

Viewpoint ■

Building a National Health IT System from the Middle Out

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The top-down approach of many national programs for healthcare information technology (IT) may be at the heart of their current problems.

The medical-industrial complex loves a big procurement, and the contracts do not get much bigger than for building nation-scale health information systems (NHIS). But do we really need government embedded in the process of IT implementation, something it so clearly and routinely struggles with? Or is it better for government to simply set the policy rules of the game, given that it is policy in which they are expert? As the new United States Administration has recently signalled a massive injection of funds into building a National Health Information infrastructure via the American Recovery and Reinvestment Act (ARRA), what lessons can be learned from the past, and what strategic shape should the Federal intervention take?

The English National Health System (NHS) National Program for IT (NPfIT) in many ways serves as an international beacon for healthcare reform, because of its clear message that major restructuring of health services is not possible without a pervasive information infrastructure. The NPfIT is rolling out working systems and delivering tangible benefits to patients and caregivers. Yet no one could deny that there have been plenty of setbacks, misgivings, clinical unrest, delays, cost overruns, and paring back of promised functionality, culminating in demands from some political quarters to shut down the program.¹ The NPfIT was bound to experience some difficulties purely on the basis of its scale and complexity.² However, it is becoming apparent that there may be another, more foundational, cause of NPfIT's problems.

The NHS remains one of the few nation-scale, single-payer health systems in the world. It thus has nation-scale management and governance structures to match, and these inevitably encourage a top-down system architecture, stan-

dards compliance, and procurement process. Such an approach is impossible in many other countries, and the United States, with its highly fragmented and decentralized health system, sits at the other extreme. To deal with its health reform challenges, the United States has embarked on a totally different, bottom-up, approach to designing health information infrastructure. Service providers have formed regional coalitions to interconnect their existing systems as best they can into health information exchanges (HIE). The expectation is that Regional HIEs will eventually aggregate into a nation-scale system.^{3,4}

What we have in the United States and England are thus two parallel natural experiments, testing diametrically opposing approaches to building a NHIS. Both hope to arrive at the same broad goal—that elements of a patient's health record are accessible across different regions and to all authorized providers, with the ability to send messages (like reports and discharge summaries) across the system securely. The NPfIT aims to create a single shared electronic record (SSEHR), stored centrally, through which all healthcare providers can add or read information from others. The Health Information Exchange (HIE) approach, in contrast, does not create a single record, but intends to allow virtual views of records, as abstracted or aggregated from regional systems.

Both approaches have undesirable consequences. For the English NHS, there is no easy migration plan for its existing systems. With the top-down approach, existing systems that do not comply with national standards will typically be shut down and replaced by compliant ones. The new compliant systems may often not fit local needs as well as the systems they replace, which were often site-specific acquisitions. There is also the additional cost of staff retraining and workflow adjustment, with the risk of introducing unexpected errors into the care process.⁵ While a single-specification NHIS can be upgraded as technology changes, the time needed to get a return on investment makes it unlikely there will be radical overhauls in the short to medium term. This makes any top-down system relatively brittle to meeting emerging service needs.⁶ For example, many assumptions about NHS service models are "hard-wired" into NPfIT plans. It is, for example, assumed that each patient is registered with one General Practitioner (GP). How would the system cope if, in a few years, the NHS moved to a system of free choice, where patients could elect to go to any

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GP they chose? How would it cope with multiple GPs entering records into the same system and the conflicts brought to the summary record because GPs had different views about a patient? Because of its scale and inertia, a top-down NHIS will have a limited capacity to adapt quickly to the significant health service delivery challenges we face in the next 20 years. Over time, top-down designs thus become increasingly out of step with service needs, and local clinical providers will have to build work-arounds to make the aging system meet emerging needs. Work-arounds are probably fine in the short-term, but will inevitably add unmanageable local variations to what was intended to be singular national design.

Bottom-up approaches like HIEs, in contrast, preserve existing systems that are often crafted to meet local needs, avoiding the cost of ripping them out, procuring new systems and retraining staff. The HIE approach is also more resilient in the face of large changes, since new technologies or system designs can be adopted locally where there is need and capacity, as long as they too connect up to the HIE.⁶ Resilience comes at a price however, as one cannot predict how expensive or feasible it will be for any given local system to participate in an HIE. Nor is it known how much information HIEs can actually make available to other providers. Incompatible data models may make reconciling the same information across different systems arbitrarily complex. The price for preservation of local systems is a weaker national system, which may have data holes, and data quality problems. The presence of interoperability standards will minimize some of these risks, but at its extreme, a bottom-up strategy sees standards development and compliance as a largely voluntary affair, and government largely disinterested in it. Government's disinterest also means that bottom-up systems are unlikely to be closely aligned with national policy goals. In large and mature technology sectors like telecommunications, industry-funded standards development is well resourced. In an emerging and still fragmented industry like health IT, standards development is unlikely to attract a similar level of resource.

However, much of this analysis is predicated on the assumption that we actually *need* a single shared national record. Here, "the great may be the enemy of the good", since much clinical benefit can be obtained by simply accessing clinical records from different sources in their native format, without the technical convulsions needed to integrate multiple records into a unitary view. While patients do change locations or travel, just how often do they? If most people are treated within their region, what is the return on investment for building supra-regional systems that meet the needs of a smaller transient population? That might be a question that generates some heat, but should help to calibrate the level of investment directed towards coherent national shared records versus making all records available nationally to be viewed in their native form.

Furthermore, it is clear from the United Kingdom experience that building a single national electronic record system is a large, complex, and high-risk project that will bear fruit only in the medium to long term. An "EHR first" or "EHR in the center" strategy therefore is likely to miss many of the easy wins needed to demonstrate success, keep political momentum, preserve end-user buy-in, and build public confidence.

What are these easy wins? The answer will vary depending on the level of IT maturity and health priorities of a nation. They might include Web-based knowledge services, decision support (e.g., electronic prescribing), improved information exchange between institutions and regions (e.g., sharing discharge summaries between hospitals and primary care, or prescriptions between primary care and pharmacies), and of course, consumer-owned and maintained personal health records.⁷ At the heart of this conundrum is the vast gap between the needs of local institutions and national governments. It seems that there will always be a mismatch between targets that are set centrally and what is needed and feasible locally. There is also usually a disconnect between the costs of meeting government plans—borne often by clinicians, and the benefits—typically accruing to industry, administrators, politicians, and ideally patients. The closer we can bring these worlds together, the more we can minimize the mismatch in their goals.

There is a third way, which might be termed the *middle-out* approach, which goes some distance toward bringing closer the needs of health providers, the IT industry, and government, by creating a common set of technical goals and underpinning standards that can sit between them. This development of shared goals, standards development, and sometimes support for standards implementation, must be well resourced. Government can specifically take a lead role when industry is weak or the national interest strong. For example, countries like Australia have directed their initial public e-health investments into developing nation-scale standards, well before contemplating any actual systems being built. The singular purpose for an organization like Australia's national E-health transition authority (NEHTA) is to define the interoperability standards that will be used to specify any future NHIS.⁸ In the United States, the health information technology standards panel (HITSP), the National eHealth Collaborative (NeHC) and the Certification Commission for Healthcare Information Technology (CCHIT) together fill a similar niche, but there may be real advantages to tasking and fully resourcing a single joint entity with the role.

The middle-out approach acknowledges that government and providers all have different starting points, goals, and resources. Government does not mandate immediate standards compliance, but helps fund the development process. When the public interest is strong, government also has a key role to provide incentives and support that encourage clinical providers to acquire systems that are technically or functionally compliant, and to pursue innovations that keep their systems compliant over time. It allows local health care institutions and service providers to gradually make their information systems meet national standards, and to interoperate with the emerging National Health Information grid. Where existing systems are in place, customized interfaces are built to standard. Where new purchases are made, they are specified as close as is pragmatically possible to standard. The cost for integration is probably the same as it would be for a bottom-up HIE, but the end product has a much richer, and higher quality, capability for information sharing. There also seems to be less opportunity for system design and implementation to be captured by the medical-industrial complex, which is otherwise likely to tie-down

and own everything from system design to implementation. Middle-out also allows government to more effectively pursue health policy goals at a national level, but constrains them to expressing those goals against the standards laid out in the middle. Government can try to meet its central goals either by careful orchestration of local elements already in existence, or by supporting the development of new public infrastructure elements that interoperate with them. With some core public interest exceptions, especially around safety, privacy, and consent legislation, the pact that government makes with local institutions is that, beyond its commitment to common goals and standards, it will try not to shape what is done locally.

However, standards are not static. They evolve in constant response to new technologies and new health care needs. Therefore, the longer a clinical IT system is in operation the less standards compliant it becomes, until at some point it has aged enough to attain "legacy" status. By definition, there is thus always a lag between standards as published and as implemented on the ground. We therefore need to see standards as *targets*, and moving ones at that, that guide the long-term convergence of local systems into an integrated but evolving NHIS. Implementation never stops.

What is so compelling about the middle-out approach, apart from its technical robustness, cost-effectiveness and flexibility, is that countries currently pursuing top-down or bottom-up strategies can migrate to the middle whenever they wish. The NHS, via middle-out, would not be locked into its current architecture, but could with time shift its strategic goals to defining how local systems interoperate, rather than defining the local systems themselves. One might even contemplate a future where the SSEHR becomes a virtual rather than an actual record. With middle-out, HIEs can converge on common standards over time. A time will soon also come when nation-states will want to integrate their individual NHIS into one or more international system(s); the middle-out approach seems the only rational way to do so.

We must understand, therefore, that building national scale health IT infrastructure is a problem entirely different from

that of simply replicating a clinical system across many different institutions (in the manner, for example, that the Veterans Administration did in the United States). Building national healthcare IT systems involves defining a policy and standards framework that can shape the convergence of public and private, local and central systems into a *functional* national system. It is also about governments doing those things that only governments can do well, like supporting public sector institutions to join the NHIS, providing incentives for the private sector where the private business case for change is weak but the national interest is strong, supporting the development of public goods such as the skilled health informatics workforce essential to the success of any NHIS, and crucially, developing the legislative instruments needed to protect the privacy and legitimate interests of citizens. And government should avoid doing what it is not good at, like designing, buying, or running IT.

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