Information Infrastructure for Public Health and Health Research: Findings from a Large-Scale HIE Stakeholder Study

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Abstract

While the information infrastructure to support public health and health research has been dramatically improving, comprehensive, nation-wide, longitudinal, person-centered information has been generally nonexistent. Yet, having such information for large populations is essential to public health and health research. The coupling of internet access, information standards and emerging electronic health records is beginning to provide an enabling infrastructure for population-wide health information capture and transfer. However, the essential infrastructure component that is still missing is effective health information exchange (HIE) that has specific public health and health research-supporting functionality at nation-wide, state-wide and community-wide levels.

To better understand the requirements for HIE at a community-wide level, our exploratory research investigated needs and attitudes of over 1200 stakeholders including members of public health, health research and consumer sectors. This paper reports on the study's finding including the functional and infrastructure recommendations of public health and health research stakeholders, and the resultant design attributes for a consumer-centric community HIE which could be linked into a nation-wide HIE network for purposes of improving care, decreasing health related costs and supporting research.

1. Introduction

Virtually all public health and health research functions are expertise and information-based. While the information infrastructure to support such functions has dramatically improved during the last 20 years, comprehensive, longitudinal, person-centered information has been generally nonexistent beyond relatively small sets that were created for specific research purposes. Yet, having such information related to large populations is now coming within our reach. The coupling of Internet access, evolving information transfer and semantic standards, and emerging Electronic Health Records

(EHRs) and Personal Health Records (PHRs) (see Glossary of Terms) is now forming the enabling infrastructure necessary for population-wide health information capture. However, for epidemiology and health research, as well as care delivery and coordination, the infrastructure component that is still missing is effective health information exchange (HIE) operated by Regional Health Information Organizations (RHIOs) and other HIE organizations (HIOs) (see Glossary) which can support specific research functionality. Therefore, the current development of RHIOs, HIOs, HIE and a nation-wide HIE infrastructure is of paramount importance to achieving an effective nation-wide comprehensive, longitudinal person-centric information resource.
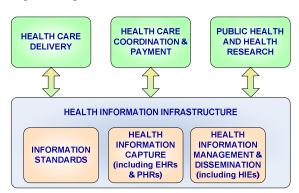

Figure 1. Multi-purpose health information environment

While the American Recovery and Reinvestment Act of 2009 (ARRA) incents *institutional* EHR adoption with over $19B [1], efforts to develop a nation-wide HIE infrastructure in the US continue to be complicated by issues including functional insufficiency for health research, consumer non-engagement, privacy and trust, *sustainable* funding, industry fragmentation and lack of social capital [2, 3]. Since 2004, when President Bush called for widespread use of EHRs by 2014 [4], nearly 400 HIE initiatives have been planned, started, or discontinued [5]. In 2008 and 2009, limited demonstrable success had occurred. As a California Healthcare Foundation (January 2008) report stated: "For those who have

been part of the Health Information Technology (HIT) world for a while, hope for a nation-wide EHR remains an unfulfilled goal, still beyond our collective grasp" [6]. There are many reasons for this, one of which is the inherent inability of many HIE models to overcome pragmatic development and operations issues [7-9]. Another is the failure of HIE models to sufficiently address the value of HIE for health research and consumer engagement that would bolster nation-wide HIE adoption.

To more fully understand the value of HIE, our recent exploratory study investigated needs and attitudes of a broad range of community stakeholders, including public health staff, health researchers and consumers. This paper reports on this study's findings. It briefly discusses the context of HIE, the design attributes that stakeholders require, the functional and infrastructure recommendations of public health and health research stakeholders, and the rationale for establishing a nation-wide network of consumer-centric HIEs for sharing individuals' health-related information.

2. Exchanging Health Information: Background

The concept of electronically sharing a patient's health information among that person's clinicians is not new – indeed the concept is more than 40 years old [10]. Success in implementing the concept, to date, has been primarily limited to sharing among facilities of the same health system, or among business partners, and is embodied in the adoption of Electronic Medical Records (EMRs) (see Glossary) and, more recently, in the adoption of nascent EHRs.

In the 1990's, a major attempt to share such information among a person's health care providers from different, perhaps competing, organizations was initiated. These efforts were embodied in Community Health Information Networks (CHINs) and received start-up funding from the federal government, as well as grants and in-kind contributions from participating organizations. CHINs failed to thrive; in fact few moved beyond their embryonic phase. The 'bottom line' reason for their failure was their lack of a viable 'bottom line': no sustainable business model was implemented. When their governmental or private-sector 'angel' funds were consumed, they collapsed [11, 12].

In recent years, the core CHIN concept of sharing a patient's information among interested parties has been instantiated in the form of HIE operated via RHIOs. Various RHIO models have emerged that define their purposes, goals, and business models quite differently. They have been promoted by federal and state governments; interested health-related corporations such as Health Care Information Systems (HCIS) vendors; health care delivery organizations; and other interested parties. But, as of 2009, some notable RHIOs had already ceased operation due to factors such as lack of a sustainable business model, lack of stakeholder adoption, consent issues, and technology challenges [8, 13-16].

So, will some form of RHIO/HIE succeed when no wide-spread successful form of CHIN did and when many current attempts are facing difficulties? What form has a reasonable chance of success? What attributes are most critical? Will public health staff, health researchers and consumers be included or excluded?

3. RHIO/HIE Critical Attributes: What Has to Go Right this Time?

The types of stakeholders and their motives have changed little in the decade between CHINs and RHIOs. So, the success or failure of a particular RHIO model for HIE will, once again, depend on its ability to create value on an ongoing basis and to be rewarded for that value at levels that meet or exceed its costs. This straightforward statement belies the labyrinth of different motives, relationships, and values of RHIO stakeholders.

Some models that have restricted goals and a well delimited set of stakeholders may succeed due to the value of efficiency and cost reduction of the information exchange transactions between the parties [17, 18]. Implementing models based on modest goals may be the most pragmatic approach to advance adoption [17]. But, where will they lead, especially considering difficulties RHIOs have experienced trying to expand from a limited initial scope to a more broad array of services [19]? This question invites an examination of the super-set of goals and consideration of a RHIO model that would be more forward looking and provide a greater set of benefits. Based on the wide-ranging discussions of centralized or federated / decentralized models in addition to physician controlled, payer controlled or consumer controlled models in many national forums, we can infer the following critical attributes for a future-state RHIO/HIE:
- Complete, accurate and timely health information to enable health-related decisions and actions;
- Appropriately authorized contribution and extraction of health information;

- Secure processes, data repositories and information transfer to prevent unauthorized access or modification of data;
- Maintenance of personal privacy; and
- Original information, coupled with identified corrections, upon which the recipient can rely.

Each of these attributes is intrinsically complex. For instance, "timely availability" requires a reliable data collection, storage, operations, and dissemination infrastructure. Further, it presumes technical and semantic interoperability, which, in turn, requires an operable level of standardization and cooperation of architectures, technologies, taxonomies, and semantic metadata, among many other factors.

These attributes also have implications for the RHIO's responsibility for HIE. Increasingly, "authorized" includes not only the clinicians and other health workers who create or record an individual's health information, but also the person whose information is being recorded and exchanged [20, 21]. Additionally, the exchanged information has value to the larger society through public health and health research; so what authorization should this additional tier of stakeholders have?

Given the history of HIE, a key question is: what inter-organizational RHIO/HIE model could succeed? "Succeed" would imply that business and technical processes were viable and sustainable for the RHIO stakeholders. "Stakeholders" would imply the traditional health industry entities, but, today, would also include the patient and the patient's advocates [22], as well as those that would derive value from the secondary use of the information: public health agencies and health researchers [23]. In fact, reasonable scenarios offer the view that the patient, or person, will prove to be the central actor in the widespread adoption and use of PHRs associated with an HIE environment, and with authorization for the use of his or her information in HIE [24, 25]. Moreover, the 'person' serves as the most effective unit of analysis for the wide variety of health research that could benefit from RHIO/HIE operations.

4. Research Context

These questions led one community, embodied in a Louisville, Kentucky HIE organization referred to as LouHIE, to join with staff from the University of Louisville, Case Western Reserve University and the Noblis Center for Health Innovation to undertake community-based research. These nonprofit organizations' research took as axiomatic the above set of RHIO/HIE critical attributes. The research objectives included, in part, investigation of a

comprehensive future state RHIO/HIE model based on health record banking (HRB) [26-29] as a potentially viable approach. HRB was pre-selected by LouHIE as a potential core business and technical approach because of its potential to reduce the complexity of informatics, technology and privacy policy design and development – issues that have caused other RHIO/HIE models (e.g., federated, provider-led, insurance-led, etc.) to fail [14]. As defined by the Health Record Banking Alliance (2008):

A health record bank or trust is an independent organization that provides a secure, persistent, electronic repository for storing and maintaining an individual's personal health related information. Specific characteristics of a health record bank include:

- **Consumer control** – *the consumer chooses to participate, thereby registering for the service and in doing so, provides consent to those who can view their information; consumers also choose which providers can deposit and withdraw from their own account; the consumer can also consent to participating in research studies;*
- **Secure repository** – *storing and maintaining the individual's lifetime clinical and financial health related information;*
- **Interoperable** – *provides linkage to relevant data sources such as hospitals, physicians, and pharmacies using appropriate standards;*
- **Personal account** – *provides a personal view into the bank and enables the storage and retrieval of information; information entered manually will be separately identifiable from other data sources [30].*

LouHIE found that while most RHIOs assume that some forms of authorized, secure, private, timely and accurate HIE can financially benefit both providers and payors, HRB posits that *all stakeholders*, including consumers, employers, public health and health researchers can benefit directly from the successful adoption and operation of a HRB approach to RHIO/HIE. The research focus followed from LouHIE's decision to emphasize the HRB approach and sought to shed light on questions including:

1. What are stakeholder attitudes to participation in HIE?
2. What are their attitudes about including public health and health research infrastructure in the HIE design?
3. Do their responses support or contra-indicate the core concepts of a HRB approach for community HIE?

5. Research Methods

Research which explored these three questions occurred during August and September, 2007. Researchers from LouHIE, the University of Louisville, Case Western Reserve University, and Noblis used a mixed methods design [31] appropriate for a community action research context [32, 33]. Multiple stakeholder groups provided input through telephone, web and paper surveys and focus groups. Over 1200 individual respondents participated representing 12 major stakeholder groups from 10 counties in the Louisville metropolitan area plus the population of consumers they serve.

The primary research objective was to advance knowledge of stakeholder and consumer *interests, perceived benefits, concerns* and *payment choices* related to participating in a community HRB for HIE. An additional objective was to gather guidance for how to develop an underlying organizational and business model that all stakeholders could support.

The sample frame was the ~1.2 million consumers living in the 10 county Louisville area, plus 12 kinds of organizations which serve them. A randomized sample of 386 consumers was used for the telephone survey, sufficient to support statistically significant results for the population (95% confidence level with a 5% margin of error). In addition, 355 non-randomly selected consumers completed a survey on paper (via the state fair, or physicians' offices) or through a web survey and 15 consumers participated in 3 consumer focus group sessions.

Organizational (non-consumer) input was gathered through web surveys and focus groups. 252 organizational leaders completed 1 of 12 web surveys designed for their stakeholder group. In addition, 194 organizational leaders participated in 1 of 23 stakeholder focus groups. For example, leaders from all major area hospitals participated in 1 of 2 hospital focus groups and 18 physicians participated in 1 of 2 physician focus groups. The definitions used for the 12 stakeholder groups were:

1. Medicaid and/or safety-net (leaders of key organizations in the community).
2. Employer (leaders of HR departments, small businesses and Taft-Hartley benefit funds).
3. Senior Citizen and/or Medicare service (area leaders of AARP, Medicare and Quality Improvement Organizations).
4. Health plan, payor or third party administrator (appropriate leaders of area health plans).
5. Health information technology related products or services (leaders of national firms serving the area).
6. Educator or trainer of healthcare workers (leaders of appropriate area colleges and universities)
7. Pharmaceutical or medical products firm (local liaisons for these firms).
8. Hospital or other in-patient provider (leaders of area hospitals).
9. Pharmacy or other medical product retailer (leaders of pharmacy chains/suppliers).
10. Public health department (area directors or program managers).
11. Physician office or other healthcare practice (practicing physicians and office managers).
12. Nurse or other practitioner (practicing nurses).

Additionally, relevant subsets of the stakeholder groups plus university health researchers were convened in a focus group to further explore public health and health research needs and opportunities.

Recruitment of participants for web surveys and focus groups was conducted through multiple channels including newspaper and television announcements generated through a press release from the Mayor's office, messages from local associations to their members, and direct telephone calls to potential participants. The Mayor's message was designed to maximize participation rates by community stakeholders.

Research instruments were developed to minimize instrumentation bias and strengthen the objectivity of the information gathered. At the start of the phone survey a description of community HRB was provided, and confirmation was obtained that the consumer understood the concept before questions were asked. For web surveys, participants read a special web page explanation and confirmed understanding of the concept prior to answering questions. For focus groups, a seven minute video was played explaining the concept followed by a set of structured questions appropriate to the group involved. For each survey type, the questionnaires were validated prior to use. For example, the consumer questions were "tested" with a small set of consumers to make sure they made sense, and the hospital and physicians questionnaires were refined through input from leaders of area hospital and physician associations.

A research team of 7 people analyzed, reviewed and discussed the results in a series of analytical meetings both during and after the research activity. The analytical process emphasized triangulation to identify key themes and patterns emerging from the inputs obtained [34, 35]. The use of multiple modes of input combined with triangulation has been shown to improve reliability and validity in qualitative, action oriented research in complex environments

[31, 34, 36]. Transcripts of the consumer focus groups were reviewed and analyzed to identify key themes, and a key themes database was generated. These themes were then cross-matched with the telephone survey and web survey results to identify consumers' key interests, perceived benefits, concerns and payment choices related to participating in a community HIE with HRB. A similar process was used to analyze data for each of the 12 organizational stakeholder groups.

Extensive discussions and analyses were then conducted by the research team to hone in on an underlying organizational and business model most likely to garner support from all sectors of the community. The team operated using a consensus model: debate and discussion continued until consensus was reached about how to interpret the data. Result summaries were then reviewed with stakeholders leading to further refinement and ultimately verification of the data interpretation.

There are important limitations to the study design. Consumer unfamiliarity with the concepts of HIE and HRB means that consumer perceptions could change as more knowledge is obtained or the environment changes. Some organizational stakeholder focus groups had a potentially significant self-selection bias: they included participants with greater than average knowledge of the concepts and technologies involved in HIE and HRB. In addition, self-selected participants were, on average, likely to either be more strongly in support of or more strongly opposed to the concepts of HIE and HRB than a random selection would have been. Self-selection bias notwithstanding, review of the responses from across the focus groups found that many groups shared common ground with each other and with consumers on a number of the key issues such as trust, privacy and the importance of medication information [37].

6. Findings - Stakeholder Participation in HIE

The research identified numerous issues related to consumer and organizational stakeholder participation in HIE and HRB, including concerns about health, privacy, health research, governance, and, effects on organizational operations, technology, and finances. The research led to the development of the following groups of requirements:

- **Individual participation.** The demand for individual consumer involvement was widespread. Twenty four percent (24%) of the consumers responding to the telephone survey said they would use an electronic personal HRB

service if it was free, 35% said they would pay $5-15 per month for it, 10% were unsure, and 31% said they wouldn't use it. In addition, increased knowledge of the concept appeared likely to increase this demand. For a non-random selection of 355 consumers who had more time to become familiar with the concept at a fair-booth, physician office or online before taking a paper or web survey, 93% said they would use the service on a free or paid basis. An inference is that in an HIE implementation, educational interventions should materially increase awareness, interest, and understanding, resulting in increased demand and adoption rates of HIE/HRB. Such consumer interest in using HIE/HRB could, in turn, provide greater motivation for other stakeholders, such as care providers, to adopt the technology. Care providers would need to be responsive to their patients' demands for the technology's use or risk the chance that their patients would go elsewhere for care where such technology is available and embraced or at least supported.

- **Trust / privacy / security.** These three findings were inextricably intertwined and universally required.
  - The need for a 'trusted environment' for HIE was essential since the majority of community respondents considered an individual's health information to be deeply personal and private. Consumers expressed a high degree of concern about being harmed by others who may inappropriately access their private information. Organizations expressed commensurate concerns about potential liabilities that could be created for them by privacy violations or uncontrolled personal health information sharing. The phone survey indicated that 57% of the population would trust a family member or friend to recommend the service, 40% would trust a physician, 8% would trust a recommendation from their employer, 3% would trust their insurance company, and a negligible percent would trust the government to recommend the service.
  - Privacy and security. Participants wanted the RHIO to assure that privacy and appropriate levels of security would be in place to insure against intrusion, unauthorized use and corruption or destruction of their health information. Consumers expected that appropriate controls would be put in place: "just like the financial industry has provided. Health care should not be any different" (a respondent's comment).

- Trusted not-for-profit community organization. Consumer participants commonly stated that they would trust a dedicated community not-for-profit more than government or for-profit organization. Respondents generally believed that not-for-profits would be more likely to stay focused on their mission than for-profits. For example, for-profits would be less likely to retain information for the long-term for public health, health research and consumers.

- **Functionality.** By functionality, we refer to the features, attributes and information that respondents identified as necessary for inclusion in the HIE/HRB to make it desirable to adopt and use.
  - Consumer choice. Consumer respondents wanted the ability to control access to their information and make choices on whether or not to participate in research programs, personalized messaging programs, or other types of services.
  - Information and services. Medication information was the most commonly required information sharing category. Most stakeholders believed that this ability could immediately save time and costs, and improve patient safety across the community. Further, a majority of consumers were interested in: streamlined registration, tracking their own records, safer emergency care, improved care quality and reduced duplicative services and costs.
  - Cellular telephone connectivity. Ability to reach many of the participants for a variety of reasons (e.g., emergency contact, public health alerts) was of interest. Respondents believed that consumers would value ability to use increasingly ubiquitous cellular phones to access health information via phone or web.
  - Public Health and Research usage. Based on consumer consent and appropriate privacy safeguards, the consumer respondents widely supported providing access to public health and health researchers.
  - Geographic ubiquity. Most respondents indicated that the HIE/HBR should not be an isolated entity. Staying within LouHIE's initial ten county area is not adequate for some consumers and stakeholders. For the HRB to work, they indicated that it must be interoperable with other HIEs and HRBs to support the mobility of today's society.
  - Portability. Closely related to geography, respondents commonly felt that their data must "remain with the consumer regardless of the

consumer's physical location." That is, that it must be web-accessible, and that there must be a network of same-model HIEs that they can "transfer to" as they relocate. They indicated that this is an essential aspect of the HIE/HRB as they envision it.

- **Value creation.** Virtually all stakeholders, including consumers, indicated that value for the individual and/or their care givers must exist if they are to participate in an HIE.
  - Payment for value received. Consumers indicated that they will choose to use or buy options or services that provide value. They were agreeable to have operational expenses off-set with other third-party revenue streams such as advertising or research as long as they have a choice to participate, and knowledge and control of their information's use by third parties.
  - Accessible to all. The majority of respondents recognized that community value of HIE increases with the comprehensive inclusion of all community members. Uninsured, under-insured and low income populations were essential to include, since these populations are most in need of the service.
  - Re-invest in the community. Many respondents indicated that the intended mission of LouHIE is important and worth supporting. They also indicated that its use of any excess revenues to fund additional community health services for those most in need was preferable to having profits go to a for-profit organization.
  - Public Health and Health Research. Most stakeholders recognized that the secondary use of health information for both public health and health research could also produce value. This usage primarily related to epidemiology, disease surveillance and reporting and clinical health research conducted by public health and health research organizations. While there was wide acceptance for use of the information for public health and health research purposes, there was generally a negative attitude toward use for commercial market research.
  - Employer Value. Employers saw value in an HIE/HRB service, and some expressed willingness to fund it for their employees, provided a majority of physicians and hospitals across the community were linked to it. Their funding would be tied to demonstration of a return on investment through cost savings or wellness improvement. Employers with regional or national footprints also needed

assurance that the service would link with national networks.

- Payor Value. Payors saw value in an HIE/HRB service provided it was aligned with emerging state and national standards, focused on gathering clinical rather than claims information, was complementary to their consumer service offerings and could generate measurable improvements in cost-savings or quality of care. Some payors saw value in being able to offer their members secure access to the HRB through their portals, with the understanding that the payor would not have access to the members' clinical information without consent.

- Hospital Value. Hospitals valued an HIE/HRB service, and expressed willingness to provide appropriate funding support, to the degree it could generate operational efficiencies such as more automated medication reconciliation, better access to lab information, and provision of better patient information in the emergency department. Permissions to use the service would have to be incorporated into patient registration workflow. Interfaces to hospital EMRs and EHRs would need to be available.

- Physician Value. Physicians saw value in a simple, standardized, *patient clinical summary* containing validated medication, allergy, lab and other summary information, which could be printed out at registration for most or all patients, automatically updated via electronic eRX and eLab networks, and integrated with nationally certified EMRs if they had them. Basic services needed to be offered free to both physicians and their patients, with consents being provided through an updated HIPAA type form at the point of registration.

- Medicaid Value. The local Medicaid HMO saw value in community-wide HIE, but needed assurances that the service could be aligned with state and Federal HIE policy; be compatible with Medicaid's current methods for enrolling members and authorizing their care; and work for the many Medicaid recipients who were unlikely to ever use PHRs or computers. To secure such assurances would require modifications in state and/or federal policy, particularly with respect to privacy and data-sharing.

7. Findings - Public Health and Health Research Infrastructure

The research also explored in some detail requirements for public health and health research infrastructure integrated with HIE/HRB. Key stakeholder requirements included:

- **Anonymized data.** A requirement of consumer respondents was that researchers usually only have access to anonymized data. Public health and health researcher respondents agreed that the anonymous data would be acceptable, but, were desirous of having real-time updates from providers which were re-identifible. Public health responders pointed out that for some reportable diseases and conditions re-identifiable health data is, or may be mandated by law or regulations.

- **Re-identifiable identity codes.** Respondents required that all data be correctly associated with the individual or individuals to which it pertained. This requires the use of blinded identity codes that can allow identity tracking, and, if needed, re-identification of all associated entities through all phases of information creation, maintenance and dissemination. The entities specifically mentioned included: person/patient, provider, and provider organization.

- **Patient-specific longitudinal clinical data.** Full clinical information that is patient specific is required. Additionally most respondents required that the clinical information be longitudinal. The HIE/HRB infrastructure should gather, maintain and make available (with permission and as appropriate) all of the available clinical information for a consumer.

- **Patient specific demographic data.** Similarly, patient demographic information including social and financial information is required. Longitudinal information, especially prior residency locations and prior health insurance coverage information was seen as important.

- **Unmodified data.** Respondents indicated the criticality of having unmodified data that is accessible as it was created. If the data was later proven to be erroneous, it should be flagged as such, with corrected information appended, rather than having the prior data be replaced. The original and corrected data should be simultaneously available and viewable.

- **Controlled researcher access.** This issue is related to trust, information security, and information accuracy. Respondents indicated the need for positive identification of individuals attempting to access the data, system based limits

for access that are consistent with approved research protocols, system based access logs, and related access control functions.

- **Ability for patients to enter and review research-specific data elements through a HIE/HRB connected PHR.** Respondents expressed the need for patients to be able to enter and review data elements through a PHR in support of specific research protocols.
- **Ability to graft additional databases and applications.** Virtually all researchers and public health officials indicated the need to be able to link the HIE/HRB anonymized data with other relevant databases, applications and registries and use the combined information in other specific or expanded research areas. Among these are:
  - Geographic / spatial databases to longitudinally track an individual
  - Epidemiology databases, including exposure to diseases and toxins in the joining of the exposure information with the geographic information related to the patient/person
  - Consumer and medical product databases
  - Disease registries
  - Surveillance applications
  - Statistical and related research software
  - Decision support software

The above responses are from a limited participant population. While being entirely valid, these responses should not be construed as a definitive list of all functionality that the public health and health research community would require.

8. Findings – Support for Health Record Banking

The research implied a number of characteristics that would be needed in the HIE environment that the respondents envisioned. These condense into core design considerations including a sustainable business model and a trust-worthy operating model which can provide new value to most or all of the stakeholder groups. Key design features supported by the research include:

- **Medication history and medication reconciliation.** This should be the initial focus of the HRB; allergies, lab results, immunizations and other data should follow (in that order).
- **Consumer opt-in.** Consumers will opt-in to the service if physicians "recommend" it at the point of care. To make this happen, basic service must be free to consumers and physicians and a simple opt-in form included at patient registration.

- **Trust for the RHIO.** Earning trust is critical and will be maximized with an all-stakeholder governed non-profit 501c(3) with government participation and appropriate government oversight of privacy and security.
- **Revenues.** Revenues should be generated through a combination of grants, contributions, and payments for special services such as messaging, advertising, alerts, provider subscription fees and fees for research access [38]. Since use of services can be tracked, a "national public radio" approach to funding could be used – where individuals and organizations using "free" basic services are periodically asked to contribute a fair share based on their usage.
- **Technology.** Technology implementation should be outsourced to a large stable company with resources to build and grow the technology. To illustrate, one consumer said they would trust Microsoft to provide the technology as long as a community non-profit governed the operations.
- **Interoperability**. The HIE/HRB should interoperate with all certified EMRs, EHRs and PHRs, and should support integration with other technologies emerging in the marketplace such as wellness or medical device technologies.
- **Research services.** An anonymized research repository, separate from the main HIE/HRB system and integratable with external research data sources, should be developed to support public health and heath research needs..

The research findings and implications both validated and expanded LouHIE's initial conceptual model. The evolved LouHIE model most closely maps to the HRB model. It puts "control" in the hands of the consumer; therefore, the complex business partner agreements necessary for privacy considerations are mediated by the consumer and have the potential to decrease inter-organizational control conflict. By placing the consumer in the center of his/her health information 'universe,' the likelihood of consumers choosing to use a HIE/HRB model is significantly increased.

However, only creating a single HIE/HRB is not a comprehensive answer. As noted above, the need was repeatedly expressed to expand beyond the geographical boundaries of a single community. This need suggests the creation of a network of interoperable HRBs which also interoperate with federated (or decentralized) and hybrid (both centralized and decentralized repository) HIEs. This is necessary to insure portability of information and to meet the Congressional mandate to have electronic health records in place by 2014.

Is development of such a national network of HRB based HIEs feasible? An analysis by some members of the research team indicated that a nationally coordinated strategy, beginning with pilots in several communities, could lead to achievement of such a vision [38]. However, the final direction for HIE that will be supported by the Federal and state governments is still under development, and may not include HRB capabilities.

9. Conclusion

America must accelerate progress in the quest to improve the health status of the population by improving patient safety, health care quality and health care efficiency. An intrinsic part of this improvement is providing our public health officers and health researchers access to complete, accurate, timely, and longitudinal patient/person-specific (but anonymized) clinical and financial information so that early detection, discovery, and intervention is increasingly effective. How can this be done?

This paper reported on an exploratory research project which investigated the needs and attitudes of over 1200 representatives of a community of 1.2 million people regarding the formation of a RHIO/HIE. The research focused on whether a HRB approach to HIE had potential to be financially and operationally feasible. Major findings included 1.) the interests and perspectives of 12 stakeholder groups and the consumers they serve with respect to community HIE; 2.) specific interests and requirements of public health and research sectors with respect to integrating health research capabilities into the RHIO/HIE; and 3.) general reactions regarding the HRB approach.

The research supports the development of a consumer permission driven HRB model at the community level, in order to achieve the development of financially sustainable HIE across the community. By creating new revenue streams from consumers, research data users, and other parties, while also reducing legal, regulatory, informatics and technology costs related to HIE administration the model offers a superior approach to that of some RHIO business models in the literature. It also offers potential to reduce the burden of government to pay for HIE infrastructure. However, for such a model to flourish at a community level, it will need to be part of a nation-wide network of RHIOs/HIEs with compatible HRB approaches Whether and how such a nation-wide network of HRBs will or can be supported through Federal or state policy remains to be seen. However, the research indicates that failure to

develop such an approach may limit the nation's capabilities to develop certain kinds of consumer consent-driven databases useful for public health and health research

10. Glossary of Terms

Electronic Health Record (EHR). "An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization [39]."

Electronic Medical Record (EMR). "An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization [39]."

Health Information Organization (HIO). "An organization that oversees and governs the exchange of health related information among organizations according to nationally recognized standards [39]."

Health Information Exchange (HIE). "The electronic movement of health-related information among organizations according to nationally recognized standards [39]."

Health Record Bank (HRB). See page 3.

Personal Health Record (PHR). "An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual [39]."

Regional Health Information Organization (RHIO). "A health information organization that brings together health care stakeholders within a defined geographic area and governs health information exchange among them for the purpose of improving health and care in that community [39]."

11. References

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