Planning and Implementing a Health Information Exchange Network

A Guide for State Designated Entities
This paper discusses the key considerations and presents our recommendations for how states should approach the areas that will be vital to establishing a successful HIE network.

Health care reform is being pushed aggressively to the top of the federal government’s agenda. The significant funding now provided through the American Recovery and Reinvestment Act (ARRA) offers an opportunity to start to build a national infrastructure for health information exchange that will open the door to new efficiencies in the health care system, better access to health care and overall improved quality of health care for citizens.

As conduits of the ARRA funds, State Designated Entities (SDEs) will play many vital roles—as organizers, architects, policy shapers, educators, guardians of the public interest and champions of change. To be successful, SDEs must manage the different elements associated with health care reform—and more specifically, with developing a statewide node of what will eventually be a national health information exchange—as the large-scale transformation it truly is. In fact, with health care reform and establishment of a Health Information Exchange (HIE) network, states likely face the largest transformation they have ever undertaken.

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The American Recovery and Reinvestment Act (ARRA), linchpin of the federal government’s major economic stimulus plan, includes more than US$36 billion to help develop a robust IT infrastructure and data exchange capabilities for health care, as well as to assist providers and other entities in adopting and using health IT.

Figure 1 illustrates the flow of funds under ARRA. Money for the health IT infrastructure and health-data exchange portions of the stimulus bill will flow two ways: The Center for Medicare and Medicaid Services will allocate the bulk of the funds (approximately US$34 billion net) through incentives to encourage providers to implement health IT systems. The Office of the National Coordinator (ONC) will manage another $2 billion. While a portion of this ONC money will help fund the development and management of national policy, governance and standards, the remainder will flow via grants and other mechanisms to the states for the planning and build out of Health Information Exchanges (HIE). There are a number of other provisions in the ARRA that will impact health IT, such as the telemedicine components of the nearly $7 billion in broadband funding, and these could also be considered as sources of funding.

The grants that ONC makes will be made available to the states and to state designated entities (SDE)—organizations designated by each state to apply for the grants and provide statewide coordination among health IT initiatives. The money that will flow to states’ SDEs is a considerable sum, yet surprisingly little attention has been paid to the role of SDEs. To date, there has been little discussion about what SDEs will look like, how these SDEs will be set up and what they will need to do to achieve high performance, so as to get the most value for the taxpayers and the individual states’ health care systems.

Despite the huge role these SDEs will play, and soon, confusion is the prevailing feeling.

Accenture’s goal in this paper is to help define the role of SDEs and how they can go about building a statewide health information exchange network. First and foremost for every state, establishing a successful SDE and from there, the state’s own high-performance node of a national network for the exchange of health data, constitutes a large-scale business transformation. Like any other transformation, it requires careful planning and logical follow through. In the sections that follow, we offer guidance.
By getting the role of the SDE clarified and its governing structure organized now, states will be in good position to mobilize quickly as soon as the ARRA funds start flowing.

The role of the SDE

While states are not obligated to set up a new organization as their SDE, the SDE’s role will exist whether it gets played by an existing state government agency or a new organization. Therefore, the guidance we offer throughout this paper holds true regardless of the organizational form the actual SDE takes; when we reference an SDE’s roles and responsibilities in this paper, it should be understood that some state entity will need to see these roles and responsibilities through to completion, whether or not the state establishes a separate SDE. However, a critical success factor for the SDE and its ability to establish a statewide HIE network will be to provide a mechanism for all stakeholders from both the public and the private industries to participate. Accenture’s point of view is that establishing the SDE as a separate public-private partnership is the foundation necessary to make this happen. There are a number of states that have already taken the step of creating an SDE. Examples of these organizations (which can serve as a useful reference) include the Delaware Health Information Network (DHIN), the NY eHealth Collaborative (NYeC) and the West Virginia Health Information Network (WVHIN).

Accenture recommends that the SDE take on responsibility for defining clear outcomes for the HIE network, and how to build the capabilities to achieve those outcomes. Here, our recommendations stem from the way separate HIEs have sprung up around the country to date, with no top-down coordination. Such an approach naturally leads to HIEs with overlapping constituents, gaps in coverage and large groups of constituents without an available connection to an HIE. Additionally, given the complexity of establishing HIEs and the ultimate objective of an interconnected network of HIEs nationwide, states need to ensure that outcomes and a roadmap are clearly defined at a central level, or the goals may never be reached.

By getting the role of the SDE clarified and its governing structure organized now, states will be in good position to mobilize quickly as soon as the ARRA funds start flowing. Read on for considerations and recommendations in setting up and running an effective SDE.
Involving all stakeholders from the outset

During the initial planning stage, one of the key activities will be to identify all of the stakeholders that will be involved in building a statewide HIE network. Figure 2 illustrates the very broad range of stakeholders who will provide input and direction, in addition to being beneficiaries of a statewide HIE network.

These stakeholders will help shape the business case that supports the HIE network; establish the outcomes and associated measurements that will determine the success of the HIE network; appropriate and/or approve the budget to fund the build out and operation of the statewide HIE network; provide guidance to the state on the governance principles and model that should be employed by the SDE to manage the HIE initiatives; and finally, prioritize the HIE services and implementation schedule.

Picking the right governance model

While the federal government will provide guidance on national HIE network governance, ultimately the states will be accountable for defining and managing the statewide governance model. The first step for states is to determine who their SDE will be—whether an existing agency within state government, or a new public-private partnership, or an existing organization within the state that would be a natural fit to be the SDE. That is the first question to resolve when proactively defining the type of governance model that will most likely lead to achieving the states’ desired health outcomes.

Determining the ideal governance structure begins with assessing the current structure of the delivery and financing of health services (diversity of public and private providers), current HIE operations (both the number of operations and the maturity of health IT infrastructure) and the size of the state (in terms of population and geographic diversity) itself. After completing this assessment, the state will understand the complexities of the health care system and what agencies are involved in the delivery of services for their state. These are the most important factors to consider when choosing the right governance model.

Additional considerations now come into play. Among others, these include how prescriptive the SDE plans to be in how the HIE network gets designed; what the desired level of centralized versus distributed control is; and the degree to which enterprise architecture, standards and common services should be defined at a state level versus at the HIE levels.
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When it has worked through these questions, a state will be well-informed when choosing the governance model that best suits its needs from among four main options, illustrated in Figure 3.

Model A may be appropriate for smaller states, where only a single statewide HIE will be established and a single organization can play the role of both SDE and HIE. This one entity would have responsibility for the governance and policy as well as the technical authority. The West Virginia Health Information Network (WVHIN) follows the Model A structure, and the State of Maryland has proposed Model A for its governance model as well.

Model A can simplify coordination and communication; however, the organization must understand when it is acting as the SDE versus when it is acting as the HIE. For example, while the statewide health IT infrastructure is being built, the SDE responsibilities will take center stage, but as the infrastructure matures the organization’s focus will move toward HIE sustainability.

For medium-size states that will have multiple HIEs, we recommend Model B, in which the SDE is a separate organization from the HIEs. In this case the SDE will be responsible for governance and policy, as well as have technical authority. For Model B to work well, the technical infrastructure complexity shouldn’t be too high; the model lends itself to a governance model where the SDE makes high-level enterprise architecture and standards decisions, but allows a high degree of flexibility at the HIE level. The State of Michigan’s governance structure and its plans to promote regional HIEs throughout the state resembles Model B.

For large states with multiple HIEs, it is recommended to use Model C. In this model, the SDE is a separate organization from the HIEs, with the SDE responsible for governance and policy, and the SDE having technical authority. This model allows for high flexibility at the HIE level.

For very large states, the SDE may be located within the state government, and the HIE may be located within the state’s public or private sector. This model, depicted in Figure 3, is similar to Model D.

Figure 3

Potential HIE governance models

A

B

C

D

State

SDE

HIE

State

SDE

HIE

State

SDE

HIE

State

SDE

HIE

State

SDE

HIE

State

SDE

HIE
Accenture’s point of view is that establishing the SDE as a separate public-private partnership is the necessary foundation.

Model C makes sense for medium-to-large states with a medium-to-high level of health IT infrastructure complexity. Model C shares similarities with Model B, but separates out the technical architecture authority from the governance responsibilities. While these roles could still reside within the same organization, in Model C the governance body clearly identifies a group of individuals to take on the role as the technical architecture authority. The State of New York follows the Model C governance structure. The New York eHealth Collaborative (NYeC) provides overall direction on governance and policy, while the Statewide Health Information Network for New York (SHIN-NY) acts as the technical authority.

Model C offers a number of advantages. First, having a separate group develop detailed enterprise architecture and standards makes it easier to achieve interoperability across HIEs within the state. Second, such a model lends itself to scale in design and deployment. Efficiencies can be achieved if the technical architecture authority group also takes on the role of designing and developing common services; when multiple HIEs have a number of the same functions to develop, it’s more efficient to design and develop these once in a way that is usable by all HIEs in the network. The technical architecture authority could define and design the common services and then develop the reusable common services, or the technical authority could designate a single HIE to develop the common service that would be reused by the entire network. Finally, rather than stifling innovation, in Model C the technical architecture authority can actually put in place processes to harvest innovation from individual HIEs and then weave them into solutions that can be reused across all HIEs within the network.

While Model D may be appealing where there is an existing dominant HIE in the state that is already starting to perform some of the SDE functions, we do not recommend this model for states with multiple HIEs in their networks. There is a high risk that the other HIEs in the network will be confused when the organization is acting as the SDE (i.e., in a governance role) and when it is acting as a peer HIE in the network. In summary, for states with a multi-HIE network, we recommend a separate governing body with equal representation from all stakeholders.

Irrespective of what model is chosen, the legal structure, accountability issues and finance issues will all need due consideration. Additionally, whether the SDE and the HIE are the same organization or different organizations, and no matter how many HIEs are in the state, the governance body must ensure that all responsibilities for both the SDE and the HIE are defined and assigned, including who will:

- Establish the mission and vision for the SDE
- Establish the roles and responsibilities of state government, the SDE and the HIEs in the network, and the relationships among these entities
- Identify and manage key stakeholders
- Establish and maintain a sustainable business model at both the SDE and HIE levels
- Establish the oversight and operations of a statewide HIE network
- Define the enterprise architecture for the HIE network and the standards for the electronic exchange of health data
- Define and develop appropriate statewide technical infrastructure
- Define appropriate statewide privacy and security policies and standards for electronic exchange of health data
- Define the specific use cases to be implemented
- Enforce specific standards and policies for electronic health information exchange so as to build and maintain public trust
- Establish the ability to monitor progress toward achieving the desired health outcomes
- Establish the ability to monitor community health statistics

Establishing a policy framework

With the governance structure determined, states also need to look at legislation from two perspectives—what is in place that may stand in the way of HIE progress and what needs to be in place from a regulatory perspective so that the SDE can be established and carry out its responsibilities accordingly. Key areas for examination include:

- Privacy policies that may exceed the rigor of federal requirements
- Bonding and taxing authority that may limit the ability to raise the necessary start-up capital and/or limit possible future revenue streams for operating budgets
- Potential Certificate of Need (CON) restrictions on IT investment (e.g., in NY, hospitals investing in IT now need to file a CON to show it connects to the SHIN-NY)
- Any Stark-like restrictions on provider collaboration (e.g., the ownership ban in California that prevents hospitals from owning physician practices)
Far from a simple technical deployment, building a statewide HIE network constitutes one of the largest business transformations states will ever see.

Building an optimal HIE network starts with understanding the importance of defining real health outcomes and how to measure meaningful improvements. Over time, the coordinating and reporting capabilities of a statewide HIE network will also play a key role in providing information that will allow states to see an improvement in their population’s health. The SDE, then, needs to work with the state and its stakeholders to identify the health outcomes it should monitor.

For example, the 2008 American Health Ranking Report includes information about infant deaths, cardiovascular deaths, cancer deaths and premature deaths, among other factors, when assessing the overall health of a state’s population.

With pending health care reform legislation focused on wellness, prevention, quality and cost reductions, a state may opt to monitor information related to chronic illness (such as diabetes and/or obesity) and preventive measures (such as immunization and cancer screening rates). Alternatively, a state may choose to focus on procedures and protocols—such as medication reconciliation and discharge planning.

Accenture believes that the health care outcomes states target will fall into three main areas: improved quality of health, improved access to health care and a more efficient health care system. While specific individual desired outcomes may vary from state to state, health care reform will result when states achieve the outcomes they have set. But to achieve their outcomes, states need a plan.

...And the roadmap to get there

Far from a simple technical deployment, building a statewide HIE network constitutes one of the largest business transformations states will ever see. Accenture experience has shown that one of the biggest reasons large business transformations fail is that they do not clearly define the outcomes that the transformation is supposed to achieve and develop a detailed roadmap for achieving them.

As just described, before implementing an HIE network, states must define what health outcomes they are trying to achieve—the specific goals around improved quality of health, access to care and creating an efficient health care system.
The outcomes, capabilities and enablers that will lead to health care reform

After defining the health outcomes, the SDE must then define the business, operational and technical models that support the achievement of these outcomes. Knowing where the state stands today (depending on current environment, the SDE may need to conduct an as-is assessment), and understanding what operating models need to be in place, the SDE can develop a roadmap that gets them from today to the target operating models for the HIE network.

The first step is to conduct a to-be assessment, identifying which processes and communications are necessary to achieve the clinical goals. The next step in developing the roadmap is to identify the capabilities required to support the health outcomes and defining the enablers required to support those capabilities. Bringing together the outcomes, capabilities and enablers, as illustrated in Figure 4, provides the high-level scope of the work required to achieve the goals.

The next step in developing the roadmap is understanding the dependencies across capabilities, and thus the sequence for developing the capabilities. In tandem, the state or SDE should also create a timeline for development and financing. Figure 5 provides a sample high-level roadmap that illustrates the sequence and interdependencies between capabilities to be deployed.

Next the SDE needs to take each of the enablers and map it to how they contribute toward creating each of the capabilities. The table in the Appendix provides a draft for this mapping.
Finally, once the detailed scope and sequence have been defined, the last step is to pull all of this information together to create a comprehensive strategy and detailed program schedule—identifying specific projects and how they contribute toward creating the enablers. Given their downstream effects on achieving health outcomes, each project within the program schedule should also have its own detailed project schedule, as well as clearly defined measures to ensure that the desired outcomes are being achieved.

By creating a master program schedule in this way, the SDE can prevent gaps that could result in not fully achieving the desired health outcomes and inefficient overlaps where different projects develop the same capabilities. As with all large-scale, complex transformations, the results may not always match the plan and changing circumstances will likely require updates/refinement to the outcomes, capabilities and enablers, and therefore to the plans that support them. Therefore, the SDE should view development of its HIE deployment roadmap as an ongoing activity that needs active monitoring for the life of the transformation.

In the sections that follow, we describe in more detail the other enablers SDEs will need in place to build an optimal HIE network.
Regardless of the implementation schedule, the SDE must define a very clear and concise timeline for reaching and maintaining critical mass for the health information exchange services it provides.

To build a sustainable HIE network, the SDE must devise a financial model that will adequately fund both the initial investment (startup costs) and the ongoing operational costs of the HIE network. Capital from the initial investments will finance the new governance model and develop the technical architecture of the HIE network. The SDE should assess and understand the opportunities, constraints and limitations of its available funding sources to pick a strategy that reflects its health care market. For example, ARRA funds will undoubtedly be a top choice to support the initial investment in a very aggressive approach. The states themselves could be a good source for the initial funding, but many states are currently experiencing budget issues. Payers are another potential funding avenue, depending on the complexity of the payer market in a particular state and how the health outcomes address the payers’ desires.

During this phase, the SDE’s investment strategy should be to generate funds from secure and reliable sources to avoid shortages that may derail implementation later. Smart practice in all cases would be to find strong initial investment sources that provide funds for the first few years without expecting or requiring a monetary ROI. In this instance, states and payers can be good investment sources as they are advocates and beneficiaries of patient safety, quality and community health. For example, the Delaware Health Information Network (DHIN) secured initial funding from the State of Delaware, matching funds from the private sector and a grant from the Agency for Healthcare Research and Quality (AHRQ).

To fund ongoing operational costs, the SDE will need to define a revenue strategy that will generate income from its high-value HIE services. The state must also spread the operational costs across all stakeholders—for example, through subscription fees, transaction fees, service/cost-sharing fees and pay-for-performance. We have seen the membership/subscription model, coupled with transaction fees, gaining increased acceptance as an approach to sustainability. A word of caution, however, transaction and
Subscription fees must be priced at a modest-enough level to avoid negative implications on adoption (connecting to the HIE network) and utilization (use of data/services provided by the HIE network). It is important that the paying stakeholder perceives value from the services being provided.

Finally, a sustainable financial model must also consider implementation strategy. Stakeholder composition and consensus, market-maturity level and technical complexity all weigh into the decision of when and what HIE services to fund. Given these factors, an SDE may opt to implement only selected services in the initial effort and to defer other services until conditions are more favorable. Regardless of the implementation schedule, the SDE must define a very clear and concise timeline for reaching and maintaining critical mass for the health information exchange services it provides.

As health care reform takes center stage and we see a move toward coordinated delivery of care (e.g., medical home, prevention and wellness programs) combined with an outcome-based payment system, developing a sustainable financial model will become much more attainable. For example, the Indiana Health Information Exchange (IHIE) has pioneered some work in this area and has not only developed a transaction-fee model, but has also seen encouraging results with regard to cost efficiencies—especially in the area of care management.
Input from specific stakeholder groups may go up and down at different points of the process, and so any management plans need to be flexible.

We discussed earlier in the paper the importance of identifying and involving all stakeholders from the outset—when initial decisions are being made to establish a strong SDE. But stakeholder involvement does not end there. Stakeholders will provide input during implementation and ongoing operations and SDEs need a flexible plan for managing how the input is received and incorporated. Additionally, input from specific stakeholder groups may go up and down at different points of the process, and so any management plans need to be flexible. For example, the SDE may request more providers to participate in discussions on new financial models and revisions for pricing structures. They may require less participation from consumer advocacy groups on discussions that pertain to technical architecture outside of security and privacy considerations. The SDE needs to anticipate and encourage stakeholder participation in areas where it will add the most value.

SDEs will need to make sure they have the appropriate balance and representation across the key stakeholder groups in both the public and private sectors. Some options to consider include appointing key stakeholders to the Board of the SDE to further ensure cross-group collaboration and foster trust and transparency among the decision makers. Because different groups will have different and potentially conflicting interests, building trust and transparency among the groups will be key; for example, consumers must trust that their data is appropriately and securely used only when specified, while providers must trust that they will not be disadvantaged competitively by participating in the HIE network. Providers also need to believe the information is secure and used properly, as well as accurate and available when needed.

We recommend that the SDEs establish subcommittees/sub-groups within the stakeholder group, to leverage subject matter expertise on critical areas of importance. Whatever mechanisms are ultimately chosen, a successful SDE will be one that adequately represents and benefits all stakeholders. We recommend the following subcommittees/sub-groups as a minimum:

- Privacy and Policy
- Standards
- Financials
- Clinical Workflow/Use Cases
- Quality and Measurement
- Provider Outreach
- Consumer Outreach and Awareness
- Technical Architecture
A number of organizations will take part in defining and promoting standards across the health IT industry in the US. The SDE will need to understand all of these efforts and act as a conduit for educating its HIE network, in addition to enforcing these standards.

The Department of Health & Human Services (HHS) is required to release a set of national standards for Health Information Technology (Health IT) systems by the end of fiscal year 2009. Standards will likely take one of three forms: use cases, which give detailed guidance (without being rigidly prescriptive) on important aspects related to adopting health information technology; data content standards, which lend consistency to data exchange through their specifications for format, data elements and overall structure, as well as terminology vocabularies that provide specific codes for clinical concepts such as diseases, problem lists, allergies, medications, and diagnoses; and cross-community interface specifications, which support clinical and patient-identity exchange between two independent entities.

Once these standards are established, the SDE will be responsible for driving compliance down through the HIE network and determining what degree of standards will be enforced at both the HIE and HIE exchange participant levels. Using these standards will likely be a condition to receiving stimulus funding from ONC, but it also represents an additional opportunity for the SDE to drive federal compliance at the state level.

A number of organizations will take part in defining and promoting standards across the health IT industry in the US. The SDE will need to understand all of these efforts and act as a conduit for educating its HIE network, in addition to enforcing these standards. Many federal agencies will have a role in this area, including ONC (with its policy and standards committees), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control, and the Federal Health Architecture, to name a few. In addition, a number of standards bodies and public/private partnerships are involved in both defining standards and certifying standards, including NIST, HITSP, CCHIT, NeHC, IHE, EHRAC, HISPC, HL7, SNOMED, LOINC, RxNorm and ICD-9/10. This is not an exhaustive list, but rather illustrates the number of different organizations involved and the challenge an SDE will face as it works to stay abreast of this fast-evolving area.
A broad set of stakeholders will participate, with the organizations identified above, in the continuing development of health IT standards. These stakeholders include providers, ancillary health care workers, consumers, purchasers, health plans, technology vendors, researchers, relevant Federal agencies, and individuals with technical expertise on health care quality, privacy and security, and on the electronic exchange and use of health information.¹ The inclusiveness of the standards developing process means individual SDEs will have the chance to participate in shaping the standards that they will eventually be required to enforce. By playing an active role in the standards development process, not only will the SDEs be able to stay abreast of the changes to standards as they arise, they will also have an early opportunity to work with many of the stakeholders who will play a role in HIE governance down the line.

¹ Visit the Health Information Technology website, http://healthit.hhs.gov, for a more complete list.
A privacy and security framework

Public trust is central to the success of any HIE, making the privacy and security framework the SDE develops for the HIE one of its most important enablers. Consumers worry about protecting their health data while providers fear liabilities associated with the unintentional security and privacy breaches. Any privacy and security framework, then, must instill both provider and consumer trust.

The challenge for the SDE is to create security and privacy policies and standards that can be applied consistently throughout the state to all applicable entities, while balancing availability of data and quality of care. Enforcing a minimum set of policies will help provide accountability and transparency to the data exchange process, easing the concerns for both the patients and the consumers and helping to establish trust and confidence in the HIE.

Developing the framework should begin with an assessment of current state laws and policies to determine the impact they will have on business practices related to electronic health information exchange. Understanding present laws around health IT and health information exchange efforts will help identify any current challenges that should be taken into account in developing new privacy and security guidelines. The security and privacy policies should take into account how the HIE will safeguard information and handle issues of authorization, authentication, accountability, consent, access, breaches of information, quality and integrity of information and provider liability. Some of the key policy and security areas that will need to be considered are patient consent and adult access to minor’s health care information. While the policies developed should protect personal health information, they should also facilitate the exchange of pertinent health information to improve the quality of care.

In addition there have been, and will continue to be, a number of federal and cross-state initiatives with respect to privacy and security. The SDE will be responsible for understanding, and participating in, these initiatives and ensuring they are reflected in the privacy and security framework for their state.

Once the privacy and security guidelines have been developed, we recommend HIEs be required to comply with the policies and standards developed by the SDE before receiving any funds to participate in the statewide information exchange. Requiring upfront compliance will ensure policies are consistent across the state and prevent a patchwork of guidelines that may hamper information exchange down the road.
Given the fact that HIEs will evolve considerably over the next few years, we recommend defining a modular HIE-enterprise architecture—one that can start small and grow as more services are identified.

While the initial efforts to build HIEs will focus on connecting local HIE exchange participants to a regional HIE, the ultimate goal is to connect all of the HIEs within a state and, eventually, across states to a Nationwide Health Information Network (NHIN). Therefore, SDEs must make key technical-enterprise architecture decisions during the planning process that account for longer-term goals.

For states that will have multiple HIEs in their network, clear definition around the technical approach is particularly important and we recommend creating a technical-governance body, as described earlier in the paper. The initial approach should focus on exchanging a core set of data while driving to quickly connect a large number of providers to the HIE. As the network matures, the scope of the data exchanged will increase and more HIE-based services will be added. For these multi-HIE states, we recommend starting with a simple HIE architecture that can provide the basis for health information exchange, but which also has the ability to grow over time as the HIEs add services and as the market (and technology) matures.

For states that will have a single HIE, the SDEs will have an easier time making these architecture decisions, but the implications are the same as for states with multiple HIEs. As envisioned, all HIEs will connect with each other to form the nationwide network supporting health information exchange, and SDEs should architect them with a view to the future. In addition, beyond point-of-care and population health uses, there will be opportunities for health information exchange for the provision of benefits (at both the federal and state level) based on an individual’s health. For example, the Social Security Administration is piloting a program with MedVirginia to provide health data electronically to improve the processing time for disability claims.
Typical health IT considerations

Given the fact that HIEs will evolve considerably over the next few years, we recommend defining a modular health information exchange enterprise architecture—one that can start small and grow as more services are identified. A modular and evolutionary strategy will lend itself to a Service-Oriented Architecture (SOA) approach that takes advantage of “best-of-breed” technologies as they arise, rather than locking into a more rigid single product solution. From that base, the SDE will need to make determinations on a number of other key aspects of the health IT architecture.

Using message-based exchanges

While the standard for exchanging health data across HIEs is likely to be based on structured documents (which are themselves passed within messages), one area with leeway is whether or not individual HIEs should have the flexibility to use other mechanisms for health-data exchange (e.g., a pure message-based exchange) between the participants and the HIE. We recommend that SDEs allow this flexibility, but require HIEs to employ an approach that can produce structured documents when exchanging data outside of their own HIE network. In this case, the enterprise architecture needs to define how these documents will be created, the retention requirements for these documents, and the relationship between health data contained within documents versus a clinical data repository (CDR).

Data content standards between participants and a single HIE

The enterprise architecture needs to define to what degree defined data content standards should apply when exchanging data between participants and a single HIE. It would be oversimplification to say that the same data content standards should apply; the SDE must consider whether applying the data content standards in this manner would be a barrier for participants connecting to an HIE. The enterprise architecture should provide guidelines about when data content standards may be relaxed, if doing so will promote the earlier connection of participants to an HIE. The enterprise architecture needs to define how these documents will be created, the retention requirements for these documents, and the relationship between health data contained within documents versus a clinical data repository (CDR).

Federated versus centralized data model

The enterprise architecture needs to define the amount of data that will be stored at the HIE level—a decision that will feed into the determination of whether the HIE should employ a federated (dispersed) or a centralized data model. This decision may differ depending on whether the data will be for the exchange of individual patient records or for population-based health usage. For individual patient records, for example, whether or not to have a centralized clinical data repository at the HIE level will more likely be a policy-based, rather than a technical, decision. Another option is a hybrid model where a core set of data is held centrally at the HIE but the remainder of the data resides with the participant.

Beyond policy, however, the decision between a federated and hybrid model is a technical decision where availability of data and performance are key considerations. An HIE may start with a federated model (where no data is stored at the HIE) but then move toward a hybrid model where key summary patient data remains in a clinical data repository at the HIE level. This approach may work especially well when taking a document exchange approach. The enterprise technical architecture needs to define what approaches are acceptable. Additionally, if the SDE plans to move toward a hybrid model, the architecture should define the timeline for that transition.

Semantic normalization of laboratory results to the LOINC standards

Figure 6

Semantic normalization of laboratory results to the LOINC standards

- **Provider A**
  - RFT
  - Rheumatoid Factor
  - Quantitative

- **Provider B**
  - RHEU
  - Rheumatoid Factor
  - Quantitative

- **Provider C**
  - RA
  - Rheumatoid Factor
  - Quantitative

- **LOINC**
  - 6928-6
  - Rheumatoid Factor: ACNC:PT:SER:QN:EIA

- **Comparison of Results**

- **Single Consolidated Health Record**

- **Analysis of Aggregated Data**
Any privacy and security framework must instill both provider and consumer trust.

Aggregation of data and protecting anonymity
The HIE will fuel a drive toward population-based health care management, which will impact the enterprise architecture in a number of ways. One point of impact concerns aggregating data. If data aggregation will happen only at the HIE level, the analytical tools need the ability to analyze data from multiple sources. If the data will be aggregated at the network level, the enterprise architecture must define how to consolidate aggregated data from the different HIEs. When deciding on the approach, the users of the aggregated data (for example, public health departments) need to remain involved, making sure the defined architecture will meet their specific requirements. Another major decision is how the HIE architecture will handle pseudo anonymization (removing patient-identifiable information) and the ability to link back to individual patient records—key privacy issues.

Semantic normalization
Semantic normalization of the data provides powerful services to different stakeholders. For example, for clinicians, it provides a single patient view. For public health, it provides a much richer quality data set to perform analytics that can be used for population health management. Figure 6 illustrates laboratory results coming from three different provider organizations, each in their own local terminology, semantically normalized to LOINC standards. This allows clinicians to view a single consolidated health record for a patient, to compare results from different providers and to analyze aggregated data. As powerful as it is, semantic normalization is also extremely complicated, and so the enterprise architecture needs to define a practical approach to allow data normalization. One approach might be to start the HIE with only the core data sets to achieve a balance between providing value while reducing complexity. Also, the decision needs to be made on where the semantic normalization will occur. Adding this as an HIE service adds costs to building and operating the HIE; however, if an HIE insists that participants only supply semantically normalized data then the cost is borne by the participants and may prove a barrier to connecting to the HIE network.

The enterprise architecture should also recognize special situations where the lack of normalization of the data does not represent a significant hindrance. For example, if two hospitals use similar but inexact terminology when using the HIE to exchange data with each other, they may not experience the same impact as when they are exchanging data with another HIE participant that is using a completely different local-terminology code set. Finally, the enterprise architecture should define the terminology mappings (local to standard) and decide how to maintain them—whether at the SDE level or at the HIE level. Understand that maintaining these terminology mappings adds a new business process to the operations of the HIE network.

Access channels
Providing access channels to the health data is one of the critical architecture decisions for an HIE. We suggest the SDE provide guidelines on how the HIE should provide health care professionals access to patient data. Ideally there should be complete integration of the data available from the network with the provider point-of-care system (e.g., EMR, practice management system). In other words, the provider should have the ability to make a decision on what data is incorporated into their systems. The SDE should also provide guidelines on how an HIE can work with the provider-system vendors and CCHIT to apply standards in this area. This requires accurate attribution of the incoming data to the source organization or entity. Another option could be providing an EHR portal for the providers to access the health data. This could be an attractive option for physicians with little or no health IT systems. A third possible option is using the “CCOW” standard to integrate an EHR portal with, for example, an EMR system. This requires the EMR vendors and the EHR portal products to be “CCOW” standard compliant.

Privacy and security
The SDE needs to define the privacy and security aspects of the enterprise architecture. This architecture needs to take into account how patients will establish and manage their preferences for sharing their health data. In addition it also needs to define the architecture for allowing clinicians and other qualified health care professionals gaining access to a patient’s health data. In order to develop a framework, the SDE should utilize the principles we’ve outlined in the privacy and security framework section. The SDE should also provide guidelines to the HIE(s) in their state on how the patient consent and preferences should be captured and how they will be shared among the different entities on the network. The SDE will be responsible for determining how patient preferences are evaluated, how conflicts are resolved and at what point they are enforced.

Common services
To gain efficiency of scale, the SDE should strive to develop and implement common services that all of the HIEs within the network can use. States with multiple HIEs will have a number of services common across the HIEs, and having all of them use the same solution for these services may offer considerable benefit. For example, all HIEs will require an electronic master-person index (eMPI). If all of the HIEs were to develop their own eMPI solution independently, not only would it be inefficient use of funding, but more importantly, it would result in different matching algorithms and thus, increased complexity, when exchanging data between HIEs.

SDEs can take two different approaches when designing and developing common services. The first approach is for the technical architecture authority to gather requirements, produce the design and actually develop the solution. In this case, each individual HIE would then integrate the common service into its own overall solution. This centralized approach allows for a high degree of control for the technical infrastructure across the whole network.
The second approach is for the technical architecture authority to gather requirements and produce the design only. The technical architecture authority would then designate a single HIE to develop the solution that all HIEs within the state could use. The advantage of this approach is that an HIE that is pioneering a specific area can be tasked with developing the common services for that area. However, in this case the technical architecture authority must take care to ensure that the common services the one HIE develops meets the requirements for all HIEs.

Fostering innovation
While maintaining control of the technical architecture will be central to achieving cross-HIE interoperability, the SDE faces the prospect of stifling innovation at the local HIE level. Therefore, we recommend the SDE put in place a formal program to encourage innovation. By fostering innovation, the SDE will encourage more participation from the HIEs in developing future health information exchange services.

While the enterprise architecture should clearly define areas that are critical for interoperability, in other areas we recommend the SDE’s technical architecture authority sets guidelines that allow HIE flexibility in the solutions they develop. In addition, recognizing the importance of harnessing local innovation and using it for the benefit of all of HIEs within the network, the SDE should develop a process to identify and evaluate innovative solutions and then turn them into common services that can be used across the network.

To gain efficiency of scale the SDE should strive to develop and implement common services that all of the HIEs within the network can use. States with multiple HIEs will have a number of services common across the HIEs and having all of them use the same solution for these services may offer considerable benefit.
The SDE (or HIE) needs a systematic approach to prioritization based on how those who get connected will contribute to desired health outcomes.

Connecting providers to the HIE network (the SDE and HIE perspective)

The SDE needs to decide what role it is going to play in connecting providers to individual HIE networks (i.e., determine the extent of their responsibility for this function versus the individual HIE’s responsibility). Irrespective of who takes the lead, it will take many years for all providers (and all of the other stakeholders) in a state to be connected to the HIE. Therefore, the SDE (or HIE) needs a systematic approach to prioritization based on how those who get connected will contribute to desired health outcomes, either by contributing clinical information for the purposes of the delivery of care; clinical information for population health purposes; or claims data integrated with clinical data.

Figure 7 shows a way of segmenting provider organizations based on their ability to contribute toward the health outcomes that the SDE has targeted, while also taking into consideration the technical maturity of each of these organizations.

Top-right quadrant

Providers that fall into this quadrant have a high contribution toward achieving targeted health outcomes and also have a high level of organization and technical maturity. Therefore, providers in this group should be the number one priority for connecting.

Bottom-right quadrant

This quadrant consists of providers that have a high level of organizational and technical maturity but contribute less to the overall targeted health outcomes. These providers will likely be very self-motivated and take the steps necessary to connect to the HIE network on their own. The SDE and HIE should provide support and guidance to ensure that they connect in the desired fashion.

Top-left quadrant

Providers in this quadrant contribute a high degree toward health outcomes; however, connecting them to the HIE network presents many challenges as they are organizationally and/or technically immature. Instead of trying to connect these providers into the HIE network right away, the focus should be on growing these providers’ organizational and technical maturity. This could mean directing ONC funds toward improving the EMR capabilities within the provider organization itself. If successful in this regard, the providers in the top-left quadrant would then move toward the top right.
A quadrant of provider-adoption priority

**Bottom-left quadrant**
These organizations have a lower contribution toward health outcomes and they are organizationally or technically immature. At the HIE network’s outset, these providers will be low-connection priority. However, as other providers become connected, and the maturity and reach of the HIE network grows, these bottom-left quadrant organizations will start to move toward the top-left quadrant.

While this quadrant approach represents the SDE and HIE priorities and goals, we note that these priorities and goals may not completely align with the priorities and goals of the provider organizations. Therefore, when developing the adoption approach the SDE (or HIE) must consider the providers’ view. The SDE may use the provider-quadrant approach when determining the priority of the other HIE network participants and when to connect them to the HIE network. This would, for example, determine when reference labs need to be connected to the network or when feeds to public health agencies need to be established.

**The providers’ perspective**
In encouraging provider adoption, the SDE will really play a marketing and education role, emphasizing a number of key benefits and providing guidance and instruction to the providers on taking the step. Some of this guidance will relate to technical decisions and some of it will relate to educating patients about how the exchange of health information impacts them (which we discuss in the next section).

Key to any successful adoption approach is first understanding the providers’ point of view. The challenges for adoption at the provider level are manifold, and extend beyond the business model to issues of governance, change management and competition. Paramount, however, is the adoption of electronic medical records (EMR) at the individual provider level. Ninety-five percent of medical care is provided locally, between the PCP office, the hospital(s), and the consulting physicians and ancillaries supporting the PCP care of the individual patient. Within that local care "ecosystem," a strong case can be made for maximum transparency and interoperability around the clinical data specific to a given patient. Though most physician offices will see a clear benefit to some degree of clinical information sharing, fewer than 10 percent of offices with five physicians or fewer even have EMR capabilities.

Apart from the ability to have a complete view of a patient health care history, which will help drive up quality of care, patient experience and clinical outcomes, the SDE should emphasize the funding providers will receive through HITECH incentives for implementing their own EMR solution. Getting the funds to build an EMR or upgrade, however, will depend on the ability to exchange health care data. The HIE network is an obvious way for providers to meet that requirement and qualify for funding, and so providers may see connecting to the HIE as an incentive. The extension of this point is the penalties providers will incur under ARRA if they do not implement a mechanism for exchange of health care data.
The patient perspective

With the large number of stakeholders involved, and with many and diverse goals for health information exchange, it is important that the SDE remembers the patient’s perspective. According to a recent report published by Accenture entitled “The American Public on Health Care: The Missing Perspective,” American people believe that information has the power to improve the quality and efficiency of the health care system. They want to know more about the cost of health care and the performance of their providers. They want access to better information about quality and cost, and they are willing to share their own health and medical data to improve quality and accountability throughout the system.

It will be critical to understand patients’ needs, address their concerns and maintain an open and transparent dialogue.

Population health

Health care reform, while still being defined, is likely to pull heavily on the ability to exchange and analyze aggregated health care data. One of the main drivers for states in developing HIEs is to arrive at the point where they have the ability to do population-based health analysis, to implement the right wellness and prevention programs. SDEs working with public health departments will have to decide what medical conditions will take priority from a population health perspective and thus, what data the public health departments will need to support their analyses. Balancing the amount of data versus the speed at which the HIE can connect new providers will influence the ability to get both the data content and statistically relevant amount of patient data as quickly as possible.

Integrating clinical and claims data

In the future, tying claims data to clinical data will likely become a significant part of health care reform, as the payment model moves from one that is transaction based to one that is outcome based. The SDE, then, should look to integrate this capability into the overall plan early. In fact, the business benefit for individual providers may be greatly enhanced by having the ability to tie claims data to clinical data earlier, and so it may make sense to move up the overall timeline for adoption of this functionality in order to drive provider adoption.

Health-based benefit programs

Finally, another area where the electronic exchange of health data will play a role is improving the efficiency of processing federal or state benefits that are based on health condition (for example, disability benefits). In this area, having an HIE will bring two clear advantages. First, the systems that process the benefits will receive standardized health data via a single channel, which will result in faster and more consistent processing of benefits. Second, because the HIE will provide the service of communicating health data to benefit payment systems, the provider will no longer need to maintain a separate automated or manual process for each benefit system.

We already see this result taking shape: The Social Security Administration is piloting a program with MedVirginia to electronically receive medical records for some disability applicants. The Social Security Press Office stated that electronic medical records will allow them to improve their service to the public by cutting days, if not weeks, off the time it takes to make a disability decision. However, as with population-based health, the real benefits in this area will not be achieved until a critical mass of providers are connected to an HIE.
The SDE should envision its role as coordinating and developing common education and training materials for each of the target groups, taking into consideration both the similarities and differences.

Once the SDE has begun to connect providers to the HIE, education and training requirements will come into play—not only with regard to how to interact with the HIE themselves, but also, how to deal with the many questions which will undoubtedly come from patients as they “meet” the HIE for the first time.

To help HIE users deal with the many issues associated with such a new, large-scale change in the way they work, the SDE can establish a committee that focuses on education and training for all stakeholders. Even if it does not establish such a committee, however, the SDE should envision its role as coordinating and developing common education and training materials for each of the target groups, taking into consideration both the similarities and differences.

The SDE should begin by developing a statewide communication plan to clarify what communication needs to be statewide (and therefore remain under the control of the SDE), and what communication should happen at the regional level (and can therefore be delegated to the HIE). The SDE may also consider developing communication guidelines to ensure that a common message about the HIE is broadcast throughout the state.

Next, the SDE should conduct a training needs analysis for all stakeholder groups. Each stakeholder will have unique requirements; however, by identifying common training needs across a number of HIEs, the SDE can play a critical role in assuring consistency of training. For example, administrative staff will need to be educated on the consent processes because they will be asked questions regularly from the public/patients.

These questions will most likely be similar irrespective of the HIE, therefore common training and education materials can be shared across the network. While clinicians will need to receive training on how to deal with clinical data coming in from new external sources, depending on the technical architecture this information could be presented to them using their existing systems. Therefore clinicians’ education and training will most likely focus on new data sources, not necessarily new systems.

Once the SDE has found the commonalities in training needs, it can then either take the responsibility of developing that training centrally or designate a single HIE to develop it for the whole network.
With ARRA providing funds to begin building the foundations of a Nationwide Health Information Network (NHIN), states have a tremendous opportunity to take a highly influential role in shaping the future of health care reform. To ensure they achieve the outcomes they desire—improved access, higher quality of care for patients and a more efficient health care system—the states must exercise considerable care when establishing their SDEs.

To be successful, the SDEs they create must be equipped to manage a whole host of critical issues—governance, stakeholder management, technical architecture, privacy and security, and education and training, to name just a few. As they embark on this health care reform, states are about to tackle what is likely to be the largest transformation they have ever seen. With careful planning, however, states can position themselves to effect a change that smooths the path for health care providers to do their jobs more effectively, better protect public health and dramatically improve quality of life for its citizens. The road to high performance will not necessarily be easy, but the potential rewards of the journey—as well as the support coming from the federal government through ARRA right now—make a compelling case for states to embrace the coming change.

Conclusion
## Appendix

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<td><strong>Policy governance</strong></td>
<td>* Review/update eHealth policy</td>
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<td>* Define operational-governance approach</td>
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<td>* Manage HIE-governance process</td>
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<tr>
<td><strong>Privacy &amp; security</strong></td>
<td>* Resolve P&amp;S policy for population</td>
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<td>* Implement privacy &amp; policy security</td>
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<td>* Implement privacy &amp; policy security</td>
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<td><strong>Health information technology</strong></td>
<td>* Develop DA &amp; analytics</td>
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<td>* Use Cases:</td>
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<td>* Quality</td>
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<td>* Biosurveillance</td>
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<td>* Public health case reporting</td>
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<td><strong>Adoption approach</strong></td>
<td>* Develop public health &amp; other population health adoption approach</td>
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<td>* Develop population health change management</td>
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<td>* Develop payer-adoption approach</td>
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<td>* Develop provider claims-adoption approach</td>
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<td>* Develop payer &amp; provider change management</td>
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<td><strong>Education &amp; training</strong></td>
<td>* Develop and deliver population health analytics training</td>
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<td>* Develop provider payment reform training</td>
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<td>* Deliver provider payment reform training</td>
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<td></td>
<td>* Develop ongoing training curriculum and delivery approach</td>
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</tbody>
</table>
About Accenture

Accenture is a global management consulting, technology services and outsourcing company. Combining unparalleled experience, comprehensive capabilities across all industries and business functions, and extensive research on the world’s most successful companies, Accenture collaborates with clients to help them become high-performance businesses and governments. With approximately 177,000 people serving clients in more than 120 countries, the company generated net revenues of US$23.39 billion for the fiscal year ended Aug. 31, 2008. Its home page is www.accenture.com.