategies for health data exchange for secondary, cross-institutional clinical research. *Computer Methods and Programs in Biomedicine.* 2010(99):230-251.

28. Chute C, Pathak J, Savova G, et al. The SHARPn Project on Secondary Use of Electronic Medical Record Data: Progress, Plans, and Possibilities. Paper presented at: AMIA Annual Symposium2011.

29. National Institutes of Health. CTSA Consortium Tackling Clinical Trial Recruitment Roadblocks. 2015; http://ncats.nih.gov/pubs/features/ctsa-act. Accessed 8/2/2015, 2015.

30. PCORnet. PCORnet - the National Patient-Centered Clinical Research Network, Frequently Asked Questions. 2015; http://pcornet.org/faqs/. Accessed 8/3/2015, 2015.

31. Doebbeling BN, Flanagan ME, Nall G, Hoke S, Rosenman M, Kho A. Multihospital infection prevention collaborative: informatics challenges and strategies to prevent MRSA. *AMIA Annu Symp Proc.* 2013;2013:317-325.

32. Shapiro J, Onyille A, Patel V, Strayer R, Kuperman G. Enabling 72-hour Emergency Department Returns Measurement with Regional Data from a Health Information Exchange. *Annals of Emergency Medicine.* 2011;58(4S):S295.

33. Hoang A, Shen C, Zheng J, et al. Utilization rates of implantable cardioverter-defibrillators for primary prevention of sudden cardiac death: a 2012 calculation for a midwestern health referral region. *Heart Rhythm.* 2014;11(5):849-855.

34. Rudin RS, PhD, Motala A, BA, Goldzweig CL, MD, MSHS, Shekelle PG, MD, PhD. Usage and Effect of Health Information Exchange A Systematic Review. *Annals of Internal Medicine.* 2014;161(11):803-811.

35. Ballard J, Rosenman M, Weiner M. Harnessing a health information exchange to identify surgical device adverse events for urogynecologic mesh. *AMIA Annu Symp Proc.* 2012;2012:1109-1118.

36. Zhu VJ, Tu W, Marrero DG, Rosenman MB, Overhage JM. Race and medication adherence and glycemic control: findings from an operational health information exchange. *AMIA Annu Symp Proc.* 2011;2011:1649-1657.

37. Zhu VJ, Tu W, Rosenman MB, Overhage JM. Facilitating Clinical Research through the Health Information Exchange: Lipid Control as an Example. *AMIA Annu Symp Proc.* 2010;2010:947-951.

38. US Department of Health and Human Services. What are some common terms used when discussing health information exchange (HIE)? 2013; http://www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/OpportunitiesCollaboration/commonterms.html. Accessed 05/27/2013, 2013.

39. Adler-Milstein J, Lin SC, Jha AK. The Number of Health Information Exchange Efforts is Declining, Leaving The Viability of Broad Clinical Data Exchange Uncertain. *Health Affairs.* 2016;35(7):1278-1285.

40. Adler-Milstein J, Bates DW, Jha AK. Operational Health Information Exchanges Show Substantial Growth, But Long-Term Funding Remains A Concern. *Health Affairs.* 2013;32(8):1486-1492.

41. Adler-Milstein J, Bates D, Jha A. A Survey of Health Information Exchange Organizations in the United States: Implications for Meaningful Use. *Ann Intern Med.* 2011;154:666-671.

42. Adler-Milstein, Julia, Bates D, Jha AK. U.S. Regional Health Information Organizations: Progress And Challenges. *Health Affairs.* 2009;28(2):483-492.

43. Arksey H, O'Malley L. Scoping Studies: Towards a Methodological Framework. *International Journal Social Research Methodology.* 2005;8(1):19-32.

44. US Department of Health and Human Services. Doctors and hospitals' use of health IT more than doubles since 2012. 05/22/2013; http://www.hhs.gov/news/press/2013pres/05/20130522a.html. Accessed 05/27/2013, 2013.

45. Medical University of South Carolina. PPRNET - Primary (Care) Practices Research Network. 2015; http://academicdepartments.musc.edu/PPRNet/index.html. Accessed 8/2/2015, 2015.

46. Kho AN, Lemmon L, Commiskey M, Wilson SJ, McDonald CJ. Use of a regional health information exchange to detect crossover of patients with MRSA between urban hospitals. *J Am Med Inform Assoc.* 2008;15(2):212-216.

47. Sridhar S, Brennan PF, Wright SJ, Robinson SM. Optimizing financial effects of HIE: a multi-party linear programming approach. *J Am Med Inform Assoc.* 2012;19(6):1082-1088.

48. Shapiro JS, Genes N, Kuperman G, Chason K, Richardson LD, Clinical Advisory Committee H1N1 Working Group NwYCIE. Health information exchange, biosurveillance efforts, and emergency department crowding during the spring 2009 H1N1 outbreak in New York City. *Ann Emerg Med.* 2010;55(3):274-279.

49. Onyile A, Shapiro J, Kuperman G. Patient Crossover Rates Vary by Disease in a Health Information Exchange. *Annals of Emergency Medicine.* 2011;58(4S):S294.

50. Bailey JE, Pope RA, Elliott EC, Wan JY, Waters TM, Frisse ME. Health information exchange reduces repeated diagnostic imaging for back pain. *Ann Emerg Med.* 2013;62(1):16-24.

51. Bailey JE, Wan JY, Mabry LM, et al. Does health information exchange reduce unnecessary neuroimaging and improve quality of headache care in the emergency department? *J Gen Intern Med.* 2013;28(2):176-183.

52. Frisse ME, Johnson KB, Nian H, et al. The financial impact of health information exchange on emergency department care. *J Am Med Inform Assoc.* 2012;19(3):328-333.

53. Magnus M, Herwehe J, Gruber D, et al. Improved HIV-related outcomes associated with implementation of a novel public health information exchange. *Int J Med Inform.* 2012;81(10):e30-38.

54. Proeschold-Bell RJ, Belden CM, Parnell H, Cohen S, Cromwell M, Lombard F. A randomized controlled trial of health information exchange between human immunodeficiency virus institutions. *J Public Health Manag Pract.* 2010;16(6):521-528.

55. Carr CM, Gilman CS, Krywko DM, Moore HE, Walker BJ, Saef SH. Observational study and estimate of cost savings from use of a health information exchange in an academic emergency department. *J Emerg Med.* 2014;46(2):250-256.

56. Vest JR. Health information exchange and healthcare utilization. *J Med Syst.* 2009;33(3):223-231.

57. Lammers EJ, Adler-Milstein J, Kocher KE. Does health information exchange reduce redundant imaging? Evidence from emergency departments. *Med Care.* 2014;52(3):227-234.

58. US National Library of Medicine. Health Information Technology and Health Data Standards at NLM. http://www.nlm.nih.gov/healthit.html. Accessed 06/21/2014, 2014.

59. Rahurkar S, Vest JR, Menachemi N. Despite The Spread Of Health Information Exchange, There Is Little Evidence Of Its Impact on Cost, Use, and Quality of Care. *Health Affairs.* 2015;34(3):477-483.

60. Adler-Milstein J, McAffee A, Bates D, Jha A. The State Of Regional Health Information Organizations: Current Activities And Financing. *Health Affairs.* 2008;27(1):w60-69.

61. EHR/CR Functional Profile Working Group. *Electronic Health Records/Clinical Research, EHR/CR User Requirements Document, Release 1.* 2008.

62. Parker C, Weiner M, Reeves M. Health Information Exchanges – Unfulfilled Promise as a Data Source for Clinical Research. *International Journal of Medical Informatics.* 2016;87:1-9.

63. Epic. Epic Interoperability. 2015; http://www.epic.com/software-interoperability.php.

64. CommonWell Health Alliance. Why CommonWell Health Alliance - Interoperability for the Common Good. 2015; http://www.commonwellalliance.org/. Accessed December 14, 2015, 2015.

65. Kruse C, Regier V, Rheinboldt K. Barriers Over Time to Full Implementation of Health Information Exchange in the United States. *JMIR Medical Informatics.* 2014;2(2).

66. Joint Commission. What you need to know about Joint Commission Primary Care Medical Home for Ambulatory Care. 2015. Accessed October 14, 2015, 2015.

67. Centers for Medicare and Medicaid Services. The Affordable Care Act: Helping Providers Health Patients, A Menu of Options for Improving Care. 2015. Accessed October 14, 2015, 2015.

68. Indiana Network for Patient Care helps officials track disease, warn of outbreaks [press release]. January 18, 2013 2013.

69. Indiana Health Information Exchange. CareWeb. 2016; http://www.ihie.org/careweb/. Accessed November 18, 2016, 2016.

70. Centers for Disease Control and Prevention. Stroke Facts. http://www.cdc.gov/stroke/facts.htm. Accessed March 25, 2016, 2016.

71. Lichtman JH, Jones SB, Leifheit-Limson EC, Wang Y, Goldstein LB. 30-Day Mortality and Readmission After Hemorrhagic Stroke Among Medicare Beneficiaries in Joint Commission Primary Stroke Center-Certified and Noncertified Hospitals. *Stroke.* 2011;42(3387-3391).

72. Fang M, Perraillon M, Ghosh K, Cutler D, Rosen A. Trends in Stroke Rates, Risk, and Outcomes in the United States, 1988 to 2008. *The American Journal of Medicine.* 2014(127):608-615.

73. Broderick J, Connolly S, Feldmann E, et al. Guidelines for the Management of Spontaneous Intracerebral Hemorrhage in Adults 2007 Update. *Stroke.* 2007;38:2001-2023.

74. Hemphill JC, Greenberg S, Anderson C, et al. Guidelines for the Management of Spontaneous Intracerebral Hemorrhage - A Guideline for Healthcare Professionals from the American Heart Association/American Stroke Association. *Stroke.* 2015;46.

75. Centers for Medicare and Medicaid Services. Clinical Quality Measures Basics. https://www.cms.gov/regulations-and-guidance/legislation/ehrincentiveprograms/clinicalqualitymeasures.html. Accessed March 26, 2016, 2016.

76. Centers for Medicare and Medicaid Services. Hospital Inpatient Quality Reporting Program. https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/hospitalqualityinits/hospitalrhqdapu.html. Accessed March 26, 2016, 2016.

77. Centers for Medicare and Medicaid Services. Hospital Value-Based Purchasing. https://www.cms.gov/Medicare/Quality-initiatives-patient-assessment-instruments/hospital-value-based-purchasing/index.html. Accessed March 26, 2016, 2016.

78. Joint Commission. Certification Comprehensive Stroke Center. 2016; https://www.jointcommission.org/certification/advanced_certification_comprehensive_stroke_centers.aspx. Accessed May 19, 2016.

79. Kind A, Smith M, Frytak J, Finch M. Bouncing Back: Patterns and Predictors of Complicated Transitions 30 Days After Hospitalization for Acute Ischemic Stroke. *Journal of the American Geriatrics Society.* 2007;55(3):365-373.

80. Olson D, Prvu Bettger J, Alexander K, et al. *Transition of Care for Acute Stroke and Myocardial Infarction Patients: From Hospitalization to Rehabilitation, Recovery, and Secondary Prevention.* 2011.

81. Coleman E, Berenson R. Lost in Transition: Challenges and Opportunities for Improving Quality of Transitional Care. *Annals of Internal Medicine.* 2004;140:533-536.

82. Owens G, Fine C, Harrington D, et al. Improving Transitions of Care for Patients with Thromboembolic Disease. *American Journal of Managed Care.* 2014;20:S81-91.

83. Buntin M, Colla C, Escarce J. Effects of Payment Changes on Trends in Post-Acute Care. *Health Services Research.* 2009;44(4):1188-1210.

84. Buntin MB, Escarce J, Hoverman C, Paddock S, Totten M, Wynn B. *Effects of Payment Changes on Trends in Access to Post-Acute Care.* RAND Health;2005.

85. Chan L, Wang H, Terdiman J, et al. Disparities in Outpatient and Home Health Service Utilization Following Stroke: Results of a 9-Year Cohort Study in Northern California. *PM&R.* 2009;1:997-1003.

86. Sandel ME, Wang H, Terdiman J, et al. Disparities in Stroke Rehabilitation: Results of a Study in an Integrated Health System in Northern California. *PM&R.* 2009;1(1):29-40.

87. Bettger JP, McCoy L, Smith E, Fonarow G, Schwamm L, Peterson E. Contemporary Trends and Predictors of Postacute Service Use and Routine Discharge Home After Stroke. *Journal of the American Heart Association.* 2015;4(2).

88. Huckfeldt P, Mehrotra A, Hussey P. The Relative Importance of Post-Acute Care And Readmissions for Post-Discharge Spending. *Health Services Research.* 2016;51(5).

89. Ottenbacher K, Karmarkar A, Graham J, et al. Thirty-Day Hospital Readmission Following Discharge From Postacute Rehabilitation in Fee-for-Service Medicare Patients. *Journal of the American Medical Association.* 2014;311(6):604-614.

90. Magdon-Ismail Z, Sicklick A, Hedeman R, Bettger JP, Stein J. Selection of Postacute Stroke Rehabilitation Facilities A Survey of Discharge Planners from the Northeast Cerebrovascular Consortium (NECC) Region. *Medicine.* 2016;95(16).

91. Brown RD, Ransom J, Hass S, et al. Use of Nursing Home After Stroke and Dependence on Stroke Severity. *Stroke.* 1999;30:924-929.

92. Bettger JP, Kaltenbach L, Reeves M, et al. Assessing Stroke Patients for Rehabilitation During the Acute Hospitalization: Findings from the Get With The Guidelines - Stroke Program. *Archives of Physical Medicine and Rehabilitation.* 2013;94:38-45.

93. Cameron J, Naglie G, Gignac M, et al. Randomized clinical trial of the timing it right stroke family support program: research protocol. *BMC Health Services Research.* 2014;14(18).

94. Weimar C, Weber C, Wagner M, et al. Management Patterns and Health Care Use after Intracerebral Hemorrhage. *Cerebrovascular Diseases.* 2003;15:29-36.

95. Coleman E, Boult C. Improving the Quality of Transitional Care for Persons with Complex Care Needs. *Journal of the American Geriatrics Society.* 2003;51(4):556-557.

96. Cameron J, Tsoi C, Marsella A. Optimizing Stroke Systems of Care by Enhancing Transitions Across Care Environments. *Stroke.* 2008;39:2637-2643.

97. Andersen HE, Schultz-Larsen K, Kreiner S, Forchhammer BH, Eriksen K, Brown A. Can Readmission After Stroke Be Prevented? Results of a Randomized Clinical Study: A Postdischarge Follow-Up Service for Stroke Survivors. *Stroke.* 2000;31:1038-1045.

98. Rennke S, Ranji S. Transitional Care Strategies from Hospital to Home: A Review for the Neurohospitalist. *The Neurohospitalist.* 2015;5(1):35-42.

99. Hill C, Varma P, Lenrow D, Price R, Kasner S. Reducing errors in transition from acute stroke hospitalization to inpatient rehabilitation. *Frontiers in Neurology.* 2015;6(227).

100. Cameron J, O'Connell C, Foley N, et al. Canadian Stroke Best Practice Recommendations: Managing transitions of care following Stroke, Guidelines Update 2016. *International Journal of Stroke.* 2016;11(7):807-822.

101. Miller E, Murray L, Richards L, et al. Comprehensive Overview of Nursing and Interdisciplinary Rehabilitation Care of the Stroke Patient - A Scientific Statement from the American Heart Association. *Stroke.* 2010;41(10):2402-2448.

102. Schwamm L, Pancioli A, Acker J, et al. Recommendations for the Establishment of Stroke Systems of Care, Recommendations From the American Stroke Association's Task Force on the Development of Stroke Systems. *Circulation.* 2005;111:1078-1091.

103. Centers for Medicare & Medicaid Services. Post Acute Care Reform Plan. 2012; https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/post_acute_care_reform_plan.html. Accessed September 22, 2016, 2016.

104. Wissel J, Olver J, Sunnerhagen KS. Navigating the Poststroke Continuum of Care. *Journal of Stroke and Cerebrovascular Diseases.* 2013;22(1):1-8.

105. Xian Y, Holloway R, Smith E, et al. Racial/Ethnic Differences in Process of Care and Outcomes Among Patients Hospitalized with Intracerebral Hemorrhage. *Stroke.* 2014;45:3243-3250.

106. Haynes H, Gallek M, Sheppard K, Drake K, Ritter L. Transitions of care for stroke and TIA. *Journal of the American Association of Nurse Practitioners.* 2014:1-10.

107. Alwell K, Khoury J, Kleindorfer D, et al. ICD-9 Code Positive Predictive Value for Stroke Subtype in a Population-based Epidemiology Study. *Stroke.* 2009;45(AWMP51).

108. Health Level 7 International. PA Patient Encounter. 2011; http://wiki.hl7.org/index.php?title=PA_Patient_Encounter. Accessed August 26, 2016.

109. Poon M, Fonville A, Salman R. Long-term prognosis after intracerebral haemorrhage: systematic review and meta-analysis. *J Neurol Neurosurg Psychiatry.* 2014;85:660-667.

110. Camicia M, Wang H, DiVita M, Mix J, Niewczyk P. Length of Stay at Inpatient Rehabilitation Facility and Stroke Patient Outcomes. *Rehabilitation Nursing.* 2015;41(2):78-90.

111. Agency for Healthcare Research and Quality. United States Health Information Knowledgebase, Patient Class - HL7 Table 0004_VD. 2004; https://ushik.ahrq.gov/ViewItemDetails?system=mdr&itemKey=74710000.

112. Health Level Seven International. Introduction to HL7 Standards. 2016; http://www.hl7.org/implement/standards/. Accessed November 13, 2016, 2016.

113. Parker CJ, Reeves M, Weiner M, Adler-Milstein J. Health Information Exchange Organizations Report Support for Research. 2016.