

Regional Health Information Organizations in the US

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INTRODUCTION

Health information technology (HIT) has been acknowledged as a possible response to the rising cost of healthcare across many industrialized nations, including the United States. The adoption of HIT in the United States has, however, lagged significantly behind other industrial nations in critical areas such as Electronic Health Records and the sharing of health information among care providers (Jha, Doolan, Grandt, Scott, & Bates, 2008). Health Information Exchange (HIE) among providers and other stakeholders is, in fact, a foundational concern in the US (Adler-Milstein, Bates, & Jha, 2009, 2011). HIE is an important concern because the vagaries of the US healthcare system spreads patient information across many healthcare providers as well as other organizations that support the provision of care as in the case of insurance agencies (Adler-Milstein et al., 2009; Vest & Gamm, 2010; Wilcox et al., 2006). Overcoming this fragmentation is difficult because the identification and transfer of patient health information among qualified members of the healthcare community must still respect concerns such as privacy and confidentiality. There have been several waves of organizations that have sought to overcome these challenges and provide HIE as a service for care providers. These organizations have gone by several names, and the objective of this article is to introduce Regional Health Information Organizations (RHIOs) as the current organizations offering HIE as a service, and discuss some of the key dimensions of their current proliferations across the US.

BACKGROUND

While RHIOs are the organizations that currently provide HIE as a service, they are not the first. There have been several waves of organizations offering HIE as a service. (Vest & Gamm, 2010). In contrast to their predecessors, RHIOs show significant variation in their organizational structure and process (Adler-Milstein, Bates, & Jha, 2009)

In the first generation (early to mid 1990s), RHIOs were typified by Community Health Management Information System (CHMIS) that were funded through private grants (initiated by the Hartford Foundation through grants to seven states and cities (Vest & Gamm, 2010)) and functioned as a centralized data repository for a geographically defined community and a transaction system for information exchange as well as billing and patient eligibility information retrieval (Vest & Gamm, 2010). An example was the IOWA CHMIS (described in (Stark, Grogan, & Allen, 1996)). These first generation organizations faced and overcame several challenges. They developed new technology to suit HIE needs, and promoted its use among care providers (Adler-Milstein et al., 2009; Vest & Gamm, 2010). In spite of these early successes, CHMISs could not overcome important problems (such as security and privacy concerns from patients, control and usage concerns from providers, lack of cooperation and consensus between competing providers (Vest & Gamm, 2010), and eventually could not sustain themselves because they could not easily transition from a grant funding model to a self-sustaining revenue model that leveraged the services they provided (Vest & Gamm, 2010).

The second generation (late 1990s) saw RHIOs take the form of Community Health Information Networks (CHINs). CHINs were commercial endeavors designed to offer cost-savings via HIE without any commitment to make public community health level data available (Vest & Gamm, 2010). An example was the Metropolitan Healthcare Council (described in Bergman, 1994). These organizations eschewed a central RHIO-managed repository in favor of a transaction-based federated data storage where independent providers maintained their own database (Vest & Gamm, 2010). Although this architecture did allay concerns of healthcare providers about surrendering their data (Bergman, 1994), many CHINs failed as competing providers limited the exchange of their information and competing technology vendors fostered schisms in the network (Bergman, 1994; Vest & Gamm, 2010).

The third, and current, generation of RHIOs (2000s) exhibits much more variation than their predecessors. Architecturally, RHIOs in this generation are agnostic – they adopt either the centralized model of CHMISs or federated model of CHINs or a hybrid architecture depending on how best they can serve their local community. Examples include the failed Santa Barbara Health Data Exchange (that adopted a context-aware federated model similar to the CHMIS centralized model, described in (Wilcox et al., 2006)) or MiHIN (that adopts a more hybrid model connecting state RHIOs with the state infrastructure). Unlike CHMISs and CHINs, however, these third generation RHIOs represent a response to unprecedented and widespread federal government support and funding that was initiated in 2000s and has continued and increased under two administrations (J Adler-Milstein, Bates, & Jha, 2011). Federal support for state-based efforts to promote HIE (and RHIOs as the organizational form), has surpassed \$550 Million (HITECH, 2009). In fact, RHIOs have enjoyed substantial private and public funding, for example, ARRA allocated \$300 million to support HIE efforts (Adler-Milstein et al., 2009), and the HITECH Act contributed additional large sums to their growth (Vest & Gamm, 2010)¹. Although not sufficiently stable, and yet to reach the organizational population numbers of CHINs (J Adler-Milstein et al., 2011), RHIOs have steadily grown in number (100+ in 2008 and 200+ in 2011) as well as in maturity of systems (Lenert et al., 2012; Vest & Gamm, 2010). Although this generation of RHIOs has demonstrated some staying power, they still encounter the same set

of challenges faced by their predecessors, such as the lack of sustainable business models, lack of trust among competitors, concerns over privacy and security and risk of legal liabilities (Vest, 2010; Vest & Gamm, 2010). These problems have contributed to the failure rates (as high as 20%) that RHIOs continue to experience (Adler-Milstein, Landefeld, & Jha, 2010).

Regional Health Information Organizations (RHIOs) and HIE in the US

RHIOs are a curious organizational form. They have been modeled as non-profit organizations aimed at providing their services as public utility to its stakeholders. Yet, unlike other public utilities such as electricity or cable companies, they do not enjoy the monopoly privilege required to sustain such a model (Adler-Milstein et al., 2009; Lenert, Sundwall, & Lenert, 2012). Over the last decade, their presence has been a subject of much discussion. During this time, RHIOs have clearly moved from being a curiosity to having a significant presence in the US. From their early presence, which was dominated by individuals or groups passionate about providing an HIE² service in a local community; they have evolved to become a small but important player in the healthcare information ecosystem. Although their footprint has remained relatively small, the overall population of RHIOs is critical because each of them acts as a significant information conduit between a number of healthcare providers, patients and financial organizations.

As an organizational form, RHIOs tend to be small (often with only 3 to 15 employees), operating in a highly complex and dynamic ecosystem that is often unique to each state, and are situated in a stakeholder ecosystem that includes care providers, regulators, vendors, and patients.

Similar to this local effort, there is a national effort to link health information across the US, as the Nationwide Health Information Network (NwHIN) envisioned by the Office of National Coordinator. In this conceptualization, a web-based model can operate as an interface between multiple types of networks and direct point-to-point exchange between providers (Lenert et al., 2012). If successful, RHIOs may be either demoted in this new ecosystem (as argued by Lenert et al., 2012 and discussed in more depth later)

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