Strengthening Health Information Exchange

Final Report HIE Unintended Consequences Work Group

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Executive Summary

Health information exchange (HIE) enables digital health data to be used at locations other than where the data are captured. It is also one of the core requirements of the Medicare and Medicaid electronic health record (EHR) Incentive Programs ("meaningful use" (MU)). An overarching goal for HIE is increasing the ability of health information technology (health IT) to improve health care processes and outcomes. There are several areas in which HIE has already shown benefits to the health care system. For example, HIE has:

- Improved quality of care by providing more complete patient information to enhance medical decision making;

- Begun to reduce costs through the elimination of unnecessary duplicate tests;

- Supported continuity of care as patients transfer among health care facilities, an aspect growing in importance with the aging population;

- Improved the information flow to health departments and facilitated stronger management of emerging infectious diseases; and

- Offered innovative ways to conduct population-based research through large databases created by some health information exchange organizations (HIOs).

However, for all technologies, in addition to the positive intended consequences of the application, there is a risk that the technology will inadvertently result in negative unintended consequences (UCs). Consideration of potential negative unintended consequences of technology is important to enable development of risk mitigation approaches.

This report describes the deliberations of Health Information Exchange Unintended Consequences Work Group (HIE UC WG), a subgroup of Unintended Consequences Technical Expert Panel (TEP), which was chartered by ONC. The HIE UC WG consisted of the authors of this report and 5 other experts selected for their knowledge and experience with HIE.

The charge to the HIE UC WG was to (i) develop a framework to categorize the kinds of UCs that can occur from the use of HIE, and (ii) develop a list of approaches that could be used to mitigate the risks of UCs from HIE. The HIE UC WG prioritized UCs that relate directly or indirectly to clinical care or that impact organizations or providers engaged in HIE. Because of other work that was being done by ONC, the HIE UC WG did not directly address unintended consequences related to privacy and security risks as they impact patients outside the care setting.

The Work Group was mindful of the dynamic environment surrounding health information exchange. In its early deliberations, the group noted that: (i) there is a sense of urgency among several health stakeholders to understand how best HIE can be used to improve care; (ii) to date, HIE has been slow to unfold and as such is still in its infancy; (iii) HIE is a key component of Meaningful Use and will be further promoted by Stage 2 of the MU rules; (iv) there are multiple approaches to HIE including query-based exchange, directed exchange, and consumer-mediated exchange; and (v) multiple stakeholders are working to advance HIE, including providers, technology vendors, state and local governments, and the federal government. The HIE UC WG

also noted that there are several challenges to the successful implementation of HIE and that these challenges, per se, are not the same as UCs. While there is some overlap between these two, the HIE UC WG decided to limit the scope of its work to UCs.

The HIE UC WG developed framing principles that guided the development of its products. First, the group noted that the intended consequence of HIE is improvement in the processes and outcomes of care and any aspect of HIE that would interfere with this goal should be considered an "unintended consequence." Second, the group noted that when considering potential solutions, it is important to distinguish between an "unintended consequence" and its "root cause." For example, an unintended consequence would be an untoward patient outcome resulting from the clinician acting on incorrect or incomplete data whereas the root cause might be a loss of data integrity during transmission. The HIE UC WG decided to focus on root causes since these are more directly amenable to actionable solutions. Third, the WG recognized that HIE initiatives are extended multi-phased projects and that interventions to mitigate the risk of UCs may be best targeted at different phases of the project. Specifically, the group indicated whether a risk mitigation activity is best targeted at the design phase, the implementation phase, or the post-implementation phase of an HIE initiative.

An annotated bibliography formed the basis of an initial framework for the categories of UCs that can result from HIE. The WG added knowledge from direct personal experience or awareness of the experience of others because the field of HIE is nascent and the amount of documented material about the kinds of UCs that can result is limited. Teleconference calls and a day-long face-to-face meeting were used to refine the categorization scheme and enable a consideration of potential risk mitigation activities.

The results of the HIE UC WG are presented in this report and are summarized in Table 1 which lists mitigating interventions by project implementation phase. There are seven categories of unintended consequences:

(i)   Incomplete, inaccurate or untimely data provided by HIE,

(ii)   Problems related to data presentation, including data overload,

(iii)   Heterogeneity of use of HIE,

(iv)   Patient perceptions or concerns about HIE,

(v)   Reputational and financial risks to organizations and providers engaged in HIE,

(vi)   Vulnerability to technically related unintended consequences, and

(vii)   Unintended consequences of administration of HIE.

Table 1 shows selected approaches to the mitigation of the risks from these UCs. In general, (i) approaches in the design phase include the creation and dissemination of information about best practices, (ii) approaches in the implementation phase involve the development of checklists to assure that best practices are adhered to, and (iii) approaches in the post-implementation phase require monitoring to track experience and make iterative refinements and also to assure that maintenance processes, which can be complex in an HIE environment, are carried out effectively. The group also identified a need for educational tools to raise awareness about the UC issues and research into the areas of patient matching and more effective approaches to data summarization in an HIE environment as well as other specific components of the various categories. The full report contains a complete listing of the recommendations, as well as background and contextual information for each category.

The HIE UC WG recommends that next steps include the review, refinement, validation and prioritization of these recommendations with key stakeholder groups, which could include:

(i)   ONC, including the Information Exchange Subcommittee of the Health Information Technology (IT) Policy Committee,

(ii)   provider organizations,

(iii)   health IT vendors,

(iv)   existing HIOs,

(v)   State Designated Entities (SDEs),

(vi)   Regional Extension Centers (RECs) and

(vii)   other such segment-specific stakeholder groups as the Health Lawyers Association, AMIA, AHIMA, AHRQ, the National Library of Medicine, CHIME, and others.

After refinement and prioritization, ONC should consider the development of tools that can mitigate the risks of high likelihood, high impact events.

The WG noted that HIE is complex, requires structures and processes that do not currently exist broadly, and requires diligence to assure that the complexity is managed well. Without explicit risk mitigation approaches, there is a significant chance that untoward unintended consequences could occur as a result of efforts to promote the use of HIE.

Table 1. Summary of HIE Work group UCS and mitigating interventions by project implementation phase

	Unintended consequence category	Design	Implementation	Post implementation
1	Incomplete, inaccurate or untimely data provided by HIE	Best practices for patient matching and selection of robust standards	Checklist to assure adherence to standards	Process to account for site-specific and HIE changes
2	Problems related to data presentation, including data overload	Best practices for design of data review and patient summary screens	Robust user training	Monitoring of problems and continued user training
3	Heterogeneity of use of HIE	Best practices to convey the value of HIE and align with system delivery reforms	Checklist for robust implementation; adequate training and support	Checklist for monitoring of use with feedback and iterative improvement
4	Patient perceptions or concerns about HIE	Best practices to include patients in governance and other aspects of program design	Awareness campaign tools; discussion guides for providers; checklist to ensure transparency of policies; options that support meaningful choice	Model feedback instruments to collect perceptions from patients and fold into evolution of program
5	Reputational and financial risks to organizations and providers engaged in HIE	Sample language for contracting and policies; white paper outlining benefits of HIE	Educational models for users about and best ways to make use of the system; compliance checklist	Best practices to remain current with federal and state law; checklist for monitoring unauthorized use of HIE data
6	Vulnerability to technically related unintended consequences	Robust technology plan, including disaster recovery	Adequate operational capabilities, including processes to coordinate across the network	Maintenance processes must synchronize across participants; Checklist to update disaster recovery plan
7	Unintended consequences of administration of HIE	Checklist to ensure regulatory requirement integration, assure sample job descriptions for adequate workforce	Checklist for robust audit program to assure compliance, Educational models for new hires and continuing education	Best practices for monitoring evolving regulatory requirements

Introduction 1

Health Information Exchange (HIE) is a capability of exchanging patient health information among health care providers regardless of the source of the information. HIE enhances patient care by providing timely access to more accurate and complete information. This has been a critical step in improving emergency department (ED) diagnosis and treatment where ED physicians rarely see a patient more than once. There have been a number of Federally supported HIE projects that have resulted in research demonstrating that cost savings can be accrued from eliminating duplicate laboratory and radiology studies and that continuity of care facilitated by HIE has improved health care outcomes.

While HIE is an integral part of the nationwide health information infrastructure and a requirement of legislated meaningful use with many potential benefits, it also has the possibility of producing unintended consequences (UCs). As a developing and complex utility, mitigating potential negative unintended consequences of HIE could be the difference between successful and unsuccessful implementations. To study the UCs of HIE, a Workgroup of HIE experts was sponsored by the Office of the National Coordinator for Health Information Technology (ONC) and the results of their work follows.

For the purposes of exploring unintended consequences, HIE is defined as the electronic transmission of healthcare-related data among disparate organizations, providers or provider groups, and potentially patients, and not within a single organization or among affiliated providers. It is also understood that HIE is a process and the unintended consequences of HIE are not limited to organized health information exchange organizations (HIOs), such as RHIOs (Regional Health Information Organizations) or CHINs (Community Health Information Networks). HIE touches all who participate. Notably, going forward, as pointed out in the ONC strategy statement that appeared in the journal Health Affairs (Williams, 2012), health information exchange will take three forms: (a) query-based exchange; (b) directed exchange; and (c) consumer mediated exchange.

A negative unintended consequence for this work is defined as *an outcome from the use of HIE capability that has a negative impact on healthcare organizations, healthcare providers, HIOs, or patients that was not intended.* Health information exchange has demonstrated its many positive outcomes and is recognized as a critical aspect of health care reform. These outcomes result from intended consequences of the HIE capability. There are also a number of unintended consequences that result in positive impacts, but to limit the scope of this project, only those potential unintended consequences with negative impacts have been studied.

It is important also to recognize that while many of the goals or intended consequences of health information exchange, such as improved quality and cost reduction due to a decrease in redundant tests, have been realized among more mature HIOs, these goals do not necessarily translate across all HIOs or all uses of HIE. HIE that has achieved greater adoption and

perception of usefulness tends to be more customized to the local health care environment. Similarly, many UCs are localized to specific communities and may not be generalizable.

There are two primary goals, with associated products, arising from the charge to the HIE UC Workgroup:

1.   To develop a framework of categorized unintended consequences and their root causes associated with HIE; and

2.   To recommend to ONC a set of tools and resources to help HIOs and providers engaged in HIE to prevent, detect, mitigate, and ameliorate hazards associated with the UCs of HIE.

Ultimately, this workgroup identified and suggested areas of research to further knowledge about unintended consequences of HIE and developed a plan to foster the identification or development of solutions to address the UCs associated with HIE.

Recognizing that the findings and outcomes of this project constitute an important step in the fostering of HIE across the country, there are three primary groups targeted for receipt of this work:

■   The Office of the National Coordinator (ONC) and several of its programs including the State Health Information Exchange Cooperative Agreement Program, the Beacon Community Program, the Health Information Technology Exchange Program, and the Health Information Technology Resource Center (HITRC).

■   The additional workgroups and activities of the Unintended Consequences project, including the Consumer e-Health Workgroup and the group that is developing checklists for the safe implementation of EHRs.

■   Other Federal agencies focused on the adoption and use of health information technology and exchange, most notably, the Agency for Healthcare Research and Quality (AHRQ) and the National Library of Medicine (NLM).

Under the direction of two leading HIE authorities, Gilad J. Kuperman, MD, PhD, FACMI, CEO of NYCLIX, and Julie J. McGowan, PhD, FACMI, FMLA, director of evaluation for numerous HIE grants, a small group of HIE experts was convened to guide the overall direction for the framework and identification of the HIE-related UCs. The Workgroup was composed of medical informaticians, a consumer advocate, leaders of existing HIEs, and authorities in the legal aspects of health information exchange (see Appendix 1 for the full list of HIE Workgroup members).

The Workgroup recognized that there were several dynamic factors that created a contextual landscape for health information exchange (and potential unintended consequences related thereto) and needed to be considered. In addition to a thorough review of the peer-reviewed and grey literature, these factors were reviewed by the Workgroup in order to establish a common

base of understanding of the health information exchange environment. These contextual factors included:

- The Workgroup affirmed a vision of HIE becoming a capability that health care providers eventually will come to rely on. A prerequisite for such reliance is that HIE be constantly available and provide data that are comprehensive, complete and accurate, within established expectations and parameters. UCs can result if data or information provided by the HIE capability are incomplete, inaccurate or unreliable, or if the HIE capability is unavailable.

- HIE, as part of meaningful use, is specified by the HITECH legislation. This highlights the critical and timely importance of identifying potential UCs that may result from HIE.

- The predominant vision for HIE from 2004 to 2008 had been a query-based exchange model. Recently, additional models – for example, directed exchange and consumer-mediated exchange -- have received substantial attention. This means that the UC framework needs to accommodate multiple HIE models.

- The HIE-related objectives for Stage 2 of Meaningful Use include the transmission of transition of care documents, secure messages to and from patients, and immunization registry data. Hospitals and eligible providers who will be working to implement these objectives over the next few years will need support to assure that unintended consequences are not encountered.

- Provider organizations that are working to develop innovative models of care that are aligned with the goals of health reform are eager to understand how HIE can best be used to support these initiatives. The urgency to adopt HIE to support these goals means that a solid understanding of potential UCs is critical.

- HIE is a capability, not an application. In contrast to an EHR, which is an "application", HIE is a capability that can be applied in vastly different ways. For example, the specifics of exchanging data to support clinical care may be vastly different from the exchange of data to support public health reporting. This means that the UC framework may need to cover a variety of different scenarios.

- The field of HIE still is in its relative infancy; as is its measures of success. There is significant uncertainty about how HIE will eventually work. This uncertainty creates challenges to the advancement of HIE. For example, provider organizations may be hesitant to invest in HIE-related technologies, organizational frameworks, privacy models or business relationships that may be obsolete within a short period of time. These challenges are not UCs per se, but create additional hurdles to be considered as part of a broader strategy to advance HIE.

- There have been a number of studies focused on the UCs in EHRs. In contrast, the study of UCs associated with HIE is just emerging. As part of its preparation, the Workgroup reviewed the literature of UCs in EHRs to determine if there were lessons that could apply to HIE. Many EHR-related UCs do in fact apply to HIE (e.g., reliance on technology, mismatches with the workflows, etc.). However, there are UCs that are specific to EHRs (because they replace existing paper-based

workflows) and UCs that are specific to HIE (because HIE requires new workflows, new capabilities and new policies).

The workgroup did not directly address unintended consequences related to privacy and security risks as they impact patients outside the care setting. At the time the UC HIE workgroup was meeting, the Privacy and Security Tiger Team of the Health IT Policy Committee was conducting hearings and developing policy recommendations based upon adherence to fair information practice policies, addressing, among other things, how to ensure meaningful patient choice for participating in HIE. ONC issued a Program Information Notice (PIN) on "Privacy and Security Framework Requirements and Guidance for the State Health Information Exchange Cooperative Agreement Program," on March 22, 2012, that "provides a common set of privacy and security rules of the road to assure provider and public trust and enable rapid progress in health information exchange to support patient care." This PIN, if widely followed, will help address some of the privacy and security related-UCs to patients associated with HIE.

Summary of Activities   2

2.1   Preliminary Work

The Workgroup on Unintended Consequences of Health Information Exchange was officially formed in late September 2011 with the appointment of the co-leaders and recruitment of Workgroup members. The first outcome of the preliminary work was the creation of the Background and Framing Concepts document, included in Appendix 2.

There were several preliminary guiding principles that transcended the evolution of the project. These include:

- Health information exchange is a capability while electronic health records are applications.

- While the focus of the project is on unintended consequences, challenges (anticipated potential negative outcomes) frequently impact UCs and should be identified and mitigated.

- There are two basic types of HIE UCs, those that arise from successful implementations of HIE and those that result from sub-optimal implementations of HIE.

- The HIE UC solutions need to be grounded in the prior and current research on EHR UCs and leverage this foundational research, where applicable.

Following the development of the general framing principals, a targeted review of the peer-review literature was completed with the intention of evaluating the literature to garner an initial list of HIE UCs. It became immediately apparent that HIE is too nascent to have resulted in more than a cursory look at UCs in the peer-reviewed literature. Because of this, a more expanded search was conducted among the gray literature with the hope of garnering discussion of UCs that had not been published. The findings were then analyzed and summarized (see Appendix 3).

The results of this expanded search for documented UCs yielded several insights. First, many of the treatises discussed challenges (i.e., lack of sufficient funding, lack of buy-in from participants, etc.) and their negative impacts, but they also frequently considered these challenges as unintended consequences. Secondly, and of greater importance, it became readily apparent that of those unintended consequences identified, the solutions to mitigating them should not be directed specifically at the UCs, but rather at the root causes of the UCs.

To attempt to organize the initial work for the Workgroup, a preliminary document, entitled Health Information Exchange Related Unintended Consequences: Preliminary HIE UC List (included in the Appendix 4), was created to identify the overarching UCs and their potential root causes, with the understanding that many of these global UCs might have more than one

root cause. Also included in this document were the methodology and related references. This document was to serve as the basis for further identification of UCs and their root causes by the Workgroup.

2.2   Workgroup Activities

Two teleconferences and one in-person meeting were held over the course of 6 weeks. The preliminary work from the literature and framework on identifying a preliminary list of UCS was used to frame the discussions. During the meetings two issues were raised that helped drive the framing of the discussions.

- The first of these was that the focus should be on intended consequences as the gold standard for determining unintended consequences. For example, the intended consequences of HIE are improved health care processes and/or improved health care outcomes. Therefore, the unintended consequences are those that harm patients or disrupt the system of care.

- The second issue related to the "chain of causation." In essence, this refers to a series of events, each of which cause a UC, and grow in magnitude. An example of this chain of causation is: 1] due to a variety of factors, data quality may be poor; 2] due to poor data quality, patient matching may be poor; 3] due to poor patient matching, the physician may receive wrong or incomplete data; 4] due to wrong or incomplete data, the physician may make an incorrect decision about a diagnosis or treatment plan; and, 5] due to an incorrect diagnostic or treatment decision, the patient may be harmed. In this chain of causation, it is very difficult to determine what constitutes the UC(s) and/or the root cause(s).

Both of these issues led to a global prioritization of UCs based on the three following groupings:

- UCs that have Direct Clinical Impact

- UCs that have Indirect Clinical Impact – Errors of Omission and Care Processes

- UCs that have Organizational Impact

These three groupings provided a framework to view UCs, and while less granular in terms of prioritization than what was originally envisioned, provided a solid structure to review the framework for the problems / UCs, root causes, and solutions and to begin a thorough discussion of tool and resource needs to mitigate the identified UCs.

At the conclusion of the three meetings, there was final agreement on a list of seven categories of unintended consequences:

- Incomplete, inaccurate or untimely data provided via HIE;

- Problems related to data presentation, including data overload;

- Heterogeneity of use of HIE capability;

- Patient perceptions or concerns about HIE;

- Reputational and financial risks to organizations and providers involved in HIE;

- Technical vulnerabilities of HIE; and

- Unintended consequences of administration of HIE.

The second concept that was raised by the Workgroup was that of 'phasing the implementation of HIE'. The Workgroup determined that the root causes, as well as potential solutions, of UCs tend to occur at different points of the planning and implementation process. Three phases were identified:

- Technical and process design phase

- Implementation phase

- Post-implementation (operational) phase

The Workgroup also identified a number of key stakeholders in the HIE community who would benefit from engagement with the initial findings of the Workgroup. These stakeholder groups could serve to validate and refine the framework and also to contribute suggestions about potential approaches to risk mitigation. The Workgroup identified the following stakeholder groups that might potentially be involved in such a series of discussions: (i) various constituencies within ONC, including the HIE Subcommittee of the HIT Policy Committee, the State HIE Cooperative Program, the REC leadership, the Beacon communities, etc., (ii) health care provider organizations, (iii) health information exchange organizations [RHIOs] (iv) technology vendors, (v) thought leadership organizations, for example, AMIA, CHIME, AHIMA and the American Health Lawyers Association, (vi) government agencies that might be involved in contributing to solutions to the identified issues, including AHRQ and the National Library of Medicine, (vii) emerging HIE accrediting bodies, and (viii) large insurance providers. The group noted that these kinds of discussions would be necessary input to the development of tools.

A variety of approaches to mitigating the risks of the UCs was also identified. The risk mitigation approaches include:

- Checklists;

- Technical specifications;

- Testing procedures and standard datasets;

- Best practices / draft language; and

- Training tools.

Section 4.0 below describes each UC category further, including background and potential solutions and tools that might be applied to mitigate the risk of each UC.

Anticipated Outcomes and Unintended Positive Consequences of Health Information Exchange 3

In 2009, Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act as part of the American Recovery and Reinvestment Act. HITECH included the concept of meaningful use of the EHRs as a requirement for the receipt of the incentives and a significant part of meaningful use is the ability to exchange health information among health care organizations. HITECH has accelerated the progress in health information exchange, however there was substantial health information exchange activity even prior to HITECH; for example, over the years, in addition to ONC, both CMS and AHRQ have provided funding for HIE initiatives.[a] The results of HIE programs are now being reported in both peer reviewed and gray literature, which document a number of positive outcomes of health information exchange. In this section, we present the positive results of experiences with health information exchange, both anticipated as well as unintended.

While health information exchange has primarily targeted the needs of the healthcare provider through the delivery of complete, timely and accurate information in support of medical decision making, it is important to note that positive outcomes of health information exchange can include greater coordination of care, consumer empowerment in health and health care decisions, and improved management of public health emergencies.

3.1 Quality of Care

One of the most obvious elements of improved quality through HIE is in the ability of the provider to have access to necessary patient information at the time of diagnosis and treatment. An early rationale for the creation of the Nationwide Health Information Network (NwHIN) was to ensure that individuals travelling around the country would receive quality healthcare predicated on access to their current health information regardless of location. Many of the first implementations of HIE were done specifically to link electronic health records in the emergency department where providers frequently need immediate information (e.g., allergies, medications) to treat emergent illnesses. This has resulted in access to recent diagnostic test results and discharge summaries, greatly improving time to treatment.[1-4]

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[a] The Deficit Reduction Act (DFA) of 2005 authorized CMS to grant states a total of $150 million in Medicaid Transformation Grants (MTGs) for the adoption of innovative methods to improve effectiveness and efficiency in providing medical assistance under Medicaid, with many of the state grants focused on advancing electronic medical records or health information systems and exchanges. Similarly, the AHRQ Health IT Portfolio has funded numerous grants related to health information exchange under the Transforming Healthcare Quality through Information Technology (THQIT) Initiative and the State and Regional Demonstrations (SRDs) in Health IT.

Timeliness of access to complete patient records is essential for all providers to ensure effective decision making. This was not an issue when most patients were treated by primary care providers and rarely had a referral. However, with today's mobile society and increasing fragmentation of care, access to a complete set of the patient's data becomes more problematic. Because of this, primary care and other specialty providers have begun to cite enhanced quality of care as one of the primary benefits of HIE.[5-7]

Patient safety is a critical component of quality. The Institute of Medicine published its landmark treatise, *To Err is Human: Building a Safer Health System*, in 2000.[8] While medical errors may happen in all aspects of medicine care, a significant fraction involve preventable adverse drug events (ADEs). HIE is uniquely positioned to prevent a significant number of preventable adverse drug events (ADEs) by providing access to information that the provider may not be aware. This impact of this has been noted by both the Congressional Budget Office[9] and in the peer reviewed literature.[10]

One of the most promising aspects of HIE is in the management of chronic diseases which frequently present with complex and co-morbid medical conditions. Treatment of diabetes is a case in point. A primary care provider will oversee the ongoing management of the disease. However, a cadre of specialists such as endocrinologists, cardiologists or ophthalmologists may be called to support issues related to a complex health condition such as diabetes If these specialists are located in different healthcare organizations, the only way to ensure that the diabetic patient is managed properly is through the type of multiple provider communication provided by the HIE.

While there are not published studies to date directly linking HIE to the improved management of chronic illness, there are a number of research projects underway, including studies currently being conducted by the Beacon Communities primarily focused on diabetes. In addition, HIE is well positioned to provide data for numerous quality improvement projects.[11] Quality Health First (QHF) is a utility that uses healthcare data contained in the Indiana Health Information Exchange to provide feedback to providers on a variety of quality indicators. Since the inception of the QHF project, participating providers have made substantial improvements in their healthcare ratings. Supported by third party payers, this quality improvement project, across a multi-county area in central Indiana, would not be possible without HIE.[12]

3.2   Cost Reductions

In the area of financial benefits of HIE that could lead in part to sustainability, reduction in inappropriate duplicate tests is a major focus. HIE can deliver timely test results from laboratories outside of the provider's organization, thus reducing the likelihood of having to reorder a recent diagnostic test requested by another organization. While reduction in low cost laboratory tests may not result in substantial savings, they do save money for the healthcare system. Recent research examining the reduction in imaging tests are proving even more financially beneficial to the healthcare environment.[13-15]

Health information exchange has even more promise in cost reduction by reducing unnecessary care. Although early research has not yet demonstrated an impact on healthcare service utilization, particularly in readmissions,[16] use of HIE data can support interventions that promise to reduce emergency readmissions and other forms of inappropriate use of resources, such as duplicate requests for pain medication in emergency departments. Some of this research is being included in final reports for Federal grants and cooperative agreements.

3.3   Population Health

While quality improvement and cost reduction were the two primary intended consequences of health information exchange, it became apparent that the aggregated data collected as the result of HIE could be leveraged to provide other benefits. Syndromic surveillance has become one of the most valuable of these positive unintended consequences. Using recent data collected from emergency departments and primary care visits, HIOs are able to detect patterns of syndromes that might indicate an emergent public health issue, allowing a more timely response that was not possible before.[17-18]

The potential to create large databases as a result of health information exchange creates many opportunities for enhancing population health. For instance, identifying geographic clusters of morbid conditions such as obesity or diabetes can be a first step in targeted prevention activities. Integrating a community information system into an HIE database enables a directed view of the environment that could be in part responsible for the health condition.[19]

3.4   Personalized Healthcare

Continuity of care requires the ability to understand the patient's status as well as their treatment plan, regardless of where care is received. Greater numbers of patients are seeking care outside of a single health system. With the aging of the population and basic primary care provided in nursing homes and assisted living facilities, access to this information becomes more challenging, yet even more essential. Health information exchanges have made significant inroads in addressing this issue by more rapidly delivering discharge summaries and ensuring improved medication reconciliation across disparate healthcare organziations.[20-21]

Consumer-mediated health information exchange puts the patient into the mix of individuals who can add or modify the personal health information that facilitates decision making by the health care provider. The concept of "patient generated insights" adds to the richness of the patient's record and fosters truly personal health care, resulting in greater patient empowerment, better compliance and improved health status.[22]

3.5   Research

The potential to create large databases as a result of health information exchange can provide a wealth of information and support for future research. Data mining techniques can be used to discover patterns leading to relationships between medical conditions or drugs. Research using such large HIE-created databases can also target local healthcare issues, such as identification of patients who pose a risk to healthcare organizations without appropriate precautions.[23]

There are a number of research initiatives currently underway that could both benefit from HIE infrastructure and inform the design of future HIE activity. These initiatives include comparative effectiveness research, patient-centered outcomes research, and population health research as mentioned above. For example, the Indiana Health Information Exchange is leveraging the HIE infrastructure it developed initially for clinical care to support a comparative effectiveness clinical trial of medication treatment for behavioral symptoms of Alzheimer's patients in a group of memory care clinics. Health information exchanges frequently bring together data from disparate settings, which are necessary to perform longitudinal analyses and outcomes studies where an intervention (e.g., surgery) occurred in one setting but the outcome (e.g., functional status) may be documented in another setting.

Many of these research initiatives are grappling with the same challenges that contribute to the success or failure of an HIE intervention, including organizational factors such as workflow, governance, etc., data issues such as quality, consistency, and timeliness, and communication considerations including privacy.

While HIE can provide data for use in these research initiatives, and can be one of the interventions to facilitate improved outcomes, the same research initiatives can provide methodology and shared study designs for the emerging HIE research agenda.

3.6   Conclusion

Health information exchange is still in its infancy in terms of its ability to support many positive healthcare outcomes. However, as HIE matures, many of these outcomes and innovations are being documented in the literature. While there remain a number of obstacles to the realization of a viable Nationwide Health Information Network (NwHIN), the early results of active HIE has led to improvements in healthcare quality, reduction in healthcare costs, and enhanced support for public health activities. Personalized healthcare and research using large patient databases are now being envisioned as the next frontier of healthcare and its pioneers are already meeting the challenges because of burgeoning HIE.[b]

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[b] As HIE becomes more common, its potential contribution to recent Big Data efforts is promising for analytic needs, as well as quality improvement. Advances in data exchange have increased the volume of data and clinical communications, generating increased physician acceptance and expectation for access to vital patient data when and where they need it across their entire community; and creating greater need for a technology that is able to sift through large amounts of data quickly, in real time, with the ability to communicate that data to the provider.

3.7   References

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Categorized Unintended Consequences, Relevant Issues, and Potential Solutions 4

4.1   Incomplete, Inaccurate or Untimely Data Provided by HIE

Healthcare providers will be eager to incorporate HIE into their workflows to improve clinical care. Having more complete data about the patient will allow the clinician to make diagnostic and therapeutic decisions about the patient's care that are more effective and efficient. However, if the data about the patient that are obtained via HIE are not complete, timely or accurate, based on well understood exchange parameters, decisions based on the data may be inappropriate.

Overview/Relevant Issues/Background

A clinician's expectation is that data obtained via HIE are complete, timely and accurate, based on exchange parameters. Examples of such exchange parameters include: the data that each provider organization is making available via the exchange capability, which providers are participating in an exchange framework, whether patient choice might limit the data that are available via the exchange capability, and the timeliness of the data that are available. If the accuracy, completeness or timeliness of the data that are returned differ from those expectations, then the HIE has essentially returned the "wrong data" about the patient. Having the "wrong data" may lead to inappropriate decision making which, in turn, may lead to ineffective and / or inefficient care and possibly untoward patient outcomes. For the purposes of this framework, the focus is on "wrong data" as an unintended consequence of HIE, even though there are downstream steps in the "chain of causation" that have more direct impacts on the patient's care.

We identified six broad categories of factors that may prevent the complete, timely and accurate transmission of data to a recipient (whether a provider, public health organization, or other) who has such expectations of the HIE capability:

- **Incorrect patient matching** – i.e., some or all of the data retrieved via HIE are from a patient other than the one that is being cared for by the clinician

- **Loss of integrity of the data during transmission** – i.e., the meaning of the data is somehow altered by the HIE process

- **Technical limitations** – i.e., a participant in health information exchange may not be able to provide a certain type of data (e.g., data from specific ancillary systems) consistently. Also, implementation details, such as the use of batch mode rather than real-time interfaces, may limit the timeliness of the data.

- **Intended limitations of data, including patient choice** – i.e., privacy laws and patient choice may dictate that certain data are not made available via health information exchange.

■ **Changes in the participants in a health information exchange** – i.e., at any given time, a clinician may have an incorrect understanding of the providers who are participating in the exchange so they may misinterpret the absence of data returned via HIE.

■ **Propagation of incorrect data** – i.e., a low quality data source – which, previously may have had impact only on its local environment (and may have had local users who are aware of its idiosyncrasies) – will now have "ripple" effects that could affect all users of the HIE.

Further information on these categories follows:

1. Problems with patient matching.

   Patient matching algorithms that are based on statistical matching of demographic data are a key component of query-based approaches to HIE. A basic characteristic of such algorithms is that they have "false positive" rates (i.e., making an incorrect match) and "false negative" rates (i.e., missing a correct match). Algorithms need to be "tuned" to have optimal performance characteristics, which depend on the use case. For example, in a clinical setting, a false positive, i.e., creating an incorrect patient linkage, would be highly undesirable; however in a public health scenario an occasional incorrect match may be acceptable. In general, tuning a patient algorithm to reduce false positives may increase the false negative rate, so there are tradeoffs to consider.

   Currently, a major hurdle to reliable and high quality patient matching is the quality and the consistency of the data coming from the source systems. There are no standards or best practices for creating "high quality" data for patient matching. Data quality varies across settings because of local idiosyncrasies.

2. Problems maintaining the integrity of data during transmission.

   There are two root causes of errors related to maintaining data integrity during transmission: (i) errors related to the structure of the data, for example, data fields that might be dropped or truncated due to mismatched expectations of structure between sending and receiving systems, and (ii) errors in data representation, for example, mismatched terminology expectations.

   Certification standards should mitigate these issues over time; however, because of the flexibility in the way that "standards" can reasonably be interpreted and because of the complexity of the data that are being transmitted, robust testing procedures would need to remain part of the landscape for the foreseeable future.

   Because of the emerging nature of HIE, provider organizations that are early adopters of evolving data representation methods need to be especially vigilant for errors related to data representation mismatches and these same organizations may need to make changes as more robust approaches to data representation are developed.

3. Unclear data-related expectations due to technical limitations, patient choice or uncertainty regarding HIE participants.

   Frequently, in a complex HIE environment, not all data classes will be made available from all participant organizations. This may be true in a query-based environment, in direct exchange environment or in a consumer-mediated exchange environment. For example, some departmental systems, e.g., pulmonary function testing or neurophysiology, from some participant organizations may not be interfaced to the HIE framework. A physician accessing data via the HIE capability may interpret the absence of data to mean that such tests had not been done when that may not be the case. Additionally, some HIE frameworks allow the patient to restrict the exchange of data among providers and so the absence of retrieved data may not mean that no data exist. Lastly, in a complex HIE framework (especially in query-based models) it may not be clear at any particular point in time which provider organizations are participating. If a physician mistakenly assumes that an organization is participating in a query-based exchange model, he or she may incorrectly interpret the absence of data to mean the patient had no testing at that site.

Potential Tools/Solutions

Because of the complexities involved, the goal for improving data accuracy and completeness should be "better," not perfect. User expectations are frequently set according to local conditions. Education about local idiosyncrasies is critical to the correct interpretation of data coming from HIE.

The quality of data in HIE is dependent on the quality of the data coming from the source systems. Fixing data quality issues at the participants organization is beyond the scope of most HIE initiatives. EHR vendors and providers must play an important role in data quality.

Examples of specific suggestions for risk mitigation approaches include:

To address patient matching challenges

The Privacy and Security Tiger Team of the Health IT Policy Committee continues to hold hearings and to develop policy recommendations on how to address challenges related to patient identification and matching. In addition, the Office of Science and Technology at ONC has been conducting concentrated work in this area. This work should be followed. The workgroup suggests that HIOs, as they develop and improve methods to ensure accurate patient identification, consider the following:

Design

- Best practices should be used of matching algorithms.
- Matching algorithms should be transparent.

- Implementation of matching algorithms should include a validation phase.

- There should be process to understand to what extent there may be idiosyncrasies in the data that may affect patient matching.

Implementation

- There should be a process to ensure that all participants adhere to appropriate data standards for matching (note: this may be amenable to a "check list").

Post-implementation

- Processes should ensure that

    – Site-specific changes to data feeds are accounted for in patient matching algorithms.

    – Sites consider the downstream impact on HIE when they are making changes to their data systems.

    – Evolving technical standards that affect patient matching or other aspects of HIE are folded in appropriately.

To address problems with maintaining the integrity of the data during transmission (structure and semantics)

Implementation

- Processes for data validity checking (checklist)
- Patient matching data sets

To address issues related to lack of data

(Note: this includes situations related to state and Federal regulations as well as patient choice.)

Implementation and post-implementation

- Educational tools for providers to:

    – Adequately describe exchange parameters in order to set appropriate expectations

    – Describe local state of completeness

    – Discuss implications of working with the set of patient data that is available via HIE.

A potential future solution to ensuring accurate patient matching would be an electronic utility that would enable EHRs to transmit a minimum data set of patient-specific demographic elements within health information exchange. This requires standardized data element

identification and the creation of the utility to work within EHR architectures. This would require a targeted research initiative.

4.2 Problems Related to Data Presentation, Including Data Overload

For HIE to assist in clinical care, the presentation of the HIE data must fit well into the clinician's work flow and the amount of data, which may dwarf the amount of data in the clinician's EHR, must be presented in a form that is comprehensible to the clinicians. These seemingly straightforward requirements, if not addressed well, can create unintended consequences.

Overview/Relevant Issues/Background

With respect to the presentation of data retrieved via HIE, there are two distinct issues: (i) the sheer volume of the data that HIE may make available; and (ii) the design of the systems intended to bring HIE data to the clinician. With respect to the latter, this is an area of rapid evolution. Factors that today are considered limitations may in the near term be addressed by advances in technology such as EHR enhancements.

HIE places an additional burden on EHRs and, with few exceptions EHRs are not currently designed to manage data coming in from an HIE. There are multiple approaches to incorporating HIE data into an EHR. The approach may depend on the form of exchange (i.e., query-based, directed, or consumer mediated) as well as the level of integration desired (for example, viewing the HIE data in a separate frame, incorporating HIE data as an EHR document, incorporating HIE data as structured and coded computable data elements, etc.).

As EHRs evolve to include HIE data, user-centered design principles should be adopted to ensure that data are appropriately formatted and summarized to assure that data coming from an HIE can be comprehended by the clinician for decision making. In general, there is a need for research to understand how to better present large amounts of data to clinicians in a way that can be cognitively processed. Several groups, including the ONC-funded SHARP-C project and the Mass eHealth Collaborative are already working on this.

Beyond simply retrieving data, it still is unclear how EHRs and data obtained via HIE will be used together to support care coordination. Specifically, the workflows that make use of HIE to support care coordination still are unclear.

Potential Tools/Solutions

Design

- Designers of HIE-enabled EHRs should employ user-centered design, ensuring that data from HIEs appearing in EHRs:

    – Take into account user needs;

    – Summarize patient's state or highlight "important" data in data review screens

- Processes should be developed to disseminate successful examples of systems that take user preferences into account and incorporate principles of user centered engineering.

Implementation

- Providers should receive adequate training on how to use the relevant applications

Post-implementation

- Ongoing training will be needed to assure that providers are kept up to date as the health information exchange capability increases, both in terms of the number of providers that are participating in exchange as well as the types of data that are available via health information exchange.

Research is also needed on how best to summarize data and present data from HIE along with data in the clinician's EHR.

4.3   Heterogeneity of Use of HIE Capability

Effective and efficient use of health information exchange is an essential part of meaningful use of health IT. Lack of use or less than optimal use of HIE is both an unintended consequence of poor implementation and a root cause of other unintended consequences of HIE. This is a challenge that must be recognized and addressed as part of planning and during implementation.

Overview/Relevant Issues/Background

Variation in the decision to use HIE may exist, resulting in poor implementation of HIE (i.e., lack of development of workflows depending on consistent use of HIE, etc.), which then results in the benefits of HIE not being realized. Variation in use of HIE may also be the result of poor implementation by an HIO. Levels of commitment and use vary at individual and/or organizational levels. Unfortunately, the value proposition that can sustain an HIO is usually predicated on the reliable use of the HIO and without such use, the perception of cost/benefit ratio may be unfavorable. A "negative cycle" would lessen the value of HIE. The negative cycle

occurs when lack of use by members of an HIO results in lack of adequate data for other members to use, causing them to drop out.

There are a number of reasons for heterogeneous use, including:

- Workflow and provider preferences not being considered in design / implementation of the HIE capability;
- Users not having confidence in the data;
- Data not being reliable;
- Lack of financial drivers or an acceptable value proposition; and
- Lack of an adequate workforce to support the users.

Mitigation factors include but are not limited to:

- Determination of the value proposition as part of design;
- Appropriate usability and usefulness based on a defined value proposition;
- Design based on current workflow within each of the member organizations; and
- Payment reform, which promises to have the greatest impact on this issue.

Potential Tools/Solutions

Understanding that the decision to adopt HIE rests at the individual (organization or provider) level and mitigation must target this, the following are examples of tools and/or solutions that would address the heterogeneity of use of HIE.

Design

- Best practices for successful business models to create a value proposition
- Best practices for incentives to encourage use of HIE, including health plan support
- White papers describing the benefits of HIE use and its concomitant value propositions
- Checklist for data consistency to minimize confusion

Implementation

- Checklist for principles of good implementation
- Checklist for principles of usability and functionality
- White papers describing ways to train providers about how HIE capabilities align with local care improvement programs
- Educational tools describing or assisting with appropriate training and support

Post-implementation/Operation

■ Checklist for monitoring the use of HIE capabilities

ONC's Regional Extension Centers are developing tools to assist with some of these issues. Extant tools need to be identified and work in progress needs to be explored, particularly at the local level and regional levels. Good solutions need to be leveraged to ensure optimum mitigation of heterogeneity of use nationally. Beyond the development of tools and solutions, new research is needed on why health information exchange is not being implemented or not being used effectively.

4.4 Patient Perceptions or Concerns of HIE

Health information exchange promises to provide substantial benefits for patients. One of the three primary forms of HIE is consumer-mediated exchange, taking a major step towards encouraging better communication between the provider and the patient. Other positive results of HIE for patients are the improvement in care coordination, especially for those with chronic illness, and the ability of patients to readily move from one facility to another without loss of personal health information. With the aging population, this positive HIE consequence will be particularly profound.

The benefits of HIE are often founded on the availability of more complete clinical information on patients, which enables not just improved care, but also other benefits, such as cost reductions associated with fewer duplicate tests, better population health data, and better research databases. However, patients may not receive all the benefits of HIE or may even face a reduction in the quality of care due to lack of patient trust in HIE. This lack of trust may result in patients choosing not to participate in HIE or limiting the sharing of information. This can be because of concerns for how information may be used under the conditions offered, the bias such information may have on a provider's clinical decisions about a patient, or unfounded negative perceptions of HIE. With respect to mitigating misunderstandings, ONC has encouraged HIOs to adopt fair information practice principles, including policies and procedures that enable patients to exercise "meaningful choice" over how their information is used in HIE. When patients do not perceive HIE as advantageous, serious UCs may arise, including patients' refusal to participate in their own health care or ineffective treatment because of reticence to share information. More work needs to be done to consider the UCs that result from a clear understanding of the policies and choices to opt out of HIE. While the UCs and the patient perceptions can happen with electronic health records in general, the concerns are magnified with HIE. Understanding these issues and addressing them from a patient's perspective is essential to improved patient care.

Overview/Relevant Issues/Background

There are a number of reasons for patient concerns and perceptions of HIE that may undermine trust and use, including:

- Concerns about inaccurate data that the patient is unable to correct;
- Concerns about inappropriate monitoring, or misuse by multiple providers who have access to all of their data;
- Concerns that providers will be biased by prior opinions and conditions and will not exercise independent judgment in diagnosis and treatment.

Mitigation factors include but are not limited to:

- Transparent HIE policies and practices that adhere to fair information practice principles and ensure "meaningful consent," including organizational Notices of Privacy Practices that address HIE;
- Patient involvement in the HIE implementation process;
- Processes that facilitate correction of patient records;
- Tools that help providers explain to patients the value of HIE and the reason for adoption;
- Affirmation about who does and does not have access to the patient's records;
- Public services announcements about HIE activities and their importance in health care delivery.
- More granular control by patients to limit HIE for individual circumstances.

Potential Tools/Solutions

Tools and solutions to mitigate negative patient perceptions of HIE fall into two categories, those targeting patients and those targeting providers. Solutions need to focus on developing a trusted structure for HIE as well as enabling parameters for sharing to support patients' needs and improved clinical care.

Design

- Best practices to identify and include appropriate patients as thought leaders on design group
- Balanced educational tools that convey the need for, and benefits of and potential risks of HIE to patients

- Consideration of applications that make HIE more supportive of patient/consumer needs for shared decision making and personal health care management, including use of PHRs.

Implementation

- Checklist to ensure transparency of policies, particularly as they affect patient data and patient perceptions of the use of their data

- Materials for providers to use when discussing HIE with patients with special emphasis on how it can help with chronic disease and continuity of care. Healthit.gov is a good resource for providers.

- Public awareness tools to emphasize the benefits and importance of HIE in health care reform. Healthit.gov offers access to an increasing number of such tools.

- Best practices on electronic methods for patients to request corrections in their records, including those exchanged via HIE

Post-Implementation/Operation

- Best practices and model feedback instruments to gather information from patients about issues, benefits, and opportunities of HIE

Patients are part of the health care community and while HIE is often focused on providers to ensure effective decision-making, quality health care outcomes cannot be achieved without the patient trust and engagement. For this reason, effective tools and solutions must be created and adopted to garner patient buy-in in the HIE capability and ideally, in patient engagement in HIE.

There is a lot of activity around e-health initiatives and some of this work may be leveraged through collaboration to create utilities that demonstrate the effectiveness of pertinent patient information on demand by health care providers. However, there is also an opportunity for a research initiative to look specifically at the perceptions of patients around health information exchange and how these might differ from their views about electronic health records.

4.5 Reputational and Financial Risks to Entities Engaged in HIE

Reputational and financial risks are major causes of reticence on the part of health care organizations about joining or fully participating in HIE. Without appropriate consideration of the potential risks and their root causes, the unintended consequences could result in unwillingness to join or to continue participation, significantly undermining the benefits of HIE.

Overview/Relevant Issues/Background

Reputational and financial risks exist for both patients and providers. Frequently, the patient and provider risks are symbiotic. For instance, an unauthorized disclosure of health information related to participation in HIE could result in a HIPAA violation and not only cause distress and harm to the patient (e.g., identify theft and unauthorized embarrassing disclosures) but also result in financial risks related to the breach and breach notification for the HIO and its member health care provider organizations. While other forms of sharing information, such as fax and mail, hold some of the same potential for risk, the magnitude of the risk is far greater with HIE when the information is being aggregated electronically or exchanged among disparate systems. Because this paper focuses on UCs that have direct or indirect clinical impact and UCs that have organizational impact, patient reputational or financial harm is not addressed in this section.

There are a number of examples of risks to providers that are unique to HIE, including:

- Senior executives hesitating to participate in HIE for reputational and financial reasons may include a perception of potential loss of income related to patient mobility resulting from enhanced access to data;

- Potential for unauthorized use of data obtained via HIE (e.g., competitive analysis, marketing, etc.);

- Potential for misuse of patient data not sufficiently protected by the HIE technology or understanding of the ramification of use;

- Potential for new types of professional liability and increased malpractice insurance premiums because of risk of untimely, inaccurate or incomplete data.

Potential Tools/Solutions

When considering potential risks and how to mitigate them, contracts and other forms of legal protections are primary. However, training and protocols can provide a foundation to prevent unintended consequences by addressing the root causes grounded in inadequate integration of HIE into operational policies and training programs of health care organizations, perceptions and technology malfunctions.

Design

- Model decision-making structure or policies and procedures that minimize reputational and financial risks to participants and that promote trust among all stakeholders affected by HIE;

- Model agreements on how to describe or market HIE among participants and any HIO, including consumer input, that addresses any reputational concerns;

- Risk management assessment tool to identify and address potential new sources of risk associated with participation in HIE, including risks related to safety, privacy and security, business continuity, or liability claims;

- Best practices around technology, including robust testing, as they relate to privacy and security protections;

- Checklist for best procedures in handling data, including encryption, use, and destruction;

- Model contract language for both participants in HIE and HIOs related to financial and reputational risks, including indemnification and disclaimer language, and language that addresses the right to reserve certain uses of data for research and quality improvement; Sample data use agreements;

- Model policies based on HIPAA, and where appropriate, the Fair Information Practice Principles that ensure that organizational policies are clear and align the interests of patients and of entities involved in HIE.

Implementation

- Educational models such as Web-based tutorials for providers training regarding appropriate and safe use of data obtained via HIE, including privacy, security,

- Checklist for required compliance training to ensure that all participants and HIO personnel understand how to comply with policies and procedures that reduce reputational and financial risks

Post implementation/Operation

- Best practices for privacy and security protocol revisions based on changes in federal or state law or rules

- Best practices for monitoring technology and data issues as technology changes

- Best practices for monitoring risks associated with compliance with policies and procedures, safety, and potential liability claims on an ongoing basis

- Checklist for monitoring of unauthorized use or disclosure of HIE data

- Standardized best practices or policies and procedures on sanctions or other actions to address breaches by participants in HIE that may create reputational or financial risks

Many of the required solutions to the unintended consequences related to reputational and financial risks can be built upon solutions and tools designed to address similar risks encountered in the design, implementation, and operation of electronic health records. Certain groups, such as the American Health Lawyers Association are actively engaged in investigating the legal issues and designing products to mitigate them. Other groups such as HIMSS are looking at technology and data management solutions.

As in other UC categories, the potential exists for targeted research in a number of areas. For instance, it would be useful to have a greater understanding of reputational or financial concerns,

including those related to loss of business or to liability or risk management, that may make some provider organizations hesitant to engage in robust HIE. It would also be useful to conduct research on innovative models for developing customized business value propositions related to HIE.

4.6   Vulnerability to Technically Related Unintended Consequences

Like other automated clinical information systems, HIE relies on technology. Technology that does not function well can disrupt clinical workflow, undermine providers' confidence in HIE (and thus hinder adoption) and, at worst, lead to an incorrect understanding of the patient's clinical state and untoward patient outcomes. HIE will have a significant impact on health care only if it becomes a routine part of clinical workflow, and providers will come to rely on the HIE capability only if they are confident the technology is sound.

Overview/Relevant Issues/Background

The majority of the technologies that underlie HIE are well proven; however, they are often being applied in novel ways under novel organizational relationships to achieve HIE capabilities. The complexity of HIE architectures introduces multiple potential points of failure. New management processes are needed to assure that the HIE technology will be robust. For example, upgrades to an HIE platform may require coordination across multiple participant organizations.

Also, organizations that provide HIE services need to have robust disaster preparedness plans. Currently, there are no best practices for HIE-related disaster preparedness and recovery planning. In addition, a provider organization that participates in HIE needs to incorporate support for the HIE capability into its own disaster preparedness and recovery planning. Notably, participation in an HIE can be part of a provider organization's disaster preparedness and recovery planning.

Potential Tools/Solutions

All of the following may be amenable to a "checklist" approach:

Design

- The initial design of the HIE plan should include disaster preparedness and recovery planning.

- Any contract between an HIE participant and an HIO should make sure that the participant is obligated to have a disaster preparedness and recovery plan for the HIE capability.

- One resource may be an emergency preparedness and recovery checklist that is available from the Health Lawyers Association Quality and Action web site (http://www.healthlawyers.org/members/practicegroups/thamc/emergencyPreparednessToolkit/Pages/default.aspx)

- The Contingency Planning Guide for Federal Systems (http://csrc.nist.gov/publications/nistpubs/800-34-rev1/sp800-34-rev1_errata-Nov11-2010.pdf) also provides helpful information related to recovery after a disruption.

Implementation and Post-Implementation/Operation

- Disaster preparedness and recovery plans by HIOs and participants should be updated on a regular basis.

- Upgrades to HIE technologies should take into account the potential need to synchronize across multiple participants.

- Planning should take into account the fact that the number of participants as well as the kinds and amount of data that will flow over the network will increase over time.

Research is also needed to understand ways to mitigate technology-related failures.

4.7 Unintended Consequences of Administration of HIE

There are many administrative and operational aspects to health information exchange. This is true whether the exchange is directed, query-based or consumer-mediated. Examples of administrative aspects of health information exchange include: (i) the need for governance activities that determine and enforce policies and other business aspects of the exchange, (ii) the need for privacy policies, including data use agreements, consent policies, privacy compliance monitoring and approaches to sanctions for breach, (iii) the need to maintain current with regulatory requirements for health information exchange, for example, certification criteria and privacy regulations, and (iv) the need to have access controls, auditing capabilities and authorization models for use of the exchange capabilities.

When looking at the unintended consequences of the administration of HIE and their root causes, it is important to recognize that administration refers not only to the administration of the actual exchange or of the HIO but also to the administrative requirements related to the HIE that are essential to each member organization. The latter are generally governed by regulatory, licensing, accreditation and consent requirements as authorized and promulgated through state laws, federal standard, accrediting organizations, reporting, compliance, and consent requirements, and authorization limitations. However, best practices regarding quality and safety frequently provide benchmarks against which standards are established and workforce issues handled appropriately can mitigate many of the administratively related UCs.

Overview/Relevant Issues/Background

There is a tendency to focus on administrative challenges faced by HIOs, which are important, but do not reach all of the unintended consequences of HIE and their root causes as they relate to administration. In addition, it is useful to distinguish between excessive administrative burdens and UCs that arise from normal or suboptimal HIE or suboptimal operation of an HIO.

Among the major root causes of UCs related to the administration of HIE are the following:

- A workforce that does not fully understand the administrative challenges related to successful HIE;

- An administration that does not look for commonalities in optimum workflow and HIE implementation;

- Technical capabilities or organizational policy mandates lagging behind regulatory requirements, for instance, most HIEs are not currently able to support the somewhat granular regulatory requirements of regulations governing information related to behavioral health and other types of health treatment;

- Lack of a technical workforce that can address necessary technical requirements within organizations as they relate to HIE.

Potential Tools/Solutions

Administrative solutions must address not only the regulatory requirements but also the human resources required to implement them. This must cross both organizations that facilitate HIE as well as the member organization and be vested within the administrations and governing bodies involved in HIE, ensuring that an HIE requirement does not prove so onerous that member institutions are unable to comply and chose instead to withdraw or not engage.

Design

- Checklist to ensure that regulatory requirements affecting the HIE are integrated into design of HIE

- Checklist on minimal standards for data curation

- Sample job descriptions to ensure hiring of necessary workforce to manage process

- Checklist to integrate workflow in design

Implementation

- Checklist for a robust audit program to ensure compliance

- Educational models for providing training for new hires across the HIE continuum and retraining as technology and processes change

Post-implementation/Operation

- Best practices for monitoring new requirements, implementation of those requirements, and appropriate training to ensure meaningful use

- Proactive approach (white papers, etc.) with partner groups to consider regulations potentially applicable to HIE and the best practices to integrate them into the process

There are two major areas of solutions that cover most of the UCs and root causes within the administration categories. These include the management for regulatory issues and the needs of an effective workforce. For the former, there is a great deal of overlap with the issues raised in the Reputational and Financial Risk category, and many of the same groups are looking at these concerns.

For issues related to workforce, there are a number of ONC workforce training initiatives, particularly in the RECs, as well as the development of competencies essential to effective management and use HIE. Collaboration with these groups, including review of extant curricula and competencies, could offer robust solutions to workforce issues.

Another area of exploration is the use of the Joint Commission or other accrediting or certifying bodies to leverage the adoption of standards to ensure optimum implementation and use of HIE.

Next Steps 5

Following the creation of a framework to understand the Unintended Consequences of Health Information Exchange, their identification and classification, and the potential solutions that might mitigate them, it is important to ensure that these are subsequently validated and refined prior to being disseminated and eventually advanced. These steps will require two phases as follows.

Phase 1 – Education and Validation/Refinement of the Framework

The results of this work need to be presented to key stakeholders. There are three aims for this phase:

- To educate targeted key stakeholders about the core issues of HIE UCs

- To validate the framework of the UC categories, root causes, and potential solutions within the HIE process continuum

- To solicit feedback about UCs experienced in practice and solutions and to understand the types of solutions that have the best chance of mitigating the specific UCs

Potential Key Stakeholders include: 1] provider organizations, 2] vendors, 3] legacy RHIOs, 4] State Health Information Exchange Awardees, 5] Regional Extension Centers, 6] Health Lawyers Association, 7] CHIME, 8] AMIA, 9] Beacon Communities, 10] IE Subcommittee of HIT Policy Committee, 11] Agency for Healthcare Research and Quality, 12] National Library of Medicine, 13] Office of the National Coordinator for Health IT, 14] HIE accrediting bodies, 15] HITRC, 16] large insurance providers (PIAA), 17] HIE governing bodies, 18] patient organizations, 19] AHIMA, etc.

Supporting Materials as part of the process include briefing papers developed around the seven categories of UCs and power point presentations that have been created as a result of the HIE UC project.

Education and Validation Methods include (in preferential order):

- Face to face presentations at key stakeholder meetings
- Teleconferences
- E-mail and other forms of dissemination and solicitation

Deliverables for Phase one include:

- A Refined Framework that includes new UCs and solutions as well as a grouping of the types of solutions determined to have the greatest efficacy in real world practice
- Summaries of all of the findings of the process

It is anticipated that Phase One will require two to three months to complete.

Phase 2 – Solutions Development

Once the Refined Framework, including new UCs and solutions, has been developed, the identification of extant solutions, the process for creating new solutions, and the dissemination of these solutions will help ensure that unintended consequences of health information exchange are prevented if possible and mitigated if not. There are three aims for this phase:

- Building on Phase 1, to identify existing tools and solutions that already exist. Potential sources include the healthit.hhs.gov and healthit.ahrq.gov websites as well as the Office of the National Coordinator initiatives such as the Regional Extension Centers.
- To identify key stakeholders who are best positioned to lead solution creation processes. These stakeholders may include some of those in the key stakeholders listed in Phase 1 but would also include Federal Agencies, Foundations, Not-for-profit groups, etc.
- To create a multi-component process for the most effective means to disseminate both knowledge about and the actual tools and solutions necessary to ensure that HIE implementation achieves its maximum objectives.

Once efficient and effective solutions to health information exchange unintended consequences have been conceptualized, the identification of extant tools and solutions is needed to ensure that these can be readily promoted and appropriate effort given to the development of solutions that do not yet exist. As an essential part of the process, a means to both promote and disseminate the solutions is the final step to ensuring that HIE plays a strong and effective role in meaningful use.

Appendix 1

HIE Workgroup Members

Appendix 1
HIE Workgroup Members

Julie J. McGowan, Ph.D., FACMI, FMLA ,Co-Chair is an emeritus professor and past chair of the Department of Knowledge Informatics and Translation and an emeritus professor in the Department of Pediatrics at the IU School of Medicine. She was a founding faculty member of the IU School of Informatics, held adjunct professorships in several other schools and was a research scientist at the Regenstrief Institute. She has been involved with public health informatics since the mid 1990's when she developed a public health information alerting system for emerging infectious diseases in Vermont. More recently, she led the evaluation of Indiana's Situational Awareness and Syndromic Surveillance contract and Indiana's Center of Excellence in Public Health Informatics funded through the CDC. She also had responsibility for the Evaluation Program for the Indiana Clinical and Translational Sciences Institute, and the evaluation of the Indiana Health Information Exchange's Medicaid Transformation contract under CMS. She continues to lead the evaluation of the Indiana Beacon Community grant.

Gilad J. Kuperman, MD, PhD, FACMI, Co-Chair, has 20 years of experience in medical informatics. His career has included the design, development, implementation and evaluation of clinical information systems. His main areas of focus has been the use of computer order entry to measure and improve the quality and safety of health care, the use of clinical decision support to improve quality, and the implementation of health information exchange among disparate organizations. Currently he is the Director for Interoperability Informatics at New York-Presbyterian Hospital in New York City. In this role, he helps the hospital address various aspects of its interoperability program, including internal interoperability (i.e., assuring smooth interaction of the multiple systems within the Hospital), interoperability with key business partners (for example, with associated physician organizations) and regional / community interoperability. Dr. Kuperman is also the Chairman of the Board of NYCLIX, Inc., the New York Clinical Information Exchange. The mission of NYCLIX is to improve care in the NYC region through the development of a regional data exchange capability. Dr. Kuperman is an author on over 60 articles related to health information technology. He is a faculty member in the Department of Biomedical Informatics at Columbia University. Also, Dr. Kuperman is Chair of the AMIA Board of Directors for 2012 and 2013 and served as the Scientific Program Committee Chair for the AMIA's 2010 Annual Symposium.

Holt Anderson is Executive Director of the North Carolina Healthcare Information & Communications Alliance, Inc. (NCHICA), a private, nonprofit consortium of healthcare providers, payers, corporate partners, professional associations and government agencies formed in 1994 with the mission of assisting NCHICA members in accelerating the transformation of the US healthcare system through the effective use of information technology, informatics, and analytics. Holt has served or is serving on various councils, committees and governing bodies including: The State of NC lead for the Nationwide Health Information Network (NHIN) Phase 1 "Architecture Prototypes" and Phase 2 "Trial Implementations" and current Emergence Implementation funded by contracts with the HHS Office of the National Coordinator for Health Information Technology (ONC); Vice Chair of the NHIN Coordinating Committee; past Co-

chair of the Data Use & Reciprocal Support Agreement (DURSA) Workgroup; Board of Directors and Vice Chair of the National eHealth Collaborative (NeHC); Advisory Committee for Region D HITECH-funded Community College Consortia for Training HIT Workforce; State Project Executive and member of RTI Technical Advisory Panel for HISPC "Privacy and Security Solutions for Interoperable Health Information Exchange" for the RTI International contract with ONC; Provider Education, Inter-organizational Agreements, and Consent Policy Options Collaboratives; Interim State HIT Coordinator. Mr. Anderson previously has served on the Steering Committee for the NC Immunization Registry and was a Governor's appointee to the Southern Technology Council and the Southern Governors' Association Task Force on Medical Technology. He served on the Social & Ethical Issues Task Force for North Carolina Vision 2030 and a North Carolina General Assembly Legislative Study Commission for Digitization of the State Archives.

Elisabeth Belmont, Esq. serves as Corporate Counsel for MaineHealth, a family of healthcare services located in southern, central and western Maine that includes Maine Medical Center, Miles Health Care, Spring Harbor Hospital, St. Andrews Hospital and Healthcare Center, Western Maine Health Care, Waldo County Hospital, NorDx Laboratories, Community Health Services, Practice Partners, Intellicare, SYNERNET, Sisters of Charity Health System, and other affiliated organizations, and has held this position since 1998. Ms. Belmont was named by NEW ENGLAND IN-HOUSE/MASSACHUSETTS LAWYERS WEEKLY as one of the 2008 Top 15 In-House Leaders in the Law; by MODERN HEALTHCARE as one of the 2007 Top 25 Most Powerful Women in Healthcare; and by HEALTH LAW 360, the Newswire on Health Law and Policy, as one of the 2007 Outstanding Women in Healthcare. Ms. Belmont is a member of the American Health Lawyers Association ("Health Lawyers") and has held a number of leadership positions in this Association including President/Chair of the Board of Directors of Health Lawyers for the period 2007-2008. Ms. Belmont currently serves as a member of Health Lawyers' InHouse Counsel Program Planning Committee. Additionally, Ms. Belmont is a member of the Editorial Board of the Health Law Reporter published by The Bureau of National Affairs, Inc. Ms. Belmont recently served as a member of the State of Maine Governor's Task Force to review Maine's privacy and security laws as they pertain to health information technology and exchange. Ms. Belmont is a nationally recognized expert in health informatics law and her specialty practice addresses a broad spectrum of issues arising from the use of information and communications technology in the healthcare industry.

Shaun Grannis, MD, MS, FAAFP is a recognized national leader in data integration technology tailored to health information exchange. Dr. Grannis serves as technical co-chair for the national Health Information Technology Standards Panel's bio-surveillance workgroup to develop standards for population health information exchange. Dr. Grannis is an HIE Consultant for s2a (www.s2aconsulting.com) and is one of two physicians who lead the clinical informatics portion of s2a's engagements. Over the past year he has served as a strategist and facilitator for the clinical aspects of a health information exchange (HIE) planning initiative for the HIE of Northern Michigan (HIENM). He has offered substantial state-level strategic advice on health information exchange roadmaps, working closely with the e-Health Initiative from 2005-2007. He has provided clinical and technical guidance to initiatives in California, New Mexico, Arkansas, Oklahoma, Louisiana, Texas, Mississippi, New Hampshire, and Michigan. Under his technical and strategic leadership, the State of Indiana has deployed a comprehensive population

health data exchange integrating real-time information from over 75 hospitals. His ongoing work on the Indiana Network for Patient Care, one of the nation's first and most advanced health information exchanges, has differentiated him as a prominent innovator and consultant on issues of HIE development and value proposition strategic planning. Dr. Grannis is a Research Scientist at the Regenstrief Institute, Inc. as well as Assistant Professor of Family Medicine at the Indiana University School of Medicine. Dr. Grannis's research interests include developing, implementing and studying technology to overcome the challenges of integrating data from distributed systems for use in health care delivery and research. His patient matching research has received recognition from the American Medical Informatics Association for outstanding contribution to the body of medical informatics knowledge. He is involved in multi-year studies that explore multiple facets of disease detection and public health surveillance challenges, including geographical de-identification, understanding temporal-spatial disease trends, and developing regional clinical reminders. He is leading a 4-year project integrating data flows from over 110 hospitals in the state of Indiana for use in disease surveillance and clinical research. He has worked with Indiana, Michigan, Texas, and other states to develop statewide data sharing initiatives.

Micky Tripathi, PhD, MPP, is the President and CEO of the Massachusetts eHealth Collaborative. The Massachusetts eHealth Collaborative (MAeHC) is a non-profit collaboration of 34 leading Massachusetts organizations. He is also a member of the Board of Directors of MA-SHARE, a community utility service for state-wide clinical data exchange in Massachusetts. Dr. Tripathi is also the co-chair of the Health Information Exchange Workgroup, one of three subgroups of the Health Information Technology (HIT) Policy Committee, which is charged with making recommendations about health information exchange to the Office of the National Coordinator for Health Information Technology in the U.S. Department of Health and Human Services. Dr. Tripathi has served as the founding President and CEO of the Indiana Health Information Exchange, an Indianapolis-based non-profit company partnered with the Regenstrief Institute to create a state-wide health information infrastructure in the state of Indiana. Prior to joining MAeHC, Dr. Tripathi was a manager in the Boston office of the Boston Consulting Group, a leading strategy and management consulting firm. As a manager in BCG's health care practice, Dr. Tripathi also served a variety of US and international clients in the non-profit sector as well as in the bioinformatics, biotechnology, and pharmaceutical industries. He holds a Ph.D. in political science from the Massachusetts Institute of Technology, a Master of Public Policy from Harvard University, and an AB in political science from Vassar College. Prior to receiving his Ph.D., he was a senior operations research analyst in the Office of the Secretary of Defense in Washington, DC, for which he received the Secretary of Defense Distinguished Civilian Service Award.

Kim M. Unertl, PhD, MSci, is an Assistant Professor of Biomedical Informatics at Vanderbilt University School of Medicine. Dr. Unertl received her B.S. in Biomedical Engineering from Marquette University in Milwaukee, WI and MSci and PhD in Biomedical Informatics from Vanderbilt University. Dr. Unertl's master's project, working with Dr. Matthew Weinger, focused on workflow and information flow in chronic disease care. Her doctoral research, under the supervision of Dr. Nancy Lorenzi, examined health information exchange technology adoption patterns, usage strategies, and information ecologies with the MidSouth eHealth Alliance in Memphis, TN. Dr. Unertl is interested in the interaction between clinical workflow

and health information technology. Her primary research interest is improving the fit between technology and work practices through the development of health information technology design and implementation strategies.

Other Participants:

Westat Project Team

- **Lois Olinger**, MA, Project Manager, Senior Study Director

- **Eric Pan**, MD, MSc, Physician Informaticist

- **Cynthia Russell**, MSN, RN, Nurse Informatics Specialist

- **Larry Stepnick,** MBA, Vice President and Treasurer, The Severyn Group, Inc.

- **Deborah Neveleff**, MBA, Consultant, The Severyn Group, Inc.

ONC Representatives

- **Kathy Kenyon**, JD, MA, Policy Analyst, Office of Policy and Planning (project officer)

- **Kristina Celentano**, MPP, State Health Information Exchange Cooperative Agreement Program

- **Christopher Muir**, MPA, Senior Program Analyst and State HIE Program Manager

Guest

- **P. Jonathan White**, MD, Director of Health IT, AHRQ

- **William B. Munier**, MD, Director of the Center for Quality Improvement and Patient Safety, AHRQ

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Appendix 2

Framework

UNINTENDED CONSEQUENCES OF HEALTH INFORMATION EXCHANGE

Background and Framing Concepts

A workgroup was officially formed on 27 September 2011 as part of an ONC initiative, with Gil Kuperman and Julie J. McGowan appointed as co-chairs. The **Charge** was to identify useful tools and products that will decrease unintended consequences (UCs) and increase the safety of health information exchange (HIE). The **Context** of the problem was the need to achieve meaningful use (MU) of electronic health records within health care reform, patient centered medical homes, and accountable health care organizations, and the need to facilitate and support transitions of care.

Framing Concepts

1. Two distinct classes of UCs with equal importance
    a. Potential negative UCs from successful implementation of HIE, for example:
        i. Data overload
        ii. Misinterpretation of data by physicians and other practitioners because they aren't clear on what data are/aren't in the system (i.e., false assumptions about completeness of data)
    b. Potential UCs that result from suboptimal implementations of the complex prerequisites to HIE, for example:
        i. Complexity in patient matching leading to mismatches
        ii. Complexity in implementing security correctly
        iii. Protracted time frames and complex organizational relationships in these projects, which lead to shifting and suboptimal implementations
        iv. Increased risk of medical malpractice claims resulting from the provision of inaccurate, incomplete or untimely data submissions
        v. Increased liability insurance premiums resulting from new types of risk exposure and the need for additional policy riders

2. Consideration of frameworks and concepts for the identification of UCs and root causes
    a. Potential organizational constructs:
        i. A broad framework that might be used to understand one or both categories: (i) technical/ interoperability/ software factors, (ii) organizational / human factors, and (iii) legal / privacy and security/antitrust
        ii. Joan Ash's framework for UCs with EHRs

       iii. Dean Sittig's 8 dimensions for evaluation of concerns associated with EHRs and considered that these may have applicability to HIE

  b. HIE is a capability (whereas EHRs are "applications"); Examples of HIE-enabled applications include:

      i. Two or more "tight" business partners exchanging data to support joint business goals, e.g., a hospital and its medical staff

      ii. "Loose" business partners exchanging data in support of a business goal (e.g. a referral network among unaffiliated PCPs and specialists)

      iii. A "RHIO" model

      iv. Reporting of data to a quality or a public health agency

      v. Clinical improvement registries and other databases for use by institutional providers and individual practitioners

      Each of these requires HIE, yet the application may be different.

The overarching goals of this project are to identify and prioritize unintended consequences of HIE and to identify and prioritize tools and products that might mitigate these UCs. The matrix below will be used to structure the outcomes. When considering the UCs and their root causes, the various frameworks and concepts noted above may provide a starting point.

Ease of Build	Most Severe Consequences	Less Severe Consequences
Tools Easiest to Build	**X**	
Tools Difficult to Build		

To begin the discussion, the expert panel will consider the following questions:

1.   Do you have comments/recommendations for additional frameworks or concepts that might be considered to assist in identifying UCs and their root causes?

2.   Do you have suggestions for other UCs / root causes that have not been identified by the literature review (second document)?

3.   Do you have comments/suggestions for the face to face meeting?

15 October 2011 (with subsequent minor revisions)

Appendix 3

Health Information Exchange:
Annotated Bibliography (1/2007 – 3/2012)

Appendix 3
Health Information Exchange: Annotated Bibliography (1/2007 – 3/2012)

1.0   Introduction: Limited Literature Search

We conducted a limited literature review on topics of healthcare information exchange (HIE) and unintended consequences published in English between January 2007 and March 2012. Using online databases PubMed and Google Everything, we identified appropriate articles, blogs, discussion boards, conference proceedings and presentations regarding HIE and unintended consequences using Boolean operators to combine the following search terms.

1.1   Search Method/Terms

PubMed:

("health information network*" OR "health information organization*" OR "health information exchange*" OR nhin OR rhio) AND (uninten* OR unanticipate* OR error* OR erroneous OR failure* OR adverse* OR accident* OR hazard*)

Google Everything:[c]

The key word(s) used in the search box was one term from each of the lists below.

List A	List B
"Indiana health information exchange"	unintended consequences
"Maine's Health Information Exchange"	patient safety
"New York HIE"	adverse event
"HIE blog"	Hazards
"healthinfonet maine"	
"healthlinc"	
"NYCLIX"	
"NY HEAL"	
"New Mexico Health information exchange"	
"HealthBridge Health information exchange"	
"CareSpark"	
"UHIN"[d]	
"DHIN"[e]	
"CurrentCare"[f]	

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[c]   Google Everything refers to a broad search of webpages, blogs, images, videos and discussion boards.

[d]   Utah Health Information Network.

[e]   Delaware Health Information Network.

[f]   An outgrowth of the Rhode Island HIE and now supported by the Rhode Island Quality Institute.

Results

We found 44 references (see reference list) to review and the unintended consequence topic(s) and challenges are identified and outlined below (and see Table 2):

1.2   Unintended Consequence Topics identified:

1. Lack of use/adoption and integration into clinical workflow [39] [27] [35 [29] [17] [19] related to inadequate consideration of workflow and low usage if new to the system or increased time constraints to access the system. [39]
    a. **Root cause**: Failure to address issues of system accessibility increases time to use the system.; a second level of authentication incurs barriers given an added step physicians is required to adopt in the workflow process.[31]

2. Incorrect Patient specific information [21] [25] [31] [4] [17] [42]
    a. **Root cause**: Patient matching errors

3. Representation of data in HIE is not the same as the representation of data in the source system Error in translating information [21] [4] [6]
    a. **Root cause(s):** a) Errors in translation from source system terminology to HIE terminology; b) Errors in transmissions. [3]

4. One patient's data presented on another patient's record, unexpected patient merge [21] [3] persistence in data errors; hard to expunge incorrect data and therefore leads to repeated misinterpretation.
    a. **Root cause**: Patient matching errors; poor performance of patient matching algorithm in the HIE

5. Incorrect patient identification if home system does not have a clean MPI [25], incomplete data on the patient or duplicate patient records.
    a. **Root cause**: Home/source system has errors, including errors from EHR

6. Data integrity erroneous data entered into the home system is passed to contaminate other systems [25] [3]
    a. **Root cause**: Data entry errors

7. Lack of interoperability standards; or incorrect interactions with another health IT system component incorrectly [9] [14] [2] [5] [34] [41]. When patient records are stored in a federated model with no universal patient identifier, patient-matching algorithms become monumentally important. Need to make sure that matching algorithms factor in the patient's consent status.[31]
    a. **Root cause**: Errors in transmission; limitations and inadequacy of standards result in errors in transmission

8. Barriers related to 1) standards, 2) security concerns, and 3) economic loss to competitors [29] [9] [37] [36] [27] [34]

   a. Standards:
      i. UC is related to a) lack of standards for exchange (recommend messaging standard such as LOINC) [1] [9] [14] [5] [41] [42]; or b) the need to re-design the system which incurs additional cost and technical burden
      ii. **Root cause:**: standards are still emerging and being refined due to the early state of development

   b. Security concerns:
      i. UC is related to increased apprehension or level of security under which health information would be shared [42]
      ii. **Root causes**:
         1. There are factors contributing to this UC:
            a. Legislation: potential for revisions to HIPAA that could become a 'game changer'. Current HIPAA rules and appropriate application. [44]
            b. Litigation: attorneys could tighten up requirements for covered entities and business associate agreements
            c. Public perception: the framework for the public trust model is still early in its development; there is a pubic fear of letting PHI being exchanged (whether rational or irrational) and causes a negative impact among patients of not letting their information be released. Gaining public trust is a challenge [41] [44]; patients can also decide that they want to opt-out (which causes a disruption in sharing of data). This can also results in providers changing the rules of engagement regarding about what the providers allow to be exchanged.

   c. Economic loss to competitors:
      i. UC is related to squeezing inefficiency out of the system which will impact the providers that are performing any duplicate services (i.e., these providers will lose business).
      ii. UC is related to making it easier to game the system (e.g., data mining the health information to maximize revenue and game the system). For example, a patient is behind on routine preventative screening that insurance will pay for) and the non PCP could data mine the health information to maximize revenue and game the system; or physicians who leave to start their own competing practice within the same community could mine the data to make direct patient contact in an effort to entice them to follow the physician to the new, competing practice.
      iii. **Root cause:** Economic loss related to provider organizations may view the data as a strategic asset and that sharing the health information may not encourage provider participation in HIE. [40] [34] [43]

9. UC is related to workforce and skills are complex and multi-faceted. The challenge is that people that are building HIE need to work with multiple departments in a large provider organization and there are not a lot of people who are skilled enough to navigate the space well, or have the breadth of skills that can deal with multiple competing priorities associated with HIE. The workforce considerations for IT staff that can bridge working with multiple departments (e.g., IT, Legal, Clinical Applications and Medical Records) and technology to decipher the technical details [31].

   a. **Root cause**: Misunderstanding privacy principals; inadequate training; and data errors and security, given the need to work across multiple stakeholders.

10. The costs of protecting against loss of data will depend on the technical architecture implemented (e.g., centralized vs. distributed) [31]; access to data becomes part of the routine workflow which, if not available in a timely manner, negatively impacts patient safety and quality of care.

    a. **Root cause**: Inadequate disaster recovery plan

11. UC is related to information not being within your provider organization's control and you can be 'blamed' by proxy that may result when breaches in security and patient identification and privacy occur outside your purview. [31] [9] [13] [26] [34] [15] [5] [28] [41] Example of Stanford Hospital in Palo Alto, CA. where the data given to a billing contractor vendor was used on a website for Student of Fortune http://www.nytimes.com/2011/09/09/us/09breach.html?pagewanted=all. New challenges with data segmentation may also contribute to potential unanticipated disclosures of health information. [28]

    a. **Root cause:** Lack of ability to control the data access based on the policies of entities participating in the HIE

2.0   Key Highlights

Lack of Standards/Interoperability

Ghosh & Marquard (2007) [12] discuss the technical barriers/structure and the proliferation of proprietary technologies that cannot exchange data, and lack data standards. Other have cited technical barriers creating interoperability between proprietary EHR system and HIE and the need for nationally recognized standards for data codes, storage and retrieval. [11] [33] [34] Shapiro (2007, p. 2) [32] describes a slow adoption of electronic lab reporting because of "mapping disparate systems and codes to a standard vocabulary" [4]. HIE remains a complex landscape with a variety of stakeholders who have their piece of patient data, whether it is the providers (office practices , clinics, hospitals, etc.), insurance companies, diagnostic companies or pharmacies each has their own "digital language" and many do not speak to each other or the plethora of EHR systems. [9] [41] The EHRs and PHR not only vary in "digital language" but also differ in complexity, length and use of technical vocabulary with different architectures and protocols. [22] The lack of standards leads to fragmented patient information and can lead to medical errors. [9][1]

EHR software is often delivered in a generic format and must be modified/customized to support HIE interfaces and data aggregations. While customization is common place among the EHR software vendors and system users, the HIE systems cannot deliver the same level of customization that providers have become accustomed which results in users become less satisfied with the number of mouse-clicks required to perform a function. [20] Furthermore HIE software will require enhancements and the HIE software is not immune to becoming errant and requiring fixes over time that must be integrated with the providers EHR software to assure that the data exchange continues to be optimal.

Barnes [3] when discussing HIE interface design, comments that data delivery to a data repository is different than to a clinician, and encourages that reports are only sent once to the clinician to avoid information overload. Barnes [3] reports that 8,000 duplicative reports were sent in a single day as a subset of the 400,000 HIE transactions for the same day.

Shapiro [32] cautions researchers, that HIE may provide only partial clinical data such as the diagnosis codes (CPT or ICD9-CM) because the HIE systems are immature they may not incorporate complete clinical notes from the EHR. And Shapiro encourages that there is an automatic screening/review of diagnosis codes to filter out erroneous cases because advanced informatics functions such as natural language processing and data mining to screen the entire record are not yet available.

Technology

Hardware integration into the workflow of the provider, issues related to workflow assessment and placing hardware where the work activity is occurring or requiring the user to open a separate application. [20] [23] [10 [29] [19] [27]

Translation Errors (data to data mismatch)

Kaelber & Bates (2007) reported issues in patient safety related to medication management issues where incorrect information was made available to providers due to errors in translating the information from one system to another. [21] [18]

Patient Matching Errors

Barnes [3] describes that the unintended merging of patients is the worst unintended consequences and emphases the importance of a carefully constructed and tested HIE interfaces. Connelly (2007) described a record linkage algorithm to assist with identifying patient matching errors due to data entry errors. [6] Patient identify must be verified. [18][6] [41] Hincapie (2011) describes the inability to successfully match patient in HIE systems related to the patients that provided incomplete or inaccurate names [17] [25]. Miller reports issues with no unique patient identifier that crosses from provider to provider. [42]

Lack of Adoption

A number of articles cite issues with the lack of adoption related to cost, lack of standards, concerns over privacy, loss over competitive advantage and liability [11] [37] [36] [27] [41]. A number of articles addressed the issue of usage and suggested frameworks to support studying these phenomena [38] [8] [39] [30]

Cost

Cost is identified as a largest barrier to HIE adoption [11] [9] [23] [5] [8] as well as concerns over security/privacy and liability is ubiquitous among small office providers [11] [9] [5]. The question is often who will pay for HIE. [33] [24] [14] Cost concerns related to hardware [11], infrastructure, and interface builds and maintenance [9] [18] [29] Williams [41] reports that originally it was believed that HIE would be regional, local or state nonprofit or government-sponsored exchange networks, however today many other approaches are emerging to include "formed accountable care organizations, exchange options offered by EHR vendors and services provided by national exchange networks".

Privacy and Security

Issue arise regarding health data ownership, HIPAA requirements for privacy and policymakers have begun to focus on data security and confidentiality and patients willing to provide consent to participate in HIE. [33] [26] [41] [42] What are the risks of unauthorized access to the health information via security breaches? Edwards (2010) writes that system breach could result in patient data being altered or removed which could lead to medical error. On the other hand if security is too rigorous providers could be wrongly "locked out" of vital patient information. [9] Patients expect privacy and security to be addressed and adequately assured. [33] [13] [23] [31] [7] [44] Data Segmentation is thought to be one approach to protect information from inappropriate access. [28] In studies patient are found to 'opt in' when asked to consent to HIE participant [20] [33] [13] [34]

Legal

Issues over unauthorized sharing of information, liability concerns around not acting on external data available or acting on data that is inaccurate as well as issues over health data ownership remains unclear and policies continues to be evolving on these points. [11][2] [26] [41] State laws addressing exchange of medical information of a minor. [15]

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Table 2.   HIE-related UCs and root causes

#	UC[7]	Unintended Consequence	Root cause	Notes	Refs
1	1	Lack of or low usage of developed HIE because doesn't fit into workflow	Inadequate consideration of planned workflow in advance of HIE development	Is this in scope? This is avoidable and may not be a UC. Per our discussion, the initial assessment indicated that this not a UC and could come off the list	[39] [27] [35] [29] [17] [19]
2	2	Incorrect Patient specific information	Patient matching errors		[21] [25] [31] [4] [17] [42]
3	3a	Representation of data in HIE is not the same as the representation of data in the source system	Loss of integrity due to errors in translation from source system terminology to HIE terminology	e.g., issues with limitation and inadequacy of standards	[21] [4] [6]
4	3b	Representation of data in HIE not the same as the representation of data in the source system	Loss of data integrity during transmission	e.g., a comment field not transmitted, a field truncated; e.g., Interface mapping incorrect.	[3]
5	4	Intermingling of data from two *different* patients in the HIE	Poor performance of patient matching algorithm in the HIE	When patient records are stored in a federated model with no universal patient identifier, patient-matching algorithms become monumentally important.	[21] [3]
6	7	Intermingling of data from two *different* patients in the HIE	Loss of data integrity during transmission; limitations and inadequacy of standards result in errors in transmission	Lack of interoperability standards; or incorrect interactions with another health IT system component incorrectly. Hard to expunge incorrect data.	[9] [14] [2] [5] [34] [31]
7	5	Incorrect patient identification if the home system does not have a clean MPI	Inaccurate data coming from a source system including data entry errors.	An HIE can perpetuate and propagate inaccuracies home system does not have a clean MPI incomplete data on the patient or duplicate patient records or contains data entry errors.	[25]
8	6	Data quality Erroneous data entered into the home system is passed to contaminate other systems	Data entry errors	Hard to expunge incorrect data and therefore leads to repeated misinterpretation	[21] [3]

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[7] UC is a map to the numbered list of UC topics on page 3.

Table 2.   HIE-related UCs and root causes (continued)

#	UC[8]	Unintended Consequence	Root cause	Notes	Refs
9	8a	Additional cost or technical burden	The industry standards are immature	Due to changes in standards (industrial driven or federal mandate) may need to redesign a system or part of a system resulting in cost and technical burden.	[9] [1] [14] [5] [41] [42]
10	8b	Increased apprehension or level of security under which health information is shared.	Security requirements changes related to legislative policy or litigation driven changes related to what is allowed to be exchanged. This can influence public opinion trust model.	Legislation potential for HIPAA2 changes will be a game changer

Litigation attorneys could tighten up on requirements for covered entity requirements and business associate agreements the framework for the public trust model is still early in its stage;

Public perception: the framework for the public trust model is still early in its development; there is a pubic fear of letting PHI being exchanged (whether rational or irrational) and causes a negative impact among patients of not letting their information be released. Gaining public trust is a challenge; patients can also decide that they want to opt-out (which limits sharing of data). This can also results in providers changing the rules of engagement regarding about what the providers allow to be exchanged | [34] [36] [41] [42] |
| 11 | 8c | Reduce revenue stream for providers | View data as a strategic asset and that sharing the health information may not encourage provider participation in HIE | Squeezing inefficiency out of the system which will impact the providers that are performing any duplicate services | [40] [34] |

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[8] UC is a map to the numbered list of UC topics on page 3.

Table 2.   HIE-related UCs and root causes (continued)

#	UC[9]	Unintended Consequence	Root cause	Notes	Refs
12	8c	Alter revenue stream for providers	View data as a strategic asset and that sharing the health information may not encourage provider participation in HIE	The non PCP could data mining the health information to maximize revenue and game the system)– for example, is a patient is behind on routine preventative screening that insurance will pay for or physician practices that have partners that leave the practice and set up a competing practice within the same community.	[40] [43]
13	9	Misunderstanding privacy principals; inadequate training; and data errors and security, given the need to work across multiple stakeholders.	HIE planners must find an IT architect that can speak both English and technology to decipher the technical details.	UC is related to HIE staff workforce and skills, needs are complex and multi-faceted. The challenge is that people that are building the HIE need to work with multiple departments in a large provider organization and not a lot of people who are skilled enough to navigate the space well, breadth of skills within the HIE that can deal with competing priorities of the multiple stakeholders.	[31] [44]
14	10	Costs of protecting against loss of data will depend on the technical architecture implemented (e.g., centralized vs. distributed)	Inadequate disaster recovery plan		[31]
15	11	Your provider organization is 'blamed' by proxy for breaches in security and patient identification and privacy	Lack the ability to control the data access based on the policies of entities participating in the HIE	Example of Stanford Hospital in Palo Alto, CA. where the data given to a billing contractor vendor was used on a website for Student of Fortune http://www.nytimes.com/2011/09/09/us/09breach.html?pagewanted=all	[31] [9] [13] [26] [34] 15] [5] [42]
16	11	Your provider organization is 'blamed' by proxy for breaches in security and patient identification and privacy	Data segmentation may also contribute to potential unanticipated disclosures of health information		[28]

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[9] UC is a map to the numbered list of UC topics on page 3.

Appendix 4

Initial HIE Related Unintended Consequences List

Appendix 4
Initial HIE Related Unintended Consequences List, 1/12/2012

Methods

The list below consists of (i) potential unintended consequences (UC) from health information exchange, and (ii) for each potential UC, a list of root causes that may lead to the UC. For each UC and root cause, a list of references is provided. The decision to identify root causes of the UCs was made with the recognition that tools to mitigate the UCs will, in most instances, need to be directed at root causes rather than the UCs themselves.

The list was derived in the following way:

- With guidance from the Committee co-chairs, the Westat staff conducted a literature review. The methodology for the review is shown elsewhere.

- Westat staff abstracted the literature and identified candidate UCs.

- Note: It was noted that unlike the literature on UCs in EHRs, the literature on UCs for HIE still is relatively immature and is largely based on conjecture rather than direct observation or measurement.

- In the subsequent review of the candidate UCs, 3 things happened:
  - The specific descriptions of the potential UCs were refined.
  - Committee chairs and Westat staff noted that often, a UC may have different root causes. Therefore, UCs were grouped with root causes.
  - Additional UCs were added by the Committee co-chairs and Westat staff based on their direct experiences with, and knowledge of, HIE.

Results

1. Lack of routine use of the available HIE capabilities (lack of integration into the clinical workflow)
   a. **Root cause(s) (note: the below all are interrelated)**:
      i. Inadequate consideration in the conceptualization of the HIE capabilities to the clinical workflow, e.g., who will be using the HIE capability, at what point in the workflow, to accomplish what task, etc.
      ii. Increased time required to access the system. Obviously, systems that are well-designed and "get you to the information quickly" are more likely to be adopted.
      iii. Time-related barriers aggravated if clinicians are required to adopt novel authentication procedures, e.g., a second factor or a second login.

      iv. A busy clinical workflow not permitting the luxury of time to "explore" the HIE capabilities; clinicians need to know if this tool will provide value. If there is uncertainty about the value of the tool, or if there is only intermittent value, it will not be used.

   b. **References:** [27] [35 [29] [17] [19] [31] [39]

2. HIE returns incorrect patient information

   a. **Root cause #1**: Patient matching errors, i.e., the HIE has linked the data from different patients into a single record (improper merge). May be due to poor performance of a patient matching algorithm. May be caused if one of the participants has a poor quality MPI.

      i. **References:** [21] [25] [31] [4] [17] [3]

   b. **Root cause #2:** Misrepresentation of data because of errors in translation from source system terminology to HIE terminology

      i. **References:** [21] [4] [6]

   c. **Root cause #3:** Misrepresentation of data due to loss of integrity during transmission, i.e., data fidelity not maintained during transmission from sending to receiving systems.

      i. **References:** [3] [1] [9] [14] [5]

   d. **Root cause #4:** A source system may have poor quality data. This might be due to data entry errors at the source or other sources of poor quality data.

Notes:
- In all of the above, once an error has been created, the HIE creates a "persistence" of the data error and may lead to repeated misinterpretation
- The likelihood of improper representation of data due to improper translation or transmission will decrease as the standards in these areas mature. However, given the current state, local interpretations of standards often are necessary and differing interpretations may aggravate data errors.

3. Early adopters of HIE may be required to do rework as the field matures

   a. **Root cause:** Building robust HIE capabilities in the current environment, i.e., where standards still are evolving, creates risk that rework may be needed as more robust standards emerge

4. HIE capabilities may be only half-heartedly adopted

   a. **Root cause #1:** Concern about economic loss to competitors

      i. Easier migration of patients to competitors.

      ii. Lost revenue, even if from unnecessary health care resource utilization.

      iii. Lost revenue by having other participants "game the system", for example, one provider could use the HIE to determine that services are needed and could provide those services. Also, there is concern about the potential for physicians leaving to start their own competing practice within the same community by using the HIE to make direct patient contact and entice patients to follow the physician to the new, competing practice.

      iv. **References:** [29] [9] [37] [36] [27] [34] [40]

b. **Root cause #2:** Uncertainty about the privacy and security model that governs HIE. Concerns might include:
   i. Potential for revisions to HIPAA, e.g., requirements for covered entities and business associate agreements, that could substantially change the rules governing HIE.
   ii. Attorney concerns about the model for managing HIE-related breaches of privacy.
   iii. Public perception. The framework for the public trust model is still early in its development. There is a segment of the public that may be apprehensive about allowing HIE. Providers may be apprehensive about whole heartedly adopting HIE until a robust public trust model is in place. Consent models are related to this.

5. Inability to support HIE because of inadequate requisite workforce.
   a. **Root cause**: Adoption of HIE requires a work force that has deep and solid understanding of a breadth of issues, e.g., technology, privacy, medical records, clinical workflow, etc.
      i. Inadequate work force may inhibit the advancement of HIE capabilities.
   b. **References:** [31]

6. Inadequate disaster recovery plans.
   a. **Root cause:** The cost of data recovery may be too high and it may be unclear when the HIE becomes part of "routine" work flow, which would suffer if the HIE capability were unavailable.
   b. **Reference:** [31]

7. "Blame by proxy" for privacy breach
   a. **Root cause:** Since information is outside of the provider organization's direct control, the provider may be blamed when another party allows a breach.
      i. Example of Stanford Hospital in Palo Alto, CA. where the data given to a billing contractor vendor was used on a website for Student of Fortune http://www.nytimes.com/2011/09/09/us/09breach.html?pagewanted=all. New challenges with data segmentation may also contribute to potential unanticipated disclosures of health information.
   b. **References:** [31] [9] [13] [26] [34] 15] [5] [28] [28]

8. Misinterpretation of data
   a. **Root cause #1:** Data overload
   b. **Root cause #2:**Misinterpretation of data because practitioner isn't clear what is / isn't in the system

9. Increase risk of malpractice claims
   a. **Root cause:** Incomplete or untimely data.

10. Inability to create a sustained robust organizational framework for HIE and for HIOs
    a. **Root cause:** In the protracted time frames that are required to implement HIOs, there may be shifts in the relationships of the component organizations (mergers, etc.) that may complicate the commitment to create a robust HIO.

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