

THE INTERPLAY OF TOP-DOWN AND BOTTOM-UP: APPROACHES FOR ACHIEVING SUSTAINABLE HEALTH INFORMATION EXCHANGE

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THE INTERPLAY OF TOP-DOWN AND BOTTOM-UP: APPROACHES FOR ACHIEVING SUSTAINABLE HEALTH INFORMATION EXCHANGE

Research in Progress

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Abstract

The exchange of patient health information across different organizations involved in healthcare delivery has potential benefits for a wide range of stakeholders. However, many governments in Europe and in the U.S. have, despite both top-down and bottom-up initiatives, experienced major barriers in achieving sustainable models for implementing health information exchange (HIE) throughout their healthcare systems. In the case of the U.S., three years after stimulus funding allocated as part of the 2009 HITECH Act, the extent to which government funding will be needed to sustain health information organizations (HIOs) that facilitate HIE across regional stakeholders remains an unanswered question. This research investigates the impacts of top-down and bottom-up initiatives on the evolutionary paths of HIOs in two contingent states in the U.S. (New Jersey and New York) which had different starting positions before the HITECH funding. Based on our analyses of interview data collected from 34 leaders at the state, HIO, and provider level, our objective is to develop a model of contextual and operational factors that influence the sustainability of HIOs. The implications of our findings for other networks of heterogeneous healthcare systems, such as in the European landscape, will also be explored.

Keywords: Health Information Exchange, Health Information Organizations, Health Information Technology, U.S. HITECH Act, Multi-level analysis, Qualitative research.

1 Motivation

Health information exchange (HIE) refers to a capability that ‘lets the data follow the patient’ by moving healthcare information across various parties involved in healthcare delivery, which can include providers (hospitals, physician practices, integrated delivery systems, safety-net providers), suppliers (labs, imaging, pharmacies), payers (public and private insurers), and public health agencies. HIE thus represents the next major thrust of health information technology proliferation, for which electronic health records used by providers are a necessary, but not sufficient condition (Jha et al., 2009). The electronic sharing of patient information *beyond* organizational boundaries is recognized as key to obtaining cost and quality of care benefits, for example, through reduced diagnostic errors, reduction of duplicate analyses, faster processing of lab reports, prescriptions and clinical documentation, continuity of patient care, and thus improved public safety and a better means for improving population health (Hillestad et al., 2005).

Although many governments worldwide have passed legislation and made significant investments to advance health information sharing, HIE proliferation has remained slow (Deutsch et al., 2010; Vest et al., 2012). For example, in Germany a major “top-down” legislative initiative towards HIE is the electronic health insurance card (elektronische Gesundheitskarte), which was to be launched in 2006 but has been postponed several times due to changing political decisions, security concerns, and a lack of support from the medical profession (Lang and Mertes, 2011). Effective January 2014, a card system will be introduced to support mainly administrative functions as a basis for future health information sharing through a telematics infrastructure operated by a national multi-stakeholder entity. According to early estimates, the costs of about Euro 14 billion for this project may not yield equivalent cost savings before a period of about 10 years (Schweim, 2007).

In the UK, since the formation of the National Health Service’s Connecting for Health (CfH) in 2005, a foundation of policies and infrastructure has led to the achievement of a national-scale clinical information exchange under the NHS National Programme for IT. Nevertheless, the results of the CfH have fallen short of what some expected in terms of coverage of information and population. Similar to Germany’s initiative, it has been criticized for the lack of payoffs for the public investment, since much of the success in information exchange has been attributed to “bottom-up” initiatives at the local level (Payne et al., 2011).

In the U.S., given the mix of national and state-level stakeholders and the pluralistic healthcare landscape, the efforts for HIE have primarily been directed at regional health information organizations (RHIOs), which typically are not-for-profit entities that coordinate across healthcare providers and other stakeholders within a defined geographic area (Lenert et al., 2012). Although both national agencies and some U.S. states have provided significant seed money and sponsored pilots over the past decade, achieving the goal of moving health information across organizational borders has been elusive and high defunct rates had been reported for RHIOs being planned and those that were operational (Adler-Milstein et al., 2008). One of the key barriers to achieving value from information exchange across a network of otherwise independent providers has been the slow adoption of electronic patient record keeping at the point-of-care (Jha et al., 2009), especially in small physician practices. In addition, the lack of technology and data transfer standards, potential revenue loss to competing providers, and patient privacy & security concerns have been reported as inhibitors (Edwards et al., 2010).

The U.S. Health Information Technology for Economic and Clinical Health (HITECH) Act signed into federal law in February 2009 has been a major catalyst for increased HIE investments in multiple ways. First, about \$21 billion in funding was allocated for incentive payments to eligible hospitals and physician practices that adopt certified electronic health record (EHR) technology and meet key objectives for federally-established “meaningful use” criteria. As of October 2013, \$17 billion in

payments had been made to 4,246 eligible hospitals and 426,261 individual physicians in Medicare and Medicaid eligible practices (CMS, 2013). In addition, the HITECH Act also granted three-year funding for two types of state-level initiatives under the oversight of a more permanently funded Office of the National Coordinator for Health IT (ONC): Regional Extension Center (REC) grants to promote EHR adoption—which also has spurred provider HIE participation (Furukawa et al., 2013)—and HIE grants (to states and state-designated entities) for implementing state-specific plans for health information exchange across providers and other stakeholders. The HITECH Act therefore provided a “top-down” stimulus to achieving HIE “bottom-up” via regional networks of providers using common standards (Lenert et al., 2012). These networks would evolve to (potentially) share data with state-level “hubs” that in turn would eventually link to a nationwide eHealth exchange (Healthway, 2013). Figure 1 depicts the different levels of potential HIE networks of healthcare providers and the interplay of top-down and bottom-up initiatives in a U.S. context. (Note: other stakeholders, such as suppliers (labs, imaging, pharmacies) and payers, are not included in this scheme).

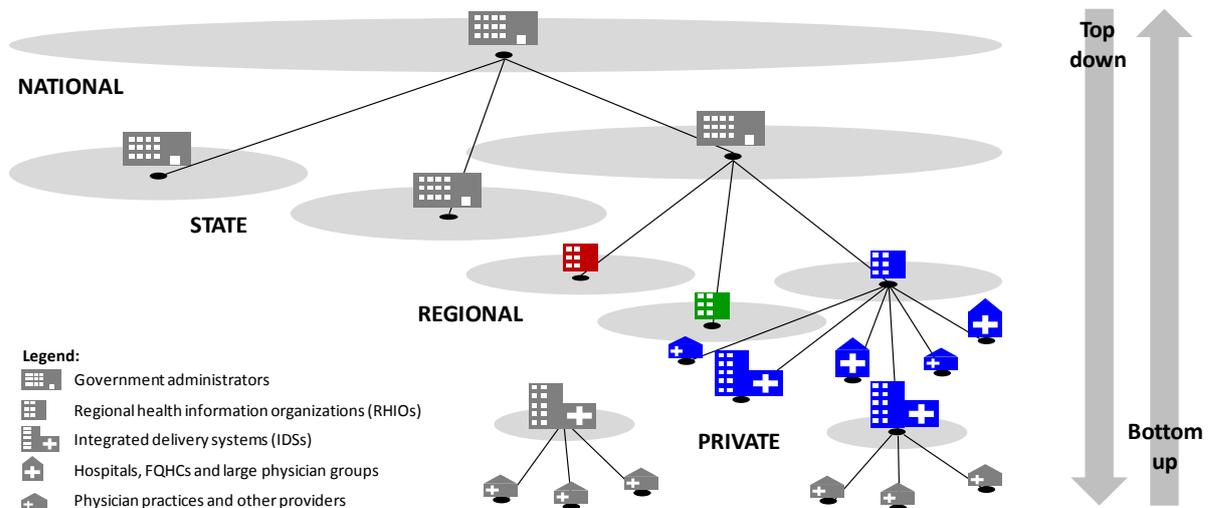


Figure 1. Multi-level network for health information exchange across providers (authors' representation).

We assume that how “top-down” and “bottom-up” strategies enable a widespread capability of health information exchange will be highly dependent on characteristics of the national healthcare systems (be it Germany, UK or the U.S.). For this current study our research design focuses on two contiguous states within the same national context (the U.S.) that have exhibited different evolutionary paths at the state and HIO levels. This study therefore is also designed to take advantage of “natural controls” due to the recent HITECH grants. More specifically, in one of the two states in which we collected interview data (New Jersey), the HITECH funding was a direct catalyst for the creation of multiple HIOs throughout the state for the first time. In contrast, in the contiguous state of New York, significant HIO funding from federal and state-level sources had already resulted in eleven HIOs and plans for a state-operated HIE infrastructure.

Although reaching a “tipping point” in EHR adoption has been reported (Conn, 2013; Furukawa et al., 2013), the extent to which government funding will be a requirement for HIO and state-level HIE activities is still being reported as a concern (Adler-Milstein et al., 2013; Dullabh et al., 2013). In the past, it has been recognized that public health reporting and other secondary uses of clinical information will benefit government agencies as well as the public (Shapiro and Kuperman, 2011), and thus ongoing government funding for this “public good” will be needed. On the other hand, some HIOs have already demonstrated sustainable business models due to private and non-profit stakeholders accruing significant value from HIE (Adler-Milstein et al., 2010). Therefore, our study is

also designed to capture factors that influence the financial and operational viability at the HIO level. Accordingly, the two research questions to be addressed by this study are:

(RQ1) Which contextual and operational factors influence the sustainability of an HIO?

(RQ2) How can a combination of top-down and bottom-up initiatives enable widespread HIE?

Next we describe our research methodology and summarize the state-level HIE characteristics for the two states we studied. We then provide some overall observations and expectations for findings that will be available for presentation at ECIS—as part of our research-in-progress submission.

2 Methodology

Following a review of relevant literature, we designed a multi-level paired case study approach and conducted interviews with 34 HIE stakeholders in leadership roles at the state, HIO, and provider level (State HIT administrators and REC directors: 7, HIO directors and managers: 13, provider CIOs and IT managers: 9, other: 5) in two contiguous U.S. states (NJ: 24, NY: 10) between June and August 2013—which was about six months prior to the end of the federal HIE grant funding period. The interviews, which typically lasted between 45 and 60 minutes, were led by two of the researchers using position-specific semi-structured interview guides and were audio recorded with consent of the participants. Relevant national, state-level, and HIO-level archival documents were also collected from public websites as well as from some of the interviewees. At the time of this research-in-progress submission, we are in a data analysis phase using deductive and inductive coding techniques as espoused by Corbin and Strauss (1990). We began with an initial code list based on prior literature that was used to develop the interview guides. Transcript codings conducted independently are then reviewed by all three investigators to resolve discrepancies in an iterative process, first at the HIO (within-case) level, and then as part of the cross-case analyses. The NJ state findings will then be compared with the NY state findings to generate a model of factors that influence HIO sustainability.

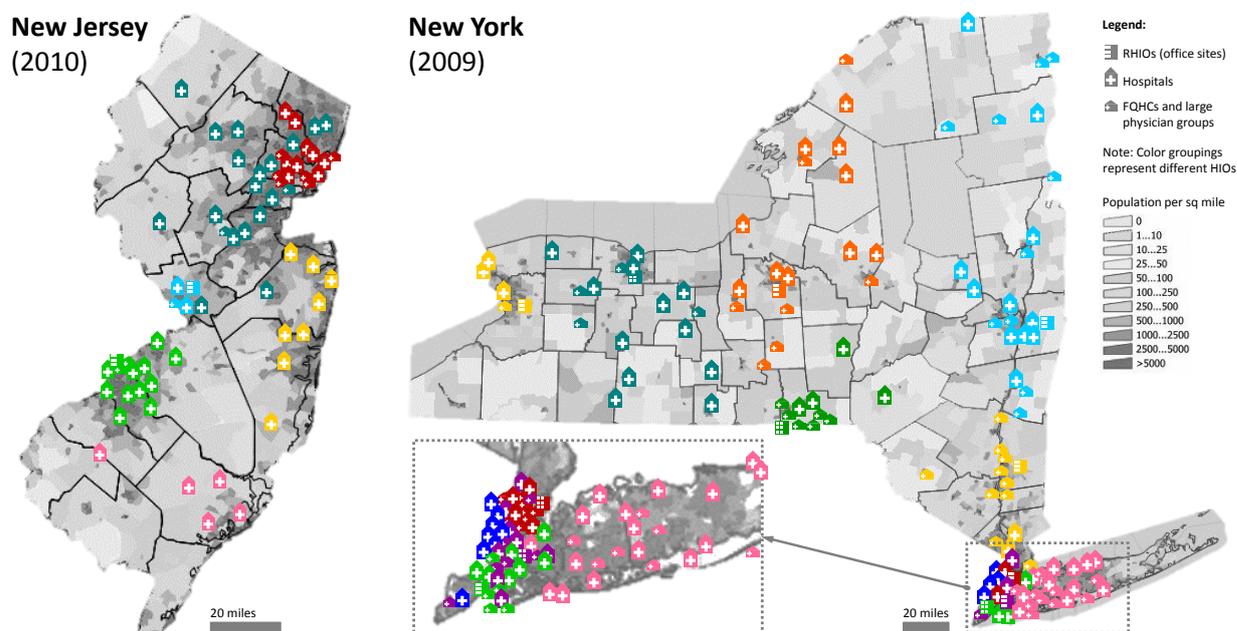


Figure 2. New Jersey and New York HIO provider participants (authors' representation using maps from New World Encyclopedia 2007, 2008)

3 Introduction to the Two State Initiatives

The state of New Jersey's (population 8.9 million) response to the national funding opportunity announcement (FOA) as part of the HITECH HIE grants was a proposal to allocate funding to multiple regional consortia that would establish non-profit entities to govern and operate as HIOs for different geographic regions across the state. This initiative was coordinated under a newly created position of an HIT coordinator reporting directly to the Governor of this state. In contrast, in the state of New York (population 19.6 million) a multi-stakeholder governance entity (the NYeC) had already been established since 2003 under the guidance of the Department of Health, which had coordinated the distribution of over \$500M in federal and state grants since 2004 to the eleven RHIOs that were already operational. The NY proposal to the HITECH FOA was to use the HIE grant specifically for investments to create a state-level HIE infrastructure, for which the architecture had already been planned.

Figure 2 illustrates the actual (NY) and proposed (NJ) HIO participants at the time of responding to the HITECH FOA. Participating HIO providers are hospitals, Federally Qualified Health Centers and large physician groups in the urban and less populated regions of the two states. States responding to the national FOA were required to report their current and future plans for Governance, Finance, Technical Infrastructure, Business & Technical Operations, and Legal/Policy. Table 1 uses this structure to provide an initial summary of the two states' HIE initiatives.

	New Jersey State [proposed]	New York State [actual and proposed]
(pop. / area)	(8.9 M / 8,721 sq mi)	(19.6 M / 54,556 sq mi)
Governance (main bodies)	New statewide HIT Coordinator to coordinate state-level standing committees with HIE initiatives and new Regional Extension Center (NJ-HITEC)	Multi-stakeholder governance entity (NYeC), statewide collaboration process between Dept. of Health (NYS DOH), evaluation collaborative (HITEC), RHIOs, and Regional Extension Centers (CHITAs)
Finance (prior funding & sustainability plans)	No State funding Sustainability plans under development by each HIO	Prior state funding: HEAL grants (\$253M), private funding (\$280M) Sustainability plans submitted by RHIOs in 2009 under evaluation
Technical infrastructure	Proposed NJHIN at state level: "network of networks" with defined core services, links from new HIOs	Plans for SHIN-NY at state level: service-oriented architecture with 4-layer protocol stack (CHIXP), federated service buses
Business & Technical Operations	State-level architecture under development: responsibility of standing committees, phased approach HIO-level: responsibility of separate organizations	State-level: Contractual structure to operate SHIN-NY underway (HEAL 10) HIO-level: responsibility of separate organizations
Legal/policy	Opt-out approach for patient participation, restrictions for sensitive data, standards and forms to be developed by new HIOs	Opt-in approach for patient participation; statewide policy guidance developed, including consumer consent model

Table 1. Overview of state HIE approaches (based on NJ, 2010; NYeC, 2009)

New Jersey (NJ) was awarded \$11.4M. The majority (\$9.8M) of this funding was distributed to four HIOs that met the established criteria. These HIOs chose different HIE technology vendors and achieved different operational stages and financial sustainability within three years. In late July 2013 the state awarded the remaining federal funds (\$1.6M) to a coalition of HIOs and other organizations to create and operate a statewide hub (NJHIN) within a six-month period.

New York was awarded \$22.4M to extend its HIE capabilities to the state-wide infrastructure (SHIN-NY upper application service layers). By July 2013, a majority of the pre-existing operational HIOs, some with regional health insurance stakeholders, had expanded operations and become financially sustainable; there were also several HIO consolidations underway in the urban New York City area.

4 Preliminary Findings and Conference Presentation

We provide here some preliminary observations that suggest that our findings will result in a significant contribution to the extant literature on HIO formation and sustainability.

Regarding RQ1, we collected interview data and archival documents on contextual and operational factors that could potentially influence HIO sustainability, such as the population served, start-up and ongoing funding models, technological architectures, privacy and security models, services provided, and governance approaches. In particular, characteristics of the payer ecosystem at the national and state levels, as well as the local HIO patient population served (i.e., rural, urban, and “underserved”) appear to be influential factors in an HIO sustainability model. This also has implications for other national HIE initiatives: for example, both Germany and the UK included their major (public and national) payers from the start.

Regarding RQ2 and the interplay of “top-down” and “bottom-up” initiatives, we find that the two populous U.S. states focused on in our study have invested in “bottom up” approaches for developing local and regional HIE, prior to investing in a state-wide capability. Although both states used top-down federal funding, only New York had invested heavily in state-wide coordination capabilities that would ensure the building of a state-level infrastructure for providing this “public good.” This observation is consonant with the findings from research in even other (considerably smaller) national contexts (e.g., Denmark), which has emphasized the importance of more modular (regional) implementation strategies in building national health information infrastructures (Aanestad and Jensen, 2011). In addition, we have observed that the ability to create mutual “trust” between otherwise independent stakeholders can be an influential factor for successful governance. This again suggests that more favourable outcomes accrue if governments start “bottom-up” (cp. Aanestad and Jensen, 2011). As one of our U.S. interviewees emphasized: “trust is local.”

For the ECIS conference presentation, our objective will be to present a model that reflects all of our preliminary findings for both research questions, as well as to propose a theoretical lens that helps us to generalize our findings beyond the specific U.S. context to other countries seeking to implement sustainable models for HIE.

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