

Improving Rural Healthcare Transitions through Health Information Exchange Final Progress Report

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Inclusive Dates of Project:

06/01/2010-03/31/2015

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Acknowledgement of Agency Support:

This project described was supported by grant R18 HS18865 and its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Agency for Healthcare Research and Quality.

Grant Award Number:

R18 HS18865

Submission Date:

June 30, 2015

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2. Structured Abstract

Purpose: To use HIE to improve patient care, we need to understand how stakeholders use exchanges. This study attempted to determine whether and how the addition of specific types of clinician users and clinical information to a regional health information exchange (HIE) impacted the acceptance and use of the HIE, care processes and patient outcomes.

Scope: A large focus of the evaluation was designed to describe trends in exchange use. We sought to measure and report on who uses the exchange, what information is accessed, and for which patients. This research investigation planned to test the hypothesis that when KeyHIE both contains more comprehensive clinical information and increases the number of applicable access utilization of the HIE will increase, care will become more efficacious and efficient with improved patient outcomes. **Methods:** Data analysis was planned to occur at multiple points during the five year period of the grant. Utilization variables were to be collected monthly throughout the course of the grant and assembled for analysis at the end of each year. Outcomes analysis, surveys as well as interviews with clinicians and focus groups were planned.

Results: After we understood how the participants use the exchange, we planned to assess perceptions of the HIE in general by users and potential users. This assessment would be based on focus groups and surveys addressing what clinicians think of HIE, why they use or don't use it, and what value the exchange actually provides.

Key Words: HIE, exchange, health information, KeyHIE, Pennsylvania, Geisinger

3. Purpose (Objectives of Study)

This project was designed to study whether and how the addition of specific types of clinician users and clinical information to a regional health-information exchange (HIE) impacts the acceptance and use of the HIE, care-process quality and efficiency, and patient outcomes.

4. Scope (Background, Context, Settings, Participants, Incidence, Prevalence)

The grant proposed to study the impact of implemented improvements in a regional HIE (which was originally designed to enable clinicians who manage transitions of care) related to effectiveness, efficiency and utilization of the HIE.

The Keystone Health Information Exchange (KeyHIE), created with support from AHRQ Implementation Grant UC1HS016162, enabled hospitals, emergency departments and ambulatory clinics in 31 counties of central and northeastern Pennsylvania to exchange test results and clinical summaries. Patients authorizing the sharing of their records enabled the clinicians providing their care to view their clinical information from across the region. KeyHIE uses technology and standards published by the Health Information Technology Standards Panel (HITSP), which will become part of the Nationwide Health Information Network (NwHIN) as it is rolled out.

The implementation of the improvements in the KeyHIE, which was the second phase of the KeyHIE project and the focus of this investigation, was designed to support safer and more effective transitions

of care. To achieve this, KeyHIE added critical transitions-of-care clinicians as exchange users – case managers, home health nurses, emergency responders, and long-term care facility clinicians. KeyHIE also expanded the exchange clinical content by adding additional laboratory and radiology reports; medication lists from pharmacy benefit management companies (PBMs) and retail pharmacies; and problem lists, allergy lists, electrocardiogram (ECG) tracings, and consultative reports. Finally, KeyHIE automated the distribution of patient information from participant Electronic Health Records (EHRs) to KeyHIE and from KeyHIE to EHRs of other participants who provided care to the patient.

This research investigation planned to test the hypothesis that when KeyHIE both contains more comprehensive clinical information and increases the number of applicable users utilization of the HIE will increase, care will become more efficacious and efficient with improved patient outcomes. Using de-identified data, the research planned to monitor the use of the HIE and corresponding outcomes over five years to test the preceding hypotheses. This was to be accomplished via baseline and follow-up surveys with clinicians to understand their motivations for using the exchange, and with clinicians and patients to understand their perceptions of the exchange's usefulness. We planned to collect detailed data from a subset of high-use clinicians regarding whether and how their diagnostic and care plans were affected by information available in the HIE and changes in patient outcomes with HIE use. Finally we planned to conduct a pre/post sub-study of care efficiency at selected provider facilities.

5. Methods (Study Design, Data Sources/Collection, Interventions, Measures, Limitations)

The KeyHIE evaluation proposal was designed to take advantage of different data and populations, for specific types of analyses. Some analyses was anticipated to apply to every use of the HIE, throughout the 31 county service area; others analyses would apply to patients with chronic conditions and/or those with case managers.

There are four components to the Keystone HIE evaluation design:

- 1) **Verifying the completeness of data captured in the HIE:** We matched KeyHIE data with EPIC data, and with hospital bills from the four KBC hospitals (all payers, all patients) and determined that KeyHIE captures all admission/discharge/transfer (ADT) data (discrepancy <0.1%). We matched KeyHIE admitting problem lists with diagnoses on final hospital bills and determined that KeyHIE problem lists do not contain accurate and complete diagnostic information (discrepancy >90%). Problem lists are based on initial patient complains, which are greatly refined during the course of an ED visit or hospital stay. We have concluded that KeyHIE is a reasonable source for ADT data and can be used to calculate 30-day readmission rates, and ED visits within 30 days of hospital discharge. We have also concluded that KeyHIE would be a more valuable tool, for clinicians and researchers, if discharge diagnoses (currently embedded in Continuity of Care Documents [CCDs] and hospital bills) could be made available in the HIE as discreet data.
- 2) **Monitoring the expanding use of KeyHIE:** Using KeyHIE data we proposed to monitor use of the HIE to understand which providers use KeyHIE, how often, and for which types of patients. We expected to see utilization increase as more valuable clinical information is available through the HIE (e.g. lab results, medication lists). We also expect to see utilization increase as more providers

participate and patient records in the HIE become more complete. We hypothesized that the routine use of KeyHIE will become pervasive in some clinical settings more than in others. We also hypothesized that use will increase as usability improves.

- 3) **Measuring Clinician and Patient Perceptions:** KeyHIE's success depends on clinician perceptions of value received when using the HIE and ease of use, and patient willingness to authorize the sharing of their medical records. We anticipated surveying all clinicians registered to use the HIE at baseline; follow-up surveys were planned for 2012 and 2014. Since KeyHIE has the most potential for improving care coordination for chronic disease patients, through better information to their case managers, we anticipated surveying case-managed patients at baseline about their case management experiences and willingness to authorize record sharing; a follow-up survey was planned for 2014. We planned to conduct focus groups and in-depth interviews with clinicians in various settings, regarding the usability and usefulness of KeyHIE.

- 4) **Measuring the impact of the HIE on critical patient outcomes:** Using KeyHIE ADT data, we anticipated a comparison of 30 day readmissions and ED visits among patients for whom KeyHIE is used and those for whom it is not used. We planned to do the same for patients whose Geisinger Health Plan (GHP) case managers use KeyHIE and those whose GHP case managers do not use KeyHIE. If it proved possible to add accurate discharge diagnoses to KeyHIE, we anticipated the focus of these analyses on patients with chronic conditions.

In year 1, we planned to install interfaces between KeyHIE and two hospitals, 21 ambulatory clinics and connect eighty case managers to the HIE. In addition to interfacing all participating organizations' laboratory systems using the standard terminology for lab results (LOINC) when technically feasible, the end of year 1 goals were to provide access to discharge summaries, history and physicals, radiology reports, and laboratory results from an additional ten regional hospitals and more than 60 ambulatory clinics.

In year 2, we planned to add interfaces with one home health agency, which would contribute medical summary information for each patient it managed. We planned to complete an interface to *SureScripts* and *RxHub* to make medication histories available. Additionally, we planned to initiate a 2 year roll out of interfaces for CCDs beginning with five hospitals and 38 ambulatory clinics.

In year 3, we planned to interface 19 additional facilities (including skilled nursing, independent living and assisted living) and continue deploying CCD interfaces. We would add consult reports and pathology reports to the exchange repository.

Year 4, we planned to add the final clinical document type, ECG traces and add emergency responders to the exchange.

Year 5 was to be dedicated to completing the research and dissemination plans.

In addition to evaluating the use of the HIE for the entire population, Abt Associates was contracted to analyze specific subgroups of patients and clinicians – such as patients with chronic illnesses and their case managers –as it was anticipated the yield and benefit would be substantial for these patients and their clinicians.

The following research questions were proposed to be addressed:

- How do clinicians who use the exchange differ from those who do not?
- How do patients whose records are accessed by their clinicians differ from those whose records are not?
- What types of information are sought via the exchange? Does this vary by clinician type? By patient type?
- Does the addition of more clinical information and more clinicians (and types of clinicians) increase exchange use?
- Do clinicians alter their diagnostic approach or care plans when using information from the exchange? In what ways?
- Why do some patients decline to authorize sharing of their records? Why do some clinicians not ask for patient authorizations? Why do some clinicians not use the exchange?
- Does healthcare efficiency change when the exchange is used? In what ways?
- Do patient outcomes improve when case managers access the exchange for information about hospitalizations?

To understand whether use of the HIE improves patient care, it was necessary to understand how stakeholders uses the HIE. A large focus of the evaluation was to describe trends in exchange use. In the first part of the evaluation, we planned to measure and report on who uses the exchange, what information is accessed, and for which patients. After we understood how and for whom the participants used the exchange, we planned to access their perceptions of the HIE. This assessment was to be accomplished with data derived from focus groups and surveys designed to evaluate the value of the HIE.

Proposed Evaluation of Exchange Use

To evaluate the HIE information expansion and correspondingly, which type of clinicians use it, and what information they accessed, we planned to query the database for the utilization variables each month, and examine trends in utilization throughout the five year grant period. Our research interest related to whether the utilization variables increased or decreased over time and the rate of change. In particular we anticipated investigations that related the expansion of the HIE to utilization. Specifically, we hypothesized clinicians may have little rationale to use the HIE until a particular type of clinical information is available points in time when new information is added may initiate periods when many new users begin to access the HIE.

Additionally, we planned to evaluate how the above use correlates with care-process quality, patient outcomes, and costs, while comparing outcomes for patients hospitalized at facilities that did not participate in the HIE, with patients hospitalized at facilities that did participate.

Evaluation of HIE User Perceptions

As with the above evaluation of utilization and outcomes, we planned to collect data from a broad spectrum of HIE users, which would enable the research to define the multiple types of clinicians utilizing the HIE and their personal characteristics.

The proposed analysis of user perception consisted of two components. First, focus groups with different types of clinicians would be used to generate general queries regarding clinician reactions to the HIE. These general queries would address topics such as the rationale led clinician use of the HIE, determination of value added time requirements, improvements in care attributed to the HIE and reasons for clinicians nonuse. These focus groups designed to assist with the determination of topics for the interviews and surveys. In addition to focus groups and interviews, we planned to conduct surveys of clinicians' and patients perceptions of the exchange.

Timing of Data Collection

Data analysis was planned to occur at multiple points during the five year period of the grant. Utilization variables were to be collected monthly throughout the course of the grant and assembled for analysis at the end of each year. Outcomes analysis was planned to begin in Year 2. Survey and analysis of perceptions of the HIE were planned at various stages throughout the grant. In Year 1, interviews with clinicians and focus groups were planned with clinician surveys anticipated by the end of that year. In Year 2, we anticipated conducting a baseline survey of the perceptions of patients whose information was accessed through the exchange. In Year 3, we proposed repeating the clinician survey with both patients and physicians being surveyed again in the terminal portion of the grant period. Thus, patients would be surveyed twice and clinicians three times. We hypothesized that continuing improvements to the HIE would affect clinician users of the HIE more immediately than the patients. For this reason, a mid-course Year 3 survey was anticipated to understand changing attitudes among clinician users. We planned to conduct a final set of focus groups in final year of the investigation. Additionally, we planned to conduct the outcomes analyses comparing patients cared for by GHP case managers and admitted to hospitals that do, and do not, participate in the exchange in the final year of the grant.

Data Sources and Collection

To accurately measure the impact of KeyHIE on patient use and care efficiency, it was imperative to obtain the proper patient demographics and diagnoses data collection. The data sources identified were needed to make an impact on reporting:

- Inpatient and Outpatient Billing Data was to be collected by each KeyHIE participating facility
- Detailed KeyHIE audit reports which identifies which KeyHIE user role accessed patient information using KeyHIE. We proposed to use the aggregated Study Data to gain an

understanding about which clinician role is using KeyHIE and what types of patient records are being accessed.

- ADT/registration information was to be correlated with the billing information and used to determine readmission rates for patients with similar conditions, as identified through the billing information. This ADT/registration information would help researchers determine if patients were readmitted to the KeyHIE-participating hospitals.

Without the alignment of complete data sources and approval for all KeyHIE participants to conduct research, precise data reporting would be jeopardized.

6. Results

At the start of this grant (May 2010) KeyHIE had 9 hospitals, 1 physician practice, 2 home health locations, and 2 long term care facilities. At the conclusion of this grant (March 2015) KeyHIE consisted of 20 hospitals, 185 physician practices, 28 home health locations, 61 long term care facilities, 1 LTAC, 1 pharmacy and 1 emergency medical service.

In June 2010, there were 800 documents accessed and 3.5 million documents in the repository. In March of 2015, there were 100,600 documents accessed and 24.2 million documents in the repository.

A list of implementations related to this grant is located in Appendix A.

Research

July 2011 – Provider Focus Groups were conducted by Abt Associates

September 2011 – Paper Patient Survey (60% response rate), Case Manager Survey (70% response rate) and Clinician Survey (35% response rate)

October 2011 – Focus Groups with five KeyHIE users and one former user.

September 2012 - Abt Associates conducted a Focus Group at Sun Home Health

September 2012 - Abt Associates conducted Focus Group for Shamokin KeyHIE users

March 2013 - Abt Associates Focus Group session at Family Medical

March 2013 Abt Associates Focus Group session at Visiting Nurse Association

March 2013 Abt Associates Focus Group session at SUN Home Health

November 2014 - Abt Associates conducted Home Health Staff site visits

Conclusion

Although most of the technical implementations went as expected during this grant, the research plan faced multiple barriers, many of which could not be overcome. The most important barrier related to obtaining necessary data to conduct the proposed research, which is discussed in detail below.

As a consequence, the majority of the research questions could not be answered and a grant extension was requested to construct and analyze a subset of data containing information from limited KeyHIE participants. The proposed approach and inability to complete analysis for the extension is described below.

Measuring the impact of KeyHIE on patient outcomes and care efficiency requires well-matched intervention and comparison groups: patients for whom KeyHIE was and was not used. The data required for this matching includes patient demographics and diagnoses. Diagnosis information is also needed to understand for which types of patients KeyHIE is used. The first task therefore, was to determine whether diagnosis information contained in KeyHIE is sufficiently complete and accurate to support such an investigation and analyses. When we compared KeyHIE diagnosis information, which comes from initial problem lists at hospital admission, with final diagnoses present on hospital bills, we found that KeyHIE data did not reflect actual patient diagnoses. For example, where KeyHIE might have an ICD9 code for 'difficulty breathing', the eventual hospital bill might contain an ICD9 code indicating pneumonia, asthma, thromboembolism, or other possible explanations for breathing problems. The concordance between KeyHIE diagnosis and hospital billing data was only 7%. We therefore concluded that KeyHIE diagnosis information is inadequate to support the matching needed to create a comparison group.

More accurate and complete information is available on hospital bills and we requested hospital billing data from all KeyHIE members, with which to create a linked research data set. Two KeyHIE members, Geisinger Health System and Evangelical Hospital provided billing data, and this became our potential research data set; other KeyHIE members declined. These two willing participants are large regional healthcare providers, but do not reflect the entirety of KeyHIE patients or users. In addition, the hospital billing data they uploaded to us reflected only the care they provided; any care the same patients received elsewhere – which is exactly the purpose for which KeyHIE is designed – was not in the research data set. This limited our ability to calculate rigorous outcome measures such as all-hospital readmissions, since many local hospitals where readmissions may occur (or where index admissions occurred) are missing from the data set.

During the contemporaneous Beacon Community program (which ended in mid-2013), KeyHIE was used by Beacon case managers for many Congestive Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD) patients who are also present in the hospital billing data we received from Geisinger and Evangelical (both also participated in Beacon). Chronic disease patients are among those for whom KeyHIE may offer the greatest advantage. After the Beacon program ended, KeyHIE use for Geisinger and Evangelical patients appreciably declined. Apparently, KeyHIE was a useful tool for the Beacon program, but much less so thereafter. The "Beacon effect" was quite pronounced and it was not possible to separately measure the impact of Beacon and the impact of KeyHIE. Therefore, only the post-Beacon period offers a true indication for which patients KeyHIE is used, absent the Beacon program. Other sources of KeyHIE use that may be increasing (outside the Geisinger and Evangelical systems) could not be obtained in our research data set because at least two other health systems declined to allow their data to be used for research purposes, and no other KeyHIE members provided billing data.

Accurate measurement of outcomes such as readmissions requires dates of death for deceased patients. The Social Security Administration (SSA) previously created and published public use death data files (at the person level) in near real time. However, starting in March 2014, SSA policy changed to ensure that a full year must pass before any death is included in the SSA public files. Our research file therefore ended in March 2014, which is less than 10 months after the Beacon program ended. The Beacon program created a temporary use case for KeyHIE that ended when that program ended. The post-Beacon period is brief, and made even briefer by the absence of SSA death data files after March 2014.

Finally, the research data set was not only limited to patients served by Geisinger Health Systems and Evangelical, but also limited amongst those to KeyHIE users at Geisinger, Evangelical, and their associated physician groups. Although KeyHIE administrative data showed that the number of active KeyHIE users increased each quarter, as new facilities and their affiliated clinicians joined the HIE, this increased use was not evident for Geisinger and Evangelical users which were the only health systems whose user activity and patient billing data were available for research purposes.

All of these considerations led us to conclude that the available research data set is too limited to support the analyses needed to answer the research questions.

Although definitive information will not be available for this report, the research group is making one last effort to obtain clinical information from Susquehanna Health. A proposal was sent to Susquehanna Health's Institutional Review Board (IRB) in an effort to allow the de-identification of their data to be performed at their institution instead of being completed by the Geisinger Honest Data Broker. If the IRB submission is approved, we surmise that the inclusion of this data will provide enough information to deliver meaningful results; albeit post-award. If approved by the Susquehanna Health IRB, data will be analyzed with the intent of addressing the previously posed research questions and summarized with a submission to AHRQ in a good-faith effort to complete the grant to the extent possible.

Research Questions. Below we briefly summarize the shortcomings of the available data for answering each of the research questions.

1. How do clinicians who use the exchange differ from those who do not?

Since important KeyHIE members, with arguably the most to gain from KeyHIE, did not agree to allow their data to be used for research purposes, we do not have access to information about all users. The subset of patients, and of users, in our data set is non-representative and would give an erroneous result if used to answer this question.

2. How do patients whose records are accessed by their clinicians differ from those who records are not?

The research data set does not include all patients, and the subset it does include overlaps with the Beacon program except for a few months. In addition, the subset of patients included in the data set comes from two large health systems that have sophisticated EHRs and much less need to rely

upon KeyHIE. The subset of patients in our data set is non-representative and would give an erroneous result if used to answer this question.

3. What types of information are sought via the exchange? Does this vary by clinician type? By patient type?

Similarly, the incomplete and non-representative nature of the data set does not permit analysis of this question.

4. Does the addition of more clinical information and more clinicians (and types of clinicians) increase exchange use?

We hypothesized that as more health systems and other care providers joined the HIE and contributed their data for sharing, the HIE would be seen as an increasingly valuable tool and use would increase, creating an adoption cycle that would motivate additional potential users to join. Our data set is limited to two health systems (founding members of KeyHIE) and we are not able to calculate increased use as more and different types of providers joined the HIE.

The major additional type of clinician(s) that began using KeyHIE extensively during this period were home health agencies. Home health agencies need information about a new patient's prior history and current clinical and discharge status to plan care, schedule visits, and facilitate care transitions. However, home health agencies frequently lack timely, complete and accurate information. We conducted a phased series of qualitative case studies with home health agencies participating in KeyHIE, to understand how the additional information they obtained from KeyHIE alters home health care delivery. The three study home health agencies reported that KeyHIE significantly improves both efficiency in their work flows and quality of patient care in multiple ways. (See draft manuscript attached.)

5. Do clinicians alter their diagnostic approach or care plans when using information from the exchange? In what ways?

We initially planned to present clinicians with cases of their own patients for whom KeyHIE was used and query ways that KeyHIE information might alter their care plans. The Geisinger IRB objected to this research plan and did not approve the use of specific patients' information in this manner. However, we did explore the ways in which KeyHIE information might alter the care provided by home health agencies, by receiving real-time "push" notifications from the HIE when their patient is hospitalized or visits the Emergency Department and is discharged back to home care, and can "pull" patient information including discharge summaries, history and physicals, structured continuity of care documents (CCDs), laboratory results and radiology reports, and medication lists. Home health agencies receive real-time "push" notifications from the HIE. The benefits for participating home health agencies include more timely and complete information about new patients, safer and timelier care, improved efficiency, better documentation, and more accurate billing. A phased series of qualitative case studies with three large home health agencies in the region who participate in KeyHIE was conducted and is described in the draft manuscript attached..

6. Why do some patients decline to authorize sharing of their records? Why do some clinicians not ask for patient authorizations? Why do some clinicians not use the exchange?

We designed, pre-tested and conducted a patient survey, which was also used for the Beacon program, to understand patient concerns about authorizing the sharing of their medical information. This information was presented at national conferences. (See attached poster.)

We conducted focus groups with clinicians who had some experience using KeyHIE and subsequently discontinued use, to understand barriers. We also interviewed a convenience sample of clinicians who could use KeyHIE but do not, to understand barriers. The overwhelming response from virtually all those we interviewed emphasized the lack of patient authorization for record sharing and consequently the lack of access to a patient's a record in KeyHIE. Clinicians who had early and frustrating experiences trying to use access information about patients who had not authorized sharing quickly became disillusioned and stopped trying.

The patient authorization ("opt in") issues are complex in Pennsylvania and despite years of effort, KeyHIE staff still working to overcome substantial policy and technology barriers.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) allows for the exchange of Protected Healthcare Information (PHI) for the purpose of Treatment according to 45 CFR 164.506. No patient authorization or consent is required to release this information to clinicians who have a treatment relationship with the patient. The information accessed for treatment purposes is not limited to specific records related to a particular visit, but may contain information from the entire patient chart for the patient in their care. Many HIEs in other states have cited these rules in support of their opt-out privacy models, where patient information is able to be exchanged between clinicians involved in their care without the need for an authorization unless a patient has specifically "opted out" of allowing their information to be exchanged.

Another federal law, 42 CFR Part 2, prohibits the exchange of drug and alcohol treatment information from designated drug and alcohol treatment centers without specific consents that indicate to whom the information will be provided and for what period of time¹. Most HIEs simply exclude facilities and clinicians providing these services from participation in their exchanges since the laws make it difficult for this information to be exchanged.

Pennsylvania is one of several states that have more stringent laws regarding the release of HIV and mental health information^{2,3}. Patients must give their explicit authorization for this information to be exchanged between clinicians practicing in PA. The combination of HIV, mental health and drug and alcohol treatment information is often referred to as "Specially Protected Data (SPD).

Adoption of opt-in consent

By 2005, when KeyHIE members first convened to discuss the regional exchange of healthcare information, Geisinger had developed an authorization form for patients – this gave Geisinger permission to share records created by Geisinger clinicians with non-Geisinger clinicians. This authorization form specifically required patients endorsement and approval for their HIV, mental health and substance abuse treatment information to be exchanged for treatment purposes. KeyHIE members endorsed this opt-in approach, and adopted the use of the form with their organization's name and logo. By the time KeyHIE services were first operational in 2007, Geisinger

and two community hospitals permitted access to their information so long as a patient authorization was signed at their facility.

This facility level opt-in approach was different from other HIEs using the opt-in approach because individual KeyHIE members were solely responsible for collecting and maintaining their own patient authorization for the release of their records. Other HIEs using the opt-in model required only a single consent to be signed that would allow the release of records by any member of the HIE. Attorneys at multiple KeyHIE facilities argued that a patient signing an authorization would be unable to know who might share their records in the future and considered this to be an inappropriate approach to obtaining patient consent. Additionally, the interface between the providers and the HIEs were unidirectional, so there was no automated way for an organization to know if an authorization had been signed elsewhere without looking into the HIE for each patient being registered.

At the time the AHRQ grant was awarded to Geisinger Clinic in May of 2010, there was no way to determine whether a clinical document in the HIE contained any SPD. As a result, all of the participating organizations determined to use Opt-in model with the promise to collect patient authorizations as required. By this time, KeyHIE had received some 400,000 authorization indicators from the 14 healthcare organizations participating in the exchange at that time. These indicators were sent to the HIE through interface message from each participating provider organization to indicate that a patient had signed an authorization form at their facility. Despite this large number of signed authorizations, the number is relatively small in comparison to the 3.5 million patients in the Enterprise Master Patient Index (EMPI) linking records from each participating healthcare provider because many organizations were unsuccessful in securing a substantial number of signed authorizations. The result was a health information exchange containing millions of clinical records, where only a fraction could be accessed by the clinical community.

Barriers posed by opt-in

Despite having a significant amount of information in the HIE, much of it was unavailable to clinicians accessing the HIE services during this time consequent to consent issues precluding access to the HIE. Geisinger and several other healthcare organizations had implemented administrative procedures to ensure that patients would be given the opportunity to sign the opt-in authorization form, resulting in 80% or higher levels of patient authorization. However, other organizations considered this process laborious and excess work for their overburdened registration staff in their organizations in these circumstances, where patients were only occasionally asked to sign the authorization form resulting in authorization rates below 10% were common. Accordingly, clinicians attempting to use the HIE services found the availability of clinical information to be highly dependent upon the organizations where their patients received care, and were often disappointed to discover the information they needed was not available. This contributed to significant non-use of the HIE.

Pennsylvania State of opt-out registry

In 2012, The PA General Assembly passed Act 121, known as “the Pennsylvania eHealth Information Technology Act”, which established the Pennsylvania eHealth Partnership Authority (Authority) and called for the creation of a statewide opt-out registry⁴. However, the legislation stopped short of enabling a statewide opt-out privacy model because it failed to address the consent requirements embedded in the regulations surrounding the SPD. The Authority further clarified that the statewide opt-out registry would only pertain to information passing through the Pennsylvania Patient and Provider Network (P3N), and did not pertain to information housed within the individual health information organizations (HIOs) like KeyHIE which used the P3N to exchange information with other Pennsylvania-based HIOs.

KeyHIE design for mixed consent model

In 2013, KeyHIE made a strategic decision to transition its HIE services to the leading HIE vendor, Orion Health. As part of this transition, KeyHIE developed a hybrid privacy model that would allow opt-in facilities to share their records based on a patient authorization while opt-out facilities could permit records from their organization to be shared *unless* a patient opted-out of the information exchange service. This change was made possible through the introduction of a new service in the marketplace whereby opt-out facilities could have all their records scanned for sensitive data and marked as restricted if any SPD was found. In this way, all records free of SPD, would then be accessed without a patient authorization unless a patient had specifically opted out of the information exchange. This service was implemented in June of 2015, and shows significant promise for reducing this substantial barrier to HIE efforts. KeyHIE has also committed to working with the PA Authority to bring this capability to all of the HIOs in Pennsylvania so more information can be exchanged in a consistent manner across the commonwealth.

7. Does healthcare efficiency change when the exchange is used? In what ways?

We initially hypothesized that case managers and Emergency Department staff would be the most enthusiastic KeyHIE users. However, when interviewed, case managers informed us that they rely on their EHRs, not KeyHIE. Similarly, Emergency Department clinicians communicated that they do not have time to search for information in KeyHIE, and are trained to meet their patients’ needs with whatever (minimal) information is readily available. Neither group were enthusiastic users. Alternatively, Home Health Agency (HHA) staff, were extremely enthusiastic users of KeyHIE and through case studies we learned about numerous efficiencies enjoyed by HHAs using KeyHIE. See draft manuscript attached.

8. Do patient outcomes improve when case managers access the exchange for information about hospitalizations?

The incomplete and non-representative nature of the data set precluded analysis of this question.

Lessons Learned

Although disappointed that we were unable to answer more of the initial research questions, we learned a great deal that should be useful to AHRQ and for others attempting this type of research related to defining the value of HIEs.

Privacy Protection: In the absence of federal regulations governing information sharing, and especially the sharing of specially-protected health information, states have developed varying policies and regulation, which continue to evolve. In this environment, healthcare providers and HIEs struggle to agree on policies and mechanisms (forms, technologies) to protect patient privacy while also supporting information sharing. As the KeyHIE example demonstrates, an “opt in” approach that requires patients to sign authorization forms at every healthcare provider they visit, requires extensive and inefficient work by every provider to educate patients, obtain their signed authorization, and file those authorizations with the HIE, before information sharing is possible. As we also learned, providers who repeatedly seek patient information and are blocked due to “missing” patient authorizations, give up in frustration. Even after Pennsylvania policy changed, and most local healthcare providers accepted an “opt out” approach, the HIE technology must still allow patients to opt out of information sharing; functionality that is only now becoming available in KeyHIE’s state-of-the-art system. The policy hurdle has been addressed, at least in part, and technology is catching up.

Collaboration for Information Sharing vs. Collaboration for Research Purposes: Although many healthcare providers in the region have agreed to share information for purposes of improving care delivery, we faced enormous barriers in persuading them to share patient-identified (linkable) information for research purposes. The competitive environment, HIPAA concerns, IRB objections, and other barriers were greater than anticipated and impossible to overcome for some key KeyHIE members. Without access to all members’ data, research about KeyHIE is incomplete and non-representative. These same issues are likely to arise for others conducting research using HIE data.

Clinical Information vs. Transactional Information: The transactional information captured in KeyHIE, especially regarding diagnoses, differs from that reported by healthcare providers, because billing information is not extracted by KeyHIE. Linking KeyHIE to not only the admission/discharge/transfer systems, but also the billing systems, was beyond the ability of this grant and the available technology. Our analysis indicates that the concordance between KeyHIE diagnosis and final billed diagnosis is negligible. Rigorous and consistent diagnosis information is essential for outcomes research. An all-payer claims database with identifiable data (for linking with HIE data) is one possible solution, but many states lack such databases, or the databases do not contain patient identifiers. We attempted to obtain hospital billing data, which includes all patients and all payers, but were only partially successful. Other researchers will likely face similar challenges in conducting outcomes research using HIE data.

Utility of Information from Other Care Providers. All of the qualitative data collected under this grant indicates that some healthcare providers have great need for information about care their patients receive elsewhere, while others have very little need for this information and do not look beyond their own EHRs for information about their patients. In part, this is because some providers have access to all the information they need, mainly from the clinician’s EHR, while others frequently in the absence of an EHR, have enormous information gaps. In part, this is because some providers have sophisticated information systems, while others are slow to adopt electronic information systems. The health

information ecology is asymmetric in terms of both the need for information from external sources, and the technological ability to securely access and store information. For example, we learned that Emergency Department clinicians are comfortable providing care with incomplete information; they are trained to conduct any diagnostic tests necessary and prefer to do this rather than searching an HIE for a recent test result which they may believe is no longer valid. Alternatively, HHAs are often “out of the loop” and need real-time information about the care their patients receive elsewhere, in order to provide safe and timely home care. Emergency Department clinicians will not pause to use an HIE, but HHAs will eagerly adopt HIE technology and create new workflows to take advantage of information that fills important gaps.

Ease of Use. In the early years, most KeyHIE users had to exit their native EHR environments and separately login to KeyHIE; many still access the HIE in this manner. The current workflows required to use KeyHIE are suboptimal. Our experience demonstrates that use increases considerably, and in unanticipated ways, when clinicians can access the HIE from within their native EHR, without a separate login. For example, one of the area’s largest physician group practices now runs an automated information query and pulls data from KeyHIE every morning, for patients with scheduled office visits that day. Future HIEs should be designed with this function which will enable healthcare provider with an EHR to access regional information about their patients. As every EHR is different, however, the technology to accomplish all of these differing vendor interfaces is complex and costly – and likely not supportable by HIE user fees.

Information Technology and Expertise. Most of the hospitals participating in KeyHIE (other than Geisinger) lack the technology and expertise to take advantage of an HIE, without additional resources. This and other grants have supported much of the necessary connectivity and vendor interfaces, but there was also a substantial in-kind contribution by Geisinger Health System, without which much of this would not have been possible.

List of Publications and Products

Hassol, A., Woo, M., Ball, S., Izrael, D., Carayon, P., Hoonakker, P.L.T., Ladd, I., Yule, C, Younkin, J., Chaundy, K., Larson, S., Walker, J.M. *Chronic Care Patients’ Attitudes Regarding Electronic Health Information Exchange*. Presented at American Medical Informatics Association meeting November 3-7, 2012.

Hassol, A., Woo, M., Ball, S., Izrael, D., Carayon, P., Hoonakker, P.L.T., Ladd, I., Yule, C, Younkin, J., Chaundy, K., Larson, S., Walker, J.M. *Chronic Care Patients’ Attitudes Regarding Electronic Health Information Exchange*. Presented at American Public Health Association meeting November 2013.

Hassol, A., Deitz, D., Goldberg, H., Honicker, M., Younkin, J., Chaundy, K., Walker, J. *Health Information Exchange: Perspectives from Home Health Care*. In submission

References:

1. 42 CFR Part 2 (federal drug and alcohol treatment regulations) <http://www.gpo.gov/fdsys/pkg/CFR-2002-title42-vol1/pdf/CFR-2002-title42-vol1-sec2-52.pdf>
2. 35 P.S. 7607 (PA law re confidentiality of HIV-related information)
3. 55 Pa. Code § 5100.32 (PA regulations re confidentiality of mental health records)
<http://www.legis.state.pa.us/WU01/LI/LI/US/HTM/2012/0/0121..HTM>

Appendix A - Implementations

July 2010 – Geisinger Medical Laboratory (GML) laboratory results publishing into KeyHIE.

August 2010 – Shamokin laboratory results publishing into KeyHIE

August 2010 – 800 laboratory results were Logical Observation Identifier Names and Codes (LOINC) mapped for GML and Shamokin laboratories.

February 2011 – LOINC mapping complete for Schuylkill Health

April 2011 – LOINC mapping complete for Evangelical Community Hospital

May 2011 – LOINC mapping complete for Moses Taylor Hospital

June 2011 – Evangelical laboratory results publishing into KeyHIE

July 2011 – KeyHIE Master Lab Test Catalog developed

July 2011 – Registration Toolkit developed to assist registration personnel with explaining KeyHIE to patients

September 2011 – Schuylkill Health’s ADT information publishing into KeyHIE

September 2011 – Moses Taylor Hospital labs publishing into KeyHIE

October 2011 – On Boarding (Tracer Bullet) Tool developed to implement participants with maximum efficiency.

December 2011 – Geisinger’s Rich Text Format (RTF) Epic documents went into production

January 2012 – Schuylkill Health’s labs publishing into KeyHIE

January 2012 – a computer-based training module was developed to coach organizations on LOINC mapping techniques

February 2012 – The Tower migration took place

February 2012 – LOINC mapping complete for CMC

May 2012 – Susquehanna Health’s ADT/Encounters are publishing into KeyHIE

May 2012 - LOINC mapping complete for Susquehanna Health

May 2012 – K2 vendor upgrade complete

May 2012 – LOINC mapping complete for FPC

June 2012 – Geisinger’s CCDs publishing into KeyHIE

August 2012 – Susquehanna Health’s clinical documents publishing into KeyHIE

August 2012 – Susquehanna Health’s lab results publishing into KeyHIE

September 2012 – Flu Shot Reminders incorporated into local school’s IVR messaging and e-mail systems

October 2012 – FPC Lab results publishing into KeyHIE

November 2012 – Schuylkill Health Transcribed Clinical Documents publishing into KeyHIE

November 2012 – Susquehanna Health Radiology and Emergency Department documents publishing into KeyHIE

December 2012 – Schuylkill Health voice documents publishing into KeyHIE

December 2012 – LOINC mapping complete for Bloomsburg Hospital

December 2012 – Bloomsburg Hospital’s lab results publishing into KeyHIE

December 2012 – ED and Admission/Discharge Alerts went live

January 2013 – KeyHIE Transform Tool to HL7 Balloting

March 2013 – Schuylkill Health’s Radiology Reports publishing into KeyHIE

April 2013 – Susquehanna Health’s Inpatient CCDs publishing into KeyHIE

April 2013 – KeyHIE’s Workflow Optimization Tool developed

April 2013 – NIST Validation Tool developed

June 2013 – KeyHIE Classic (Provider Portal) Sunset

June 2013 Presbyterian Senior Living LIVE with KeyHIE Transform

June 2013 Community Medical Center (CMC) Laboratory Results publishing into KeyHIE

July 2013 Geisinger ECGs publishing into KeyHIE

July 2013 Susquehanna Health Outpatient CCDs publishing into KeyHIE

September 2013 Geisinger Inpatient and Outpatient CCDs publishing into KeyHIE

February 2014 – Discharge notification alerts went live