QUERY-BASED EXCHANGE: KEY FACTORS INFLUENCING SUCCESS AND FAILURE

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Executive Summary

The last few years have seen a number of HIOs cease operation or merge with a competitor, effectively closing. Additionally, many industry experts predict that a number of HIOs will be closing or consolidating in the next two years. The literature on HIOs typically faults lack of a sustainable business plan or a lack of valuable services for the closure of HIOs, but these explanations only scratch the surface and are a proxy for deeper level challenges. As HIOs move from directed exchange strategies to query-based exchange, it will be vitally important for them to understand the lessons offered by their predecessors, both successful and failed. In order to dig deeper into the failure of query-based exchanges and provide insights on the roots of success, the Audacious Inquiry (AI) project team examined two HIOs that closed operations and three that consolidated with a stronger competitor.[1] The team interviewed individuals involved with each HIO, including the executive director or CEO where possible. Other interviews were conducted with stakeholders such as former customers, former board members and state or federal government partners. In order to ensure a complete view of the HIOs, every attempt was made to interview at least three individuals who were directly or indirectly involved with the HIO in varying ways. To verify that the findings are generalizable to all HIOs, the project team developed 30 questions that were sent to and completed by six successful HIOs[2] and three of the closed HIOs. Relevant results are included in Appendix B.

While hospitals and providers generally agree that access to clinical data from disparate sources is clinically valuable, their agreement often does not translate into support of an HIO, either through the contribution of data or financial support. Further, recent history suggests that achieving the kind of ubiquitous use among providers or other users that can drive a financial value proposition takes time—and likely more time than HIOs have modeled in their sustainability plans. Still, HIOs must stick with this core mission while also exploring other services that can bring in additional funding to bridge the gap. Stakeholders must see significant value from an HIO in order to be motivated to participate meaningfully. Through our research, we identified four key determinants of value that can push an HIO to its tipping point; the point at which the value becomes self-evident and the services are used on an on-going basis.

- ➢ Data Provider Distribution: HIOs must provide enough data from enough stakeholders to make use of the HIO's query functionality valuable for providers who frequently have access to data through hospital portals.
- ➢ Data Diversity and Saturation: HIOs must provide more than one type of clinical data and must reach high levels of data availability within the HIO.
- ➢ Breadth and Relevance of the User Base: HIOs must identify the right early adopters; those who find value from the available clinical data due to the type of data or the source of the data.
- ➢ Utilization Rates: The HIO must reach a high number of queries and/or record returns and reviews in order to demonstrate value.

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[1] Closed HIOs include CareSpark. Consolidated HIOs include Minnesota HIE (MN HIE) and Galveston County HIE. Additional HIOs were studied but declined to be included in the public report.

[2] Successful HIOs include: Chesapeake Regional Information System for Our Patients (CRISP), Delaware Health Information Network (DHIN), HealthInfoNet, Indiana Health Information Exchange (IHIE), Michiana Health Information Exchange, and Rochester RHIO.

While these determinants can help an HIO reach its tipping point, there are a number of other factors that influence an HIO's failure or success. HIOs must ensure that the large data stores in their trading area participate not only in the governance of the HIO, but also in data sharing with the HIO. The large data stores will also need to be willing to financially support the HIO and need to be informed of this from the beginning. A factor in getting these data stores involved is having the right organizational leadership that can espouse the benefits of HIE, while ensuring that the promises made are delivered upon. Even with the right HIO leader, an HIO may suffer failure if the state leadership is not supportive of the effort or does not place a high priority on HIE. HIOs that find themselves in such a situation must be quick to show value and continued tangible progress to their stakeholders. They will need to bring services to market quickly, and for query-based services, ensure that clinical data is available shortly after the launch of the HIO. HIOs that lack organizational focus on core goals will struggle to bring relevant services to market and are likely to burn through initial funding creating services that do not provide real value to stakeholders. Finally, HIOs need to be able to innovate and react quickly to market changes; however, most HIOs are hampered in their ability to make changes to their technology platform. Many HIOs do not have the ability to customize or adapt their technologies due to vendor arrangements. These HIOs will be less able to react to market demand or build new innovations without relying on their vendor to have the resources and desire to build the services. All of these factors to a varying degree contribute to an HIO's success or failure.

The United States is still in an early chapter of the history of health information exchange. For HIOs that are in midstream implementing initial technology and spending HITECH dollars, the lessons of earlier successes and failures are instructive and ought not to be ignored. For many, there is an opportunity to take a fresh look at business models, timeframes, and funding commitments before grant funding is fully exhausted.

Introduction

It's a vital goal of all start-up enterprises to reach a tipping point, at which point their model has become financially self-sustaining. HIOs are no different. They have, in the case of ONC grantees, received seed capital which at some point will be exhausted and must be replaced by other, sustaining, and sustainable sources of revenue. More concretely, for HIOs, reaching the tipping point means that they have signed on a large number of paying customers to contribute and consume data; secured enough available data within the HIE to make it useful within its service area; and cultivated a large number of satisfied, repeat users who have integrated the HIO into their regular workflows. If an HIO has accomplished these things—no small task, to be sure—utilization is likely to continue growing on its own as "the story begins to sell itself." Only then will an HIO begin to gain momentum, both operationally and financially.

Based on the history to date of HIOs—which is marked by both successes and failures—some lessons can be drawn about how to keep an organization running long enough to reach the tipping point. The stories of some HIOs may even suggest a few ways to speed this process up. As preparation for this report, the AI team surveyed the literature on HIOs and comparable organizations that were known as RHIOs, CHINs, or other terms. In addition, we interviewed a range of stakeholders involved in a number of successful (e.g. still operating and generally well regarded) HIOs as well as stakeholders in several that have closed or were consolidated out of existence. The AI team also drew on its first-hand experience, along with that of its colleagues operating HIOs in multiple states. This report is intended to offer a framework for understanding core ideas and influencing factors behind successful HIOs offering query-based services.

Historically, it has proven difficult for many HIOs to maintain a steadfast focus on core goals while at the same time reacting to the evolving landscape around them. They function in a volatile environment and have frequently changed priorities and leaders. Further, without significant movement on value-based payment models, many in the industry believe that stand-alone, query-based HIE solutions may not be sustainable if they don't develop value-add services above and beyond patient look-up. But despite this volatility, the successful HIOs have managed to keep their focus on their original goals, even if achieving them takes longer than anyone anticipated. Our analysis of those HIOs shows that they have had success across four broad categories (data provider distribution, data diversity and saturation, breadth and relevance of user base, and utilization rates). They have also stayed true to what one might think of as the "five rights" (right information, right person, right format, right channel, and right time in the workflow).

Part 1 –Delivering Value in HIE Operation: Determinants for Reaching a Tipping Point

Reassessing the Value Determinants of Query Based Exchange

There is a general agreement in the healthcare community that the ability for a provider to electronically search for and find patient data in real time has significant value and can have positive impacts on the safety, quality, timeliness, and ultimately the cost of care. Most query-based HIE efforts set out with a primary goal of improvement in these areas. However, a pivotal challenge is the speed with which an HIO can reach the tipping point—that is, arriving at the necessary distribution of facility participation in a medical trading area, data saturation level, volume of utilization, and breadth of the user base—to generate enough consistent clinical and financial value for paying participants that utilization grows on its own, and the HIO services become ubiquitous. For query-based HIOs, reaching the tipping point may take significantly longer than many have anticipated and may require a different set of expectation setting processes, based on our research and analysis.

This does not mean that HIOs should stop trying to deliver clinical value—they need to stay focused on this mission; indeed it is at the core of many of their existences. However, there must be a clear set of expectations surrounding the level of data and commitments necessary to achieve success. Forecasting this tipping point and developing an appropriate strategy to increase the odds of reaching it, has only recently begun to become possible, given the short histories of the vast majority of HIOs. In retrospect, the ultimately fatal failures of some early HIOs offer important lessons for other initiatives currently underway. It is important that HIOs not outrun their startup funding while assuming that the inherent value of query-based exchange will soon make their initiatives self-sustaining, because history suggests they are just around the corner from failure.

The Tipping Point

Arriving at the true tipping point for query services that will make an HIO a clinical necessity is dependent on reaching certain milestones against four interrelated metrics. There are other important factors in developing a successful HIE organization capable of offering query services and holding the trust of the community which it services. Those factors are important to any inter-organizational health data trading effort. But above all else, we believe that HIOs need to focus on these four key determinants in order to be successful.

Determinant 1: Data Provider Distribution

Provider access to electronic health information is not uncommon. It is also a reality that virtually all query-based exchanges make their data available through a secure web portal, at least for now. Ambulatory providers frequently will have credentials to information systems for hospitals where they are privileged or for a local radiology system where they refer patients for imaging. The capability to offer a wider set of clinical data (more than one or two types of data) from a broader distribution of data sources (more than just a few locations) is important. If the focus is too narrow, the value proposition may not exceed the threshold necessary to cause a provider to switch to use the HIO over their direct access. In fact, if the offering is too narrow, the HIO's offering may have the opposite effect—by adding another set of user credentials and a new web portal to a provider's workflow, the HIO may be increasing provider frustration levels. How much data does an HIO need to make available? The answer may vary by the

medical trading area the HIO serves and/or population centers, but a focus on freeing data from too limited a set of data providers may not create the necessary value proposition.

Determinant 2: Data Diversity and Data Saturation

Many HIE efforts develop roll-out plans with an incremental deployment philosophy. This approach is frequently appropriate and necessary to gain the buy-in and confidence of important stakeholders such as seasoned IT professionals, who are skeptical of a nascent organization's ability to effectively manage a broader scope of work. However, in working towards the tipping point, single data types and low levels of data are major barriers. From a data diversity perspective, if the HIO is focused on offering a medication history service or a lab results service, the value proposition compared to existing processes and data access methods will likely remain below the threshold at which a provider would modify behaviors. In terms of data saturation (i.e. the volume of data available through the HIO), there must be a focus on data sources that produce high-volumes of clinical data and can commit the technical resources needed to enable connectivity. These sources are generally hospitals and regional/national laboratories and radiology centers. Large ambulatory practices or independent physician associations (IPAs) could be potential sources to a given HIO, but generally, at the current point in time, pursuing integration for outbound data from an ambulatory EHR tends to be time consuming, expensive, complex, and may bear little by way of high volumes of data.

It is also important to consider that the value-proposition from even large data sources will take time to evolve. For example, as hospitals come on board and begin making clinical content available for the following 30 days, users of the system will only find it valuable if they are treating a patient who has been hospitalized in those 30 days. For the following month, it would only be valuable for someone who had been hospitalized in the past 60 days, and so on. There are certainly exceptions with data from non-emergent outpatient services, regional lab / radiology centers, or medication history information from Surescripts, but the general challenge of reaching the tipping point is highly influenced by the volume of relevant clinical data available through the exchange.

Determinant 3: Breadth and Relevance of the User-Base

Identifying early adopters who are cognizant of the initial limitations on data availability and willing to stick with the HIO as data volumes grow is important. Equally important is identifying which users, given the diversity of data providers and saturation of data, will receive the most benefit at a given point in the HIO's maturity. If sources of data are primarily hospital-based, pursuing primary care physicians as customers may result in poor adoption, because their patient panels in a given week may only include a few recently hospitalized patients whose data is in the HIO. Similarly, targeting users whose case load and case mix will justify a recurring need to query the exchange will ensure on-going active engagement and reduce the risk of attrition. Once customers have had a bad experience with the HIO, convincing them to return a second time will be all the more difficult.

Hit rate, or the frequency with which a user is able to find relevant and valuable clinical data through the HIO, is another dimension of the same challenge. If a provider is only able to locate data 10 to 20 percent of the time he or she performs a patient search, and this rate does not improve relatively quickly, the HIO will likely lose that individual user due to perceptions (or the reality) that the HIO does not offer significant amounts of relevant clinical data. Therefore, understanding the data that is available through the HIO and targeting providers who are most likely to find something valuable is critical. Finding relevant clinical data is not only influenced by the type of care settings but also by the geographic relevance of the data. If an HIO has numerous sources of data on one community and deploys its tools in communities that are not serving the same patient population, the HIO will face questions regarding its

value proposition. While this point seems obvious, HIOs do not always have the necessary medical trading area information to know if patients are moving between the various data sources and HIO user areas. In pursuing the path of least resistance, meaning selecting data providers and end-users who are willing to work with the HIO without being coerced, aligning geographic relevance with end-users is an important consideration.

While there is a tendency to think about query-based exchange as a support resource for unplanned treatment and diagnosis decisions, there are other non-research public health purposes that have significant value. Thinking beyond the traditional use cases is important. For example, in many states hospitals and other provider entities have an obligation to track the health status of cancer patients whom they have diagnosed or to whom they have provided treatment. This process tends to be extremely manual and duplicative. By engaging cancer registrars at hospitals in the query use case, an HIO can offer a valuable non-treatment (and frequently regulatory-mandated) use case. Moreover, query-based exchange can be applicable during planned care as well. While unplanned care represents a significant component of the value offering of a query-based exchange, clinicians providing planned care can benefit from access to an HIO for query services, particularly when treating new patients.

Determinant 4: Utilization Rates

The volume of queries into an HIO is an important metric for gauging progress towards the tipping point. It is also frequently used as a proxy for value / success measurement (i.e. if the HIO continues to be queried it must be producing value). There are certainly issues with using that metric as a value proxy, such as in the case of an HIO that has established automated queries into the network upon a patient registration or visit. There are other measures, such as the percentage of queries that a) result in a patient being found and b) result in a clinical document being reviewed (i.e. query hit rate, document open rate) that can be more appropriate for measuring utilization. However, HIOs are challenged in delivering increasing rates of utilization. Low utilization volumes or stagnant growth can similarly be noted as an indicator of a value deficiency.

Careful consideration of user workflow is critical when discussing HIO utilization rates. Indeed, there are important lessons from the clinical decision support (CDS) world that apply to the deployment of HIE query tools. After all, HIE is a form of clinical decision support. Recognizing that most query-based HIOs still rely on web-based portals to launch queries implies significant workflow challenges. An HIE which has broad participation, a highly diverse data set with deep saturation, and a relevant user population may show query volume growth without sufficiently addressing workflows because of the sheer value of the service. However, an HIO that additionally addresses clinical workflow can accelerate adoption dramatically.

The Agency for Healthcare Research and Quality (AHRQ) developed a CDS model in medication management called the "CDS Five Rights Model," aimed at improving outcomes (this model is different than the Five Rights focused on medication use, i.e. right patient, drug, dose, route, time).[3] The majority of the CDS Five Rights Model is highly applicable (and correlated to the points described above) to successfully deploying query-based HIE tools and pulling the tipping point forward. The five rights are below with modified descriptions to be specific to query-based HIE.

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[3]http://healthit.ahrq.gov/images/mar09_cds_book_chapter/CDS_MedMgmnt_ch_1_sec_2_five_rights.htm

- ➢ The **right information**: is the right information available through the HIO to address a clinical end-users treatment or diagnosis needs?
- ➢ To the **right person**: is a physician, nurse, mid-level, scribe, or other care team member the right person to be interacting with the data?
- ➢ In the **right CDS intervention format**: is the data formatted in a consumable way?
- ➢ Through the **right channel**: is a web-portal sufficient, or would single-sign on and patient context passing be necessary; how tightly tied to an EMR or health information system does the query process need to be in order to be successful?
- ➢ At the **right time in workflow**: is the data helpful in advance of an encounter (planned), at the time of patient arrival, at initial history and physical, or at some other point in the course of care?

To summarize, the challenge for an HIO to make the HIE query resource valuable is in serving up the right information, to the right person, at the right time, using the right tools, and the right moment in their clinical workflow.

Part 2 – Other Lessons from the Short History of HIOs

Governance and Stakeholder Involvement

One differentiator between successful HIOs and failed HIOs studied is whether key participants move beyond passive engagement toward active participation in the HIO, by contributing and consuming clinical data. It is a relatively low burden for hospitals or other potential data providers to show support for an HIO by attending board and committee meetings and talking about how beneficial the HIO would be for patients. It takes a much deeper level of commitment to provide the resources (both financial and technical) necessary to connect the hospital to the HIO and to overcome competitive concerns.

In order to become valuable, HIOs need to achieve a large distribution of organizations willing to share more than just demographic information for their patients or members. If the majority of hospitals in the trading area are not willing to share data with the HIO, it will be considerably more difficult for it to make a sustainable value proposition. CareSpark and MN HIE both struggled with finalizing sharing agreements with the majority of hospitals in their trading areas. In the CareSpark trading area there were two main health systems with 21 hospitals between them. The systems were extremely competitive with one another and had no desire to share clinical data. In spite of this competitive dynamic, CareSpark was able to sign agreements with both of the health systems, but one agreed only to contribute radiology reports to the HIO. The second health system chose not to provide data at all. MN HIE was only able to sign sharing agreements with two hospitals, and only one of those hospitals ever shared clinical data. CareSpark, DC RHIO, and MN HIE struggled to create connections with hospitals in their service areas, failing to unlock the largest sources of valuable data to potential users. Without larger amounts of clinical data flowing from the hospitals in the trading area, use of the query functionality for these HIOs was minimal.

Including hospitals and providers in planning and governance, and even persuading them to share data with the HIO, still may not be enough to ensure the HIO is viable. Successful HIOs have also been able to set the expectation early in the process that fees will be charged to exchange participants in the future. CareSpark began with grant funding and throughout its life pursued grants and payer funding rather than hospitals and other providers, the direct consumers of its services. The two large health systems were not

willing to share data with the HIO, let alone fund it, and the providers who helped start the HIO were given the expectation that they would never have to pay to support the HIO, because they believed it would be funded by payers and by grants. When the payers stopped supporting CareSpark and grants dried up, the HIO was unable to obtain funding from the hospitals or providers, in many ways it's most important constituents, largely because they did not see value in the HIO's service offering (tying back to shortcomings in achieving success in the four metric focus areas). In the case of DC RHIO, stakeholders were aware that they would eventually have to participate in funding the HIO; however, they were not given any indication of when they would need to fund the HIO, or how much it would cost them. Nor did they have meaningful input into how these decisions were made. When DC RHIO did not secure anticipated HITECH funding, the HIO did not have alternative funding sources.

Organizational Leadership

Most HIOs are small organizations with small (or outsourced) staff. They do not have a large C-suite, typically staffing only a CEO or executive director and a handful of other employees. Consequently, it is the responsibility of the chief executive to not only set the strategic vision, but also oversee sales and marketing and manage the day-to-day operations, including complex technical implementation and integration projects. Successful HIOs are those that retain a leader who is passionate about HIE, able to clearly and persuasively articulate the benefits to stakeholders, is politically savvy, and has the ability to manage projects within budget and set timelines. This is a comprehensive set of skills, and finding a leader who possesses all of them and is willing to work for a small non-profit with an uncertain future is a daunting task. The original CEO of CareSpark was a HIT evangelist and very good at marketing the HIO to providers and the board. However, while the view of CareSpark that was presented to the board, stakeholders, and media was incredibly positive, the organization faced project execution challenges.

HIOs are often in a position of not having a compelling proposition with regards to hiring and retaining the right chief executive. On the one hand, as noted, the job is highly demanding and requires a wide range of specialized skills. On the other, HIOs are grant funded non-profits or in some cases, government entities or public-private partnerships; such organizations often have certain expectations about modest levels of compensation in comparison to their private section counterparts. In the case of CareSpark, the HIO was not willing or able to offer a high salary for the CEO position, offering between $60,000 and $75,000. When the original CEO left the organization, the HIO was unable to fill the position because of the low salary, leaving the organization without a leader for months. In important ways, the good HIO leader may have more in common with the startup entrepreneur or seasoned senior IT executive than the public health professional versed in demonstration projects and federal grants.

State-Level Involvement

The state HIT coordinator typically drives, or at least significantly influences, a state's HIE plans. In most states, the state HIT coordinator is appointed by the governor. When a new governor with different priorities takes office, he appoints a new state HIT coordinator, which has the potential to change a state's HIE plans, particularly when there has been a political party change. Additionally, new governors will typically have different priorities. HIOs may lose or possibly gain the support of the governor or health department. This change in leadership will most likely have a large impact on HIOs. This impact is not always negative (the Pennsylvania governor change in 2010 brought additional funding to regional HIOs), but it can lead to the faltering or failure of an HIO. In Minnesota, there was a gubernatorial change after the 2010 election. After the administration changed, there was a change in strategy. Originally MN HIE was working closely with the Department of Health with a plan for the HIO to support the Medicaid

MMIS system. There was also a commitment to fund the HIO under the State Health Information Exchange Cooperative Agreement Program (SHIECAP), but when the administration changed, the state HIE strategy also changed, and the Department of Health informed MN HIE that it would not receive additional funding.

DC RHIO faced a similar issue with the District administration. When the new administration took office, a new state HIT coordinator was appointed. The DC RHIO helped write the original strategic and operational plans, and while not the state-designated entity, the HIO felt it was promised the role of district wide HIO. After the administration changed, the plan for more robust HIE changed as well, and the SDE notified the DC RHIO that they would not be receiving the expected grant. While 2012 will not have a large number of gubernatorial elections (13), 2014 will see more than half of states with an election. A change in the administration of these states has the potential to change the path of HIE and the financial viability of state HIOs and sub-recipients of SHIECAP funds.

While HIOs have very little control over the political winds blowing atop their states' governments, the stories of MN HIE and DC RHIO underline the need for HIOs to have a relentless focus on their mission and attempt to accelerate their tipping point to viability as much as possible while engaging in the politics inherent in state level programs.

Community Factors that Influence HIE Value

A trading area where the major health systems all utilize the same EHR can make the task of reaching its tipping point even harder for an HIO. Many EHR vendors are, if inadvertently, competing directly with HIOs by offering tools for users to communicate with one other and share patient records, regardless of organizational affiliation. If the vendor allows health systems in a trading area to share with one other using the EHR, the health systems are likely to see a community HIO as redundant. Additionally, if health systems are acquiring ambulatory practices in the area, they may have their own proprietary strategy for exchanging data within their delivery networks. A trading area that has a lower number of independent physicians is also not likely to have a successful HIO. In Minnesota, the majority of hospitals utilize Epic, and the state has a large Epic user group. The hospitals were able to work through the user group to build connections to one another using the Care Everywhere product. Additionally, the health systems in the trading area were acquiring physicians at a fast pace and setting them up on the same EHR system. This led to a lack of willingness by the health systems to participate in the HIO. What MN HIE originally saw as a positive, a high EHR adoption rate, turned out to be a negative in the context of their plans and their goals.

Time to Market with Key Services

The successful HIOs we reviewed ranged in the amount of time it took to deploy core infrastructure; however, they all came to market extremely quickly with services once planning was completed, and infrastructure went live. In most cases, this means pushing stakeholders extremely hard to bring data feeds into production, starting with the largest and most relevant sources of data. In contrast, CareSpark had a larger gap of time between core infrastructure and first data live, and both CareSpark, and MN HIE had over a year and two and a half years respectively between first data live and clinical data live. MN HIE was able to stand up its infrastructure very quickly, once the decision was made on a vendor; however, it took them four years to obtain stakeholder agreement and buy-in before choosing a vendor. While the DC RHIO was up and running with clinical data quickly, they were only able to get three of the

13 hospitals in their trading area sharing clinical data, and two of the hospitals were part of the same health system. This was a recipe for the unproductive burning of critical program cash.

In addition to spending money on unproductive vendor licensing agreements, the longer it takes an HIO to get clinical data flowing, the less likely stakeholders are to stay engaged. Having clinical data available relatively quickly increases the chance that providers will find valuable information in the HIO, rather than feeling like querying the HIO wastes their valuable time. Additionally, based on the information gathered from the successful and unsuccessful organizations, HIOs need at least half of the hospitals in their trading area sharing clinical data in order to have the breadth and depth of data available to ensure that hit rates are high.

Organizational Run & Burn Rate

It has been frequently noted that HIOs need to have a business / revenue generation mindset in order to be successful. Failed HIOs have followed a pattern of seeking grant funding first and then stakeholder funding. The consequence of this approach is that the HIO builds infrastructure and services to meet the needs of the various grants, leading to a variety of services that do not improve provider workflow, patient care coordination, or cost efficiency and are therefore not valuable to stakeholders. These points are not to say that grant funding is not an incredibly important component of arriving at the point in which valuable services can be offered, but rather that in ensuring delivery on grant obligations, future paying customers may be overlooked, or at least prioritized lower. Even worse, some HIOs set up infrastructure to seek new grants at the expense of selling viable services to long-term customers. Developing a business mindset requires an HIO to have an intense focus on its core mission and goals; changing the goals only when the stakeholders feel that it is the best move for the HIO.

CareSpark was almost entirely grant funded from the beginning, with demonstration projects providing additional funding as the HIO developed. The grants and the demonstration projects may have distracted from the original mission of the HIO, which was to improve the health of its people through health IT. While the services developed under the grants could eventually be value-add services (i.e. electronic PQRS), they were not necessarily additive or complementary to the core mission, and they did not accelerate the HIO towards a point where the value proposition was compelling. Without a rich set of available clinical data to query, providers did not see the value in participating in the HIO, even if grant funders were impressed with proposals and plans. The DC RHIO was funded by a grant that required specific participants and a specific technology vendor. The HIO was not allowed to use its funding to secure buy-in from and build connections to all of the hospitals in the area, but was limited to six specific clinics and two hospitals. Once connections were built to these groups, the HIO could use its funding for additional connections (two additional connections were covered by the grant). Additionally, the HIO was required to use a specific vendor that came with a hefty price tag. Consequently, the DC RHIO was handicapped in what they could do because of the grant requirements.

Vendor vs. HIO Influence on Progress

While HIOs will always be somewhat reliant on their vendors for updates to their system, successful HIOs have the ability to make changes to their infrastructure and develop new services without total reliance on their vendor. Successful HIOs employ technical resources or work closely with contracted resources to update and maintain their system. HIOs that cannot make changes to their infrastructure are reliant on their vendor's willingness, availability, and ability to make changes. With the current pace of health IT implementation, many HIE vendors are experiencing difficulties in maintaining adequate

knowledgeable staff, and most likely do not have the ability to make every update requested by an HIO. In addition, the large HIE vendors typically rely on long-term roadmaps and to some extent, user groups, to prioritize customer requests, leaving individual HIOs with much less choice on which new services to roll out and when. The pace of innovation is significantly slowed for HIOs that rely on their vendors for technical work and the development of new capabilities. CareSpark, DC RHIO, and MN HIE did not have the ability to make any changes to their system, aside from adding and modifying users. Additionally, none of the HIOs staffed technical resources (aside from those employed by CareSpark for oversight). These HIOs had significant vendor costs, in part due to their reliance on their vendors for technical resources. In contrast, almost all of the successful HIOs we reviewed are able to make changes to their system without submitting a change request to their vendor, and they employ their own technical resources. Consequently, their vendor costs tend to be lower than the HIOs that outsource all of the technical work to their vendor.

Conclusion

This market assessment and research process has led to a number of conclusions about drivers of success, factors in failures, and the reality regarding the level of maturity necessary to reach the tipping point in query-based health information exchange. HIOs must be reactive to changing realities on the ground, but rather to recognize the importance of setting a goal and working towards it relentlessly and modifying the strategies and tactics to achieve that goal along the way. A key finding is that the point at which the value of clinical data exchange becomes apparent on a continuous basis is further along the maturity curve than many HIOs recognize. As the data in the findings indicates, driving towards that point requires successful execution against the four key metrics and the five rights, and the faster these areas can be accomplished the quicker the HIO will meet with success.

For HIOs that have started down the path of offering query services, the findings of this report suggest that a core focus must be on increasing the volume and breadth of data available through the HIO. This point is not an epiphany, but rather a reinforcement of the need to move beyond pilot mode quickly. Pilots can be important to encourage timid partners to put a toe into the data sharing waters. Pilots can also be the place where HIO efforts fade as they struggle to prove value; a goal that may not be obtainable within the limiting boundaries inherent in a pilot.

For HIOs that are pursuing a backbone strategy to support sub-networks, we see substantial risk. These HIOs may offer limited access to state-level data sources but are reliant on sub-networks to connect and exchange data to prove value. These sub-networks will invariably focus inwardly on their challenges, leaving higher level connectivity to be addressed at some point in the future. What will allow these efforts to reach the tipping point? HIOs pursuing a backbone strategy should be particularly attentive to these realities as these efforts evolve.

We think there is reason to place particular emphasis on the need for an organization to have some level of engagement, and ideally control, over their technology solution. There are realities, even for major health systems, around the limitations on controlling your own technical destiny. However, an HIO's outsourcing of all technology operations to a vendor partner puts the entity in a difficult position not only in understanding technical issues and making technical decisions, but also in having the ability to focus energy and resources against services that will drive revenue.

Query-based exchange continues to hold extraordinary promise to influence healthcare delivery and outcomes. We know that many organizations have been successful and continue to evolve and to serve

the communities in which they operate. We also know that numerous HIOs have exhausted resources and relationships in those same pursuits. The complexity of the undertaking can detract from the vision of the opportunity. The findings of this report provide insight and guidance on key influencers to driving towards a successful query-based HIO.

Office of the National Coordinator for Health Information Technology
Query-Based Exchange: Key Factors Influencing Success & Failure
September 30, 2012

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Appendix A – Case Studies

CareSpark

In 2004, the volunteers working to establish CareSpark received a grant from the Foundation for eHealth Initiatives totaling $100,000. The organization received matching funds of almost $500,000 from other interested parties. The funds supported a feasibility study as well as a planning process, and in 2005, CareSpark was officially established with a strategic business plan in place. One of its first initiatives was to join the Accenture Consortia prototype architecture project for the Nationwide Health Information Network (NHIN). CareSpark began building its infrastructure based on NHIN standards in early 2006. CareSpark pursued a best-of-breed approach, contracting with multiple vendors, including: Initiate, AnaKam, Healthvision, Oracle, and others. In total, CareSpark worked with 13 national and local vendors that provided not only the infrastructure, but also the technical resources, since CareSpark did not employ technical resources on staff. It was able to negotiate in-kind or below market cost for services from these vendors in the original contracts, in return for serving as a pilot or R&D site. However, most of the contracts were short-term in nature with significant price escalation upon renewal. By 2008 CareSpark's infrastructure was built and the HIO went live with query functionality through a web portal.

CareSpark was predominantly funded through state and federal grants (approximately 90-95 percent of the funding), including: a Social Security Administration health IT initiative grant to demonstrate electronic disability determination, a portion of the Tennessee REC grant, and a CMS grant for proof of concept on electronic PQRI submission. Although a few organizations provided initial funding, including the payers in the area, none of the 38 participating organizations paid fees. There were three major issues with the CareSpark funding plan. First, participants in the HIO were under the impression that they would never need to pay fees to support the HIO. One of the major reasons CareSpark's transition from grants to a fee model failed was the HIO's failure to set expectations with regards to fees. When participants were eventually asked to pay, they declined. Second, because CareSpark was supported throughout its life by grants, the HIO was built to meet the requirements of the grants, not necessarily the requirements of the community. CareSpark had a hodge-podge of services that did not necessarily support the original mission and vision of the founding organizations. Finally, CareSpark had accumulated approximately $1.2 million in debt from the organization's startup. Its well-known indebtedness made the job of negotiating and collecting fees even harder for the HIO's leadership.

While CareSpark was primarily focused on the obligations of its grant funding, operational and leadership issues led to execution problems on these projects as well. SSA and CareSpark agreed to "terminate for convenience" the disability grant project, which was a no fault termination. In addition, with a large amount of debt and an undefined sustainability plan, the state of Tennessee pulled back its allocation of State HIE Cooperative Agreement funding from CareSpark. While the interim CEO and State HIT Coordinator were initially successful in convincing two large health systems to contribute to the HIO after the loss of grant funds, there was disagreement among the health systems and the Board of Directors about the ongoing operations of the HIO and the health systems ultimately never delivered financially. Without sources of funding to cover the organization's debt and ongoing operations, the Board of Directors voted to close CareSpark in 2011.

Along with these financial issues, a number of other factors contributed to CareSpark's closure. One of the largest issues was the lack of meaningful participation from the two very competitive health systems in the trading area. At the time of the initial go-live, several medical practices had signed up to participate. However, the two largest health systems in the area were not included in CareSpark's

governance; one health system was contributing radiology reports, but no other data was flowing to the HIO, and they were minimally utilizing the query service. From 2008 to 2011, CareSpark was able to sign data sharing agreements with 38 organizations and accumulate 160,000 unique identities in the MPI and just over a million records. This was less data than it might seem—only a few of the 38 participating organizations actually contributed data, most of which was immunization records. Consequently, when providers queried the exchange, they typically came up empty, making it difficult to demonstrate an ROI to users. From the launch of services in 2008 until 2011, the HIO was only able to increase query rates from 10 per month to approximately 100 per month across the entire network.

Another issue was the best-of-breed technology approach. The HIO contracted with more than a dozen vendors to provide various services including infrastructure, technical resources, and project management. While CareSpark was able to negotiate free or close to free services from some vendors, their arrangement changed as the smaller vendors were purchased by larger vendors. When vendors were acquired, they were no longer interested in offering free or below market services, and began to aggressively renegotiate their contracts with CareSpark. In addition, because CareSpark invested in major infrastructure as early as 2006, and agreed to be a beta or R&D site for many components, much of the technology was outdated by 2010 and needed to be upgraded. Such an upgrade was, by then, dramatically out of reach given the organization's financial position. Finally, CareSpark did not staff technical resources, but rather outsourced all of the technical work to consultants and the technology vendors. They were reliant on vendors to make changes and bring services to market.

Finally, in hindsight, it seems clear that there were a number of leadership issues within the organization. The original CEO was an able HIT evangelist and marketer. She was able to convince the large IPAs, providers, and payers in the area to participate in the HIO. However, she struggled with getting the hospitals past their competitive issues and agreeing to share large amounts of data. While selling a vision is important for any start-up organization, HIOs included, it is never too early to plan for sustainability—providers were given the expectation that they would never have to pay to participate in the HIO because the HIO would be funded by grants. When grant funding was no longer available and providers were asked to fund the HIO, they refused because of the expectation that had been set and because they had not been offered an adequate value proposition. At least one former CareSpark board member felt that staff did not adequately communicate with the board about progress being made and challenges faced—in retrospect, the board may not have understood what became obvious after CareSpark closed: it had not come close to delivering value to its participants. Because the board members were not given an accurate picture of the HIO, the decisions they made were not necessarily the best for the organization, and may have accelerated its indebtedness and eventual closure.

DC RHIO

In 2006, the Washington, D.C. Department of Health provided a grant to six community health centers to implement the eClinical Works EHR system. The project was completed in 2008. During the project period, in order to advance electronic health information exchange, the D.C. Department of Health provided a grant of $6 million over a three year period to the D.C. Primary Care Association (DCPCA) to launch the DC RHIO as a proof of concept. The pilot had a limited project scope that included the six community health centers and two of the city's hospitals. Additionally, the grant required the DCPCA to partner with the National Institute of Medical Informatics (NIMI). In 2007, when the grant was issued, the DC RHIO attempted to engage the health centers and hospitals that were part of the project scope, but found it difficult to gain their participation. It took the HIO 18 months to finalize the governance structure and data sharing agreements with these core stakeholders.

Once the governance and data sharing agreements were in place, the HIO started its technical implementation. From the very start, the HIO faced issues with the technical implementation, particularly with the six clinics using eClinical Works. The HIO worked on building HL7 interfaces to the clinics but found it challenging to collaborate with eClinical Works, causing the integration to be more costly and time consuming than originally planned. The two participating hospitals, both part of the same health system, also moved slowly, primarily because of human resource constraints and the low prioritization of a "demonstration" project. Once the clinics and hospitals were finally connected, they began sharing data including: patient demographics, clinic observations, allergies, diagnoses and procedures, lab results (only from the clinics and hospitals), discharge summaries, and hospital radiology reports, but overall the amount of data was low. The HIO was unable to engage the major labs in the area (LabCorp and Quest), leading to a low level of lab results available through the HIO.

When the State HIE Cooperative Agreement Program was originally announced, there was a discussion in the Department of Health on whether the DC RHIO should be the state designated entity and apply to the program or simply be the district-wide HIO. At that time the Department of Health Care Finance was part of the Department of Health, and the decision was made to have the Department of Health Care Finance apply for the grant and manage the financial aspect of the grant while engaging the DC RHIO to do all of the technical work. While the planning process was taking place, a new administration was elected. The new administration made the Department of Health Care Finance a stand-alone agency and appointed a new State HIT Coordinator within the department in May 2011. Throughout the process of creating the plans for the grant, the DC RHIO was not receiving any funding from the Department of Health. In addition, its original grant funding expired in September of 2010, and the HIO was not charging the clinics or the hospitals for participation. Beginning in September 2010, the HIO was funded with DCPCA's own funds, which it envisioned as a bridge to forthcoming HITECH dollars. However, in September 2011, the Department of Health Care Finance notified the DC RHIO that it would not be receiving the expected funding.

In November, the DC RHIO ceased operations. When the HIO closed, it was testing connections to two additional organizations, but was not yet live with those organizations. Usage of the HIO was low, with between 500 to 1,000 queries per month. While the DC RHIO was also working towards a Direct implementation, it had not yet been implemented.

DC RHIO faced a number of challenges. First, due to the legislation that created its original funding stream, the HIO did not have a choice of vendors. DC RHIO was required to partner with NIMI, who was involved in early HIE work in the District. The leaders of NIMI developed the Azyxxi platform for Washington Hospital Center. The HIO was planning to use the Azyxxi platform when it was purchased by Microsoft and renamed Amalga. While the platform itself did not have any inherent problems, the pricing structure was an issue. the product pricing was not tied to usage of the infrastructure, meaning that rather than the cost of the infrastructure decreasing as more users were brought on board, the price increased each year regardless of how many users there were. Because of the pricing structure, the cost for infrastructure alone from 2010 to 2014 would have been $20.9 million, rivaling the total operating budgets of large HIOs that cover multiple states. DC RHIO did not have the resources or expertise to negotiate a better deal from Microsoft. Furthermore, the HIO did not staff its own technical resources, but outsourced the work to the same vendor which added to the cost of the platform.

DC RHIO also struggled in keeping stakeholders involved. Rather than a formal board structure, the HIO had an advisory committee. As the HIO progressed through the grant, the frequency of and attendance in committee meetings decreased. Because of the lack of meetings, the stakeholders did not know what was happening with the HIO, which translated into their staff not knowing about the HIO. The HIO also

suffered from data availability and system reliability issues. A lack of knowledge of the HIO along with a lack of available data most likely led to the low usage rates.

Finally, the HIO faced a lot of competition in the District. Using the Medicaid Transformation Grant, the Department of Health built the Medicaid Patient Data Hub. For a time there was discussion about whether one of the HIOs should be decommissioned. Eventually it was decided that the Medicaid Patient Data Hub would connect to the DC RHIO and pull information on Medicaid patients to be used for population health, but a technical architecture was never finalized. The DC RHIO also faced competition from health systems working to build their own HIOs. Rather than working with the private HIOs, the DC RHIO had a go-it-alone strategy. For instance, the Children's IQ Network is a pediatric-specific HIO located in the District and operated by Children's National Medical Center. While the DC RHIO was in discussions with the Children's IQ Network to connect, the parties never reached an agreement and a connection was not built.

Galveston County HIE

The Galveston County HIE, located south of Houston, Texas, began discussions around building an HIO in 2008. The HIO was built and run by the University of Texas Medical Branch (UTMB), who received a grant in 2008 from the Houston Endowment, a private foundation, in the amount of $330,000 to build the HIO. In 2011, the HIO applied to the Texas Health and Human Services Commission's local HIE grant program and received a $75,000 planning grant, with a potential subsequent grant of $285,000 for building the HIO upon approval by the state of the plan. At the time of the planning grant, the HIO had commitment letters signed by 650 area physicians and one hospital, but none were actually connected to the HIO or sharing data. The HIO built a master patient index and clinical data repository to facilitate health information exchange across the county and a primary use case of population health management. While the repository was built, it was not in production when the HIO decided to consolidate into the Greater Houston Healthconnect in April 2011. In July 2011, the Galveston County HIE officially closed when it dissolved its governance structure.

The Galveston County HIE had three main issues. First, it faced a leadership problem. Because the HIO was built by UTMB, it did not have any full-time staff. Consequently, it did not have an individual that was a health IT evangelist who could promote the use of the HIO. A second issue was the gap between the HIO functionality and the use cases. The exchange was not being built for real-time data, which was not a problem for the use case of population health management. However, for clinical exchange at the point of care, the lack of real-time data became an issue. Third, UTMB controlled 50-60 percent of the healthcare market, which made other health systems hesitant to join. The health systems were concerned about losing competitive advantage by sharing their data into a central repository largely controlled by the health system with a dominant market position. Consequently, none of the hospitals in the trading area were participating in the HIO. In the end, it may be telling that the HIO consolidated with Greater Houston Healthconnect—Galveston County, while a distinct medical trading area, is also part of the greater Houston metropolis and may have been too small a geographic area, with too challenging market dynamics (such as a single, dominant provider entity) to succeed on its own.

Minnesota Health Information Exchange (MN HIE)

In Minnesota, preliminary discussions around building an HIO began in 2004, predominantly among the state's major private payers and several of the largest health care delivery systems. In September of 2007, MN HIE was established as a legal entity. In July of 2008, the first participation agreements were signed

with MN HIE, and the initial set of services went live in November 2008. The MN HIE was established with six participating organizations, including a mix of health care systems, health plans and state government:

- Blue Cross Blue Shield of Minnesota
- Fairview Health Services
- Health Partners
- Medica
- MN Department of Human Services (state Medicaid agency and state employee benefits program)
- UCare

The six organizations committed $12 million in seed funding over a three year period. The participating organizations agreed to fund the HIO for three years while service offerings were being created and market adoption grew. At the end of the three year period, the plan was for the sponsor organizations to review how the HIO was doing from a sustainability perspective and make a decision about ongoing commitments. When services went live, they included a master patient index, a record locator service, and medication history. The payers provided member demographics on over four million covered individuals to create a centralized Master Patient Index (MPI) and provided access to medication history and member eligibility information for their members. The HIO also provided access to immunization records maintained by the Minnesota Department of Health. In 2010 it was also receiving CCDs from one health system (Fairview Health Services) and was working to expand to others.

The Minnesota Department of Health collaborated closely with MN HIE on the development of the Minnesota Department of Health's proposal to ONC for the State HIE Cooperative Agreement Program. Although Minnesota's proposal included references to the possibility of multiple HIOs operating in the State, the MN HIE was widely thought to be the prime candidate for state grant funding. Objections to an alleged unfair competitive advantage were raised in the media and at the state legislature. In January 2011, when a new governor took office, new commissioners of state agencies were appointed, and control in the legislature changed parties. As a result, the process for managing the distribution of SHIECAP funding changed. A new plan was developed to spread the SHIECAP funds among multiple certified recipients via an RFP process, dividing the funding into three separate categories representing different functional aspects of HIE development and adoption. Minnesota had established a certification process for providers of HIE services. HIO certification required that the entities be chartered as a Minnesota not-for-profit business. Since MN HIE was established as a Delaware LLC seeking not-for-profit status, this meant that MN HIE would need to re-organize under Minnesota statute. In 2011, MN HIE was granted a provisional HIO certification with this stipulation. But the MN HIE Board, in reviewing the costs and effort involved, as well as the difficulty in attracting a critical mass of sustaining user organizations, opted for a different path. Consequently, MN HIE did not receive SCHIECAP funds.

In 2011, the board decided to combine business operations with another certified HIO in the state. By the end of 2011, board governance of CHIC was modified to accept representation from the former MN HIE Board of Sponsors, business operations were being combined, and the operation of MN HIE was shut down.

These political and funding issues alone may have been insurmountable for MN HIE. However, MN HIE faced a number of additional challenges. The biggest was the lack of involvement from hospitals and IDNs. While MN HIE was able to engage one health system, and one IDN, the other health systems did

not feel the need to participate, mainly because the majority utilized the Epic EHR system, making a community HIO unnecessary in their opinion. While the health systems that were engaged with MN HIE also utilized Epic, they had a strategic interest in improving care transitions to long-term care and chose to participate for that purpose. Additionally, only one of the health systems was sharing clinical data with the HIO. Making the hospital engagement process more difficult was the consolidation happening in the market among physicians. Minnesota's major health systems were purchasing ambulatory practices and bringing them onto the same EHR, making it difficult for the HIO to engage ambulatory physicians.

The HIO struggled to gain adoption among providers and had only 500 users signed up when it consolidated into the Community Health Information Collaborative (CHIC). The average number of queries per month at its peak was approximately 250. At the end of the three year seed funding period, the payers agreed to pay subscription fees making up 60 percent of the revenue, with fees from providers making up the remaining 40 percent. However, because adoption was so low the payers did not believe that the HIO could attract the needed 40 percent. The problem was compounded by the loss of the state funds, leading the board to explore consolidation with CHIC.

Another issue that hindered MN HIE was its overreliance on a single vendor. MN HIE's contract with its primary vendor cost almost $200,000 per month. While the vendor stood up the HIO very quickly, MN HIE was reliant on this third party for all technical services.

A final issue that hindered MN HIE was its sustainability model. There was not a compelling story for customers to subscribe to the services. The MN HIE model projected that the operating costs would have been approximately $.08 per member per month, given the state population. At the time, commercial vendors were marketing a similar configuration at 10 times this cost. It appeared to be a workable model from a cost perspective. However, it was difficult for customers to quantify an ROI for services that ran between $45 and $60 per physician per month. Technology vendor contracts were a large part of the operating cost for MN HIE. The technology costs resulted in a price point that was not acceptable to the market at that time. While the technical infrastructure was put in place very quickly, the cost structure proved unworkable. The Beacon grantee in MN reported that new NWHIN standards enabled a peer-to-peer HIE architecture that was far less expensive to install and maintain than that which MN HIE had deployed 4 years earlier. The MN HIE Board therefore terminated the contracts with its previous technology vendors when they voted to consolidate with CHIC and instead pursue use of the latest developed standards.

Appendix B – Comparison of Successful and Unsuccessful HIOs (Data as of June 2012)

	Successful HIEs						Closed HIEs		
	CRISP	DHIN	HealthInfoNet	IHIE	Michiana HIE	Rochester RHIO	CareSpark	DC RHIO	MN HIE
Total number of users	736	6,368	5,718	6,000 ambulatory and 140,000 inpatient[4]	3,000	3,000	481	380	Less than 500
Number of users querying in last 30 days	70	1,379	1,154	8,807	1,200	1,250	75	40	Volume decreased over last months of the HIO
Average number of queries per month	1548	38,500	3,000	333,333	285,000[5]	30,000	167	960	250
Number of hospitals in trading area	46	8	39	173	20	25	23	13	140
Percent of hospitals with sharing agreement	100%	87%	87%	77%	70%	96%	61%	62%	1.4%
Percent of hospitals sharing clinical data	59%	75%	87%	46%	70%	88%	22%	23%	.7%
Number of unique identities	Over 3.26 million	Over 1.29 million	Over 1.1 million	Over 12.3 million	1.5 million	1.4 million	Over 1.2 million	500,000	4.2 million
Number of labs	Over 11.3 million	Over 18 million	15 million	4.3 billion[6] and 84.5 million text reports	1.152 billion	52 million	Over 1.6 million[7]	500,000	0
Number of radiology results	Over 3.2 million	Over 4.05 million	3.5 million	17.5 million	5 million	7.5 million		300,000	0
Number of immunization records	0	0	8,000	Unknown	800,000	0		75,000	10 million
Number of care summaries	0	Over 7.13 million	1.1 million	2,143,097	200,000	0		0	300,000

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[4] IHIE was unable to separate out inactive users, which are included in these numbers

[5] This number includes providers who utilize the EHR that is run on the HIE platform. Each time a provider accesses a patient record for an encounter, the HIE is queried.

[6] This is the total number of clinical results/observations.

[7] CareSpark was not able to specify what types of records were contained in the HIE.

	Successful HIEs						Closed HIEs		
	CRISP	**DHIN**	**HealthInfoNet**	**IHIE**	**Michiana HIE**	**Rochester RHIO**	**CareSpark**	**DC RHIO**	**MN HIE**
Ability to make changes to the HIE technology	Configuration changes only; developing other technologies independently	Configuration changes only	Yes	Yes	Yes	Configuration changes only	No	No	No
Ambulatory practices sending data to the HIO	None	None	Encounters, CPT Codes, Allergies, Immunizations, problem lists, visit notes: 170	Yes	Immunizations: 300 CCD: 50	None	Immunizations, Labs, Medications, Radiology: 8	ADT, Insurance, observations, medications, problem lists, diagnoses, lab results: 7	None
Employ technical resources	Yes	No	6	Regenstrief provides technical resources	8	6	2	0	0
Contract with technical resources	8	Yes	5	No	2 part time	0	12	Number varied	Unknown
Payers part of funding plan	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Payers part of HIO founders	No	One payer	Yes	Yes	No	Yes	Yes	Yes	Yes
Number of months between agreement to pursue HIE and deployment of core infrastructure	13	60[8]	10	Unknown	8	10	18	4	14
Number of months between agreement to pursue HIE and first data live	13	60	10	Unknown	12	12	24	2	14
Number of months between agreement to pursue HIE first clinical data live	13	60	10	Unknown	12	12	36	6	14 (med history) 26 (labs, immunizations, other)

[8] DHIN was formed in 1997 and decided to pursue clinical exchange in 2003. In 2005 a strategic plan was created and an RFP for HIE infrastructure was released. A vendor was selected and a contract was executed in September 2006, with the infrastructure going live in March 2007.

Appendix C – Literature Review

Over the last few years, much has been written about the sustainability of RHIOs and HIOs, particularly because sustainability has proven elusive for many HIOs so far. According to a 2010 study of 179 HIOs, only 75 were operational and 33 percent of those HIOs were at that point in time financially viable.[9] The 2011 eHealth Initiative (eHI) annual HIE survey had similar findings with 75 operational or advanced HIOs and 24 sustainable HIOs.[10] In addition to small numbers of sustainable HIOs, there have been a number of major failures over the last few years, with 10 HIOs closing in the July 2010 to July 2011 time period.[11]

One study traced the development of HIOs from the original Community Health Management Information Systems of the early nineties to the Community Health Information Networks (CHINs) of the late nineties, to RHIOs in the 2000s.[12] All of the various models of HIOs had the common problem of a lack of a sustainable business model and lack of valuable services.[13] Closely coupled with the sustainable business model is the lack of service offerings that providers and hospitals find valuable and are willing to pay money for. These are very general concepts, and on their face not particularly instructive. However, some smaller studies lend some clues to why some HIOs survive and others fail. A report on the failure of the Santa Barbara RHIO found that a major reason for the failure was the lack of a value proposition for the providers to utilize the HIO and the inability to develop a sustainable business model, potentially because the HIO was funded by grants.[14] The grant funding meant that it did not have to determine which services were valuable in the beginning because the HIO was not asking any stakeholders to pay for the services.[15] Numerous other studies have found the same issue in RHIOs and state HIOs.[16, 17, 18]

In addition to the Santa Barbara case study that identified grant funding as an obstacle to its sustainability, a 2009 study looked at characteristics of operational HIOs and had similar findings. The study analyzed characteristics to determine their association with an HIO being operational and financially viable.[19] While not statistically significant, the study found that receiving grants for a higher level of the planning funding was associated with less likelihood of being financially viable over the long term. Alternately,

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[9] A Survey of Health Information Exchange Organizations in the United States: Implications for Meaningful Use. Julia Adler-Milstein, David W. Bates, and Ashish K. Jha. Ann Intern Med: May 17, 2011.

[10] 2011 Report on Health Information Exchange: The Changing Landscape. G. Morris, S. Silberman, and J. Covich-Bordenick. Washington, DC: July 2011.

[11] Ibid.

[12] Health Information Exchange: Persistent Challenges and New Strategies. Joshua Vest and Larry Gamm. J Am Med Inform Assoc 2010;17:3 288-294. http://jamia.bmj.com/content/17/3/288.full.

[13] Ibid.

[14] The Santa Barbara County Care Data Exchange: What Happened? Robert H. Miller and Bradley S. Miller. Health Aff September 2007 26:5w568-w580. http://content.healthaffairs.org/content/26/5/w568.full.

[15] Another Lesson from Santa Barbara. Donald L. Holmquest. Health Aff September 2007 26:5w592-w594. http://content.healthaffairs.org/content/26/5/w592.full.

[16] Health Information Exchanges and Megachange. Darrell West and Allan Friedman. The Brookings Institution. Washington, DC: February 2012. http://www.brookings.edu/research/papers/2012/02/08-health-info-exchange-friedman-west.

[17] "Building Sustainable HIEs." James S. McIlwain, M.D., and Kipp Lassetter, M.D. Health Management Technology: February 2009.

[18] Health Information Exchange Business Models: The Path to Sustainable Financial Success. Deloitte Center for Health Solutions. Washington, DC: 2006. http://www.providersedge.com/ehdocs/ehr_articles/Health_Info_Exchange_Business_Models.pdf.

[19] The study defined financially viable as the percent of funding from stakeholders versus grants and gifts.

receiving funding from stakeholders instead of outside parties was associated with a higher level of financial viability and was statistically significant. [20] Likewise, a 2008 case study of four HIOs, two which are quite successful and two who were just beginning at the time (one is now closed and one is not yet operational) found that the willingness of stakeholders to provide funding for start-up costs was a key factor in the success of IHIE and HealthBridge. [21] The study indicated that the two new HIOs, (CareSpark and Tampa Bay RHIO) did not have funding support from stakeholders and posited that this would negatively impact the HIOs. Both of these studies theorized that a lack of funding from stakeholders would lead the HIO to build services that were not necessarily in line with what the stakeholders were willing to pay for.

The case study of IHIE, HealthBridge, CareSpark, and Tampa Bay RHIO also found that the competitive dynamic among stakeholders led to a lack of real participation in the new HIOs. Without true participation, meaning sharing and consuming data, an HIO cannot become sustainable. While the successful HIOs had a comparable level of competition among their stakeholders, they were able to overcome the competitiveness through limited use cases that did not affect the stakeholders' perceived market value and allowed them to continue competing in other areas. This helped to establish the HIO as a trusted neutral third-party. In the two new HIOs, while some stakeholders were involved in planning the HIO or in the governance of the HIO, they were not sharing or accessing data, perhaps because the HIOs did not have specific use cases planned. [22] Other studies have pointed to the competitive dynamic among stakeholders as a key barrier in their willingness to share information across a service area. [23, 24, 25, 26]

In addition to competition among stakeholders, community and state HIOs face their own competition from private HIOs. A recent article in the Journal of the American Medical Informatics Association highlighted the competition between community HIOs, which are most often set up as a public good, and private HIOs that support business objectives for a single organization or network. Typically, private HIOs are created by health systems, integrated delivery networks (IDNs), and recently, accountable care organizations (ACOs). These organizations have no requirement to provide a certain set of services or provide services to all providers and hospitals. Their governance structures are centralized. In contrast, community HIOs and certainly those with State HIE Cooperative Agreement funding offer a public good, meaning they offer services that are not necessarily revenue generating, and they support all providers, regardless of their ability to pay to participate. Many community HIOs also do not have other revenue streams to support their organization, leaving them at a disadvantage to private HIO networks that can fund the organization through other lines of business. As private HIOs gain market share, it becomes

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[20] Characteristics Associated with Regional Health Information Organization Viability. Julia Adler-Milstein, John Landefeld, Ashish K Jha. J Am Med Inform Assoc 2010;17:1 61-65. http://jamia.bmj.com/content/17/1/61.full.

[21] Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? Joy Grossman, Kathryn Kushner, Elizabeth November. HSC Research Brief No. 2: February 2008. http://www.hschange.org/CONTENT/970/.

[22] Ibid.

[23] Health Information Exchange: Persistent Challenges and New Strategies. Joshua Vest and Larry Gamm. J Am Med Inform Assoc 2010;17:3 288-294. http://jamia.bmj.com/content/17/3/288.full.

[24] Best Practices for Community Health Information Exchange. Center for Community Health Leadership: Accessed May 2012. http://www.allscriptscenter.com/Best+Practices.htm.

[25] Health Information Exchanges and Megachange. Darrell West and Allan Friedman. The Brookings Institution. Washington, DC: February 2012. http://www.brookings.edu/research/papers/2012/02-08-health-info-exchange-friedman-west.

[26] Secrets of HIE Success Revealed: Lessons from the Leaders. National eHealth Collaborative. July 2011. http://www.nationalehealth.org/ckfinder/userfiles/files/REPORT%20SecretsofHIESuccessRevealed.pdf.

difficult for community HIOs to garner enough participants to financially support the HIO. [27] Another recent article indicated that state HIOs that are a public-utility model, rather than an elevator, orchestrator, or capacity-builder[28] are in direct competition with private HIOs, and private HIOs have the advantage.[29] State HIOs with their many geographically diffuse stakeholders cannot innovate as quickly as private exchanges. Additionally, state HIOs are in essence forcing organizations with no business relationship and no business need to exchange data, whereas private exchanges are built based on business need. Finally, state HIOs may not be able to offer services as cheaply as private HIOs, who can subsidize the services that do not generate profit with other lines of business.[30]

In 2008, the National Opinion Research Center (NORC) convened a panel of industry experts to discuss HIE sustainability. In addition to defining what sustainability means, the panel identified a number of obstacles to sustainability. One of the major obstacles they identified was the fee-for-service reimbursement system that compensates providers for the quantity of care they deliver, not the quality of care. Without payment reform, which encourages better care coordination, the panel did not believe that stakeholders would see financial value in participating in the HIO.[31] In addition, the recent recommendations from the National eHealth Collaborative (NeHC) on how HIOs can move forward, indicated that new care delivery models were necessary to realize the value of HIE.[32] Other studies have indicated that because of the current payment models, the benefits of HIE accrue to those who typically are not paying for the service, mainly patients and payers; causing hospitals and especially providers to be less willing to pay for the services of the HIO.[33, 34]

The NORC panel also identified inconsistent privacy policies as an issue for HIOs. The industry experts were concerned about the inconsistencies between privacy policies on the federal and state level and the limitations that these policies would have on an HIO's ability to exchange information in a valuable way.[35] Others have noted that the privacy and security concerns of hospitals and more specifically providers can lead to a lack of participation in the HIO. In addition, patient concerns about the privacy of their data and the ability of employers, payers, or the government to have greater access to their data can lead patients to forgo participation. Without patient participation the HIO cannot reach a critical mass of

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[27] Shifts in the Architecture of the Nationwide Health Information Network. Leslie Lenert, David Sundwall and Michael Edward Lenert. J Am Med Inform Assoc: published online January 21, 2012. http://jamia.bmj.com/content/early/2012/01/21/amiajnl-2011-000442.full?sid=17c13830-aadd-4b69-9209-922951e31d30.

[28] These terms are used to describe the types of models states are using under the SHIECAP. For more information on the models see: Evaluation of the State Health Information Exchange Cooperative Agreement Program: Early Findings from a Review of Twenty-Seven States. NORC: January 2012. http://www.healthit.gov/sites/default/files/pdf/state-health-info-exchange-coop-program-evaluation.pdf.

[29] Open for Business: Private Networks Create a Marketplace for Health Information Exchange. Chris Dimick. Journal of AHIMA 83, no.5 (May 2012): 22-26.
http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_049598.hcsp?dDocName=bok1_049598.

[30] Ibid.

[31] Health Information Exchange Economic Sustainability Panel: Final Report. NORC at the University of Chicago. Prepared for: U.S. Department of Health and Human Service Office of the National Coordinator for Health Information Technology. April 2009. http://cdm266901.cdmhost.com/cdm/ref/collection/p266901coll4/id/2144.

[32] Health Information Exchange Roadmap: The Landscape and a Path Forward. National eHealth Collaborative. April 2012.

[33] Health Information Exchange: Persistent Challenges and New Strategies. Joshua Vest and Larry Gamm. J Am Med Inform Assoc 2010;17:3 288-294. http://jamia.bmj.com/content/17/3/288.full.

[34] Health Information Exchanges and Megachange. Darrell West and Allan Friedman. The Brookings Institution. Washington, DC: February 2012. http://www.brookings.edu/research/papers/2012/02/08-health-info-exchange-friedman-west.

[35] Health Information Exchange Economic Sustainability Panel: Final Report. NORC at the University of Chicago. Prepared for: U.S. Department of Health and Human Service Office of the National Coordinator for Health Information Technology. April 2009. http://cdm266901.cdmhost.com/cdm/ref/collection/p266901coll4/id/2144.

data, making the HIO less valuable to its stakeholders.[36, 37, 38, 39] Privacy issues and the amount of time and money needed to overcome them was identified as one of the reasons for the Santa Barbara failure.[40] In addition, one recent study found that states with stricter privacy laws for data sharing had a lower number of HIO failures and a higher number of HIOs that were exchanging data. The authors believed that their finding was due to a higher level of trust from the HIO stakeholders and patients due to the stricter data sharing laws.[41]

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[36] Health Information Exchange: Persistent Challenges and New Strategies. Joshua Vest and Larry Gamm. J Am Med Inform Assoc 2010;17:3 288-294. http://jamia.bmj.com/content/17/3/288.full.

[37] Health Information Exchanges and Megachange. Darrell West and Allan Friedman. The Brookings Institution. Washington, DC: February 2012. http://www.brookings.edu/research/papers/2012/02/08-health-info-exchange-friedman-west.

[38] Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? Joy Grossman, Kathryn Kushner, Elizabeth November. HSC Research Brief No. 2: February 2008. http://www.hschange.org/CONTENT/970/.

[39] A Report to the President: Realizing the Full Potential of Health Information Technology to Improve the Healthcare of Americans, the Path Forward. *Executive Office of the President:* President's Council of Advisors on Science and Technology. Washington DC*: 2010.* http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf.

[40] From Santa Barbara To Washington: A Person's And A Nation's Journey Toward Portable Health Information. David J. Brailer. Health Aff September 2007 26:5w581-w588. http://content.healthaffairs.org/content/26/5/w581.full.

[41] Impact of Health Disclosure Laws on Health Information Exchanges. Idris Adjerid and Rema Padman. AMIA Annu Symp Proc. 2011; 2011: 48–56. Published online October 22, 2011. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243116/.