It feels like we are as far as ever from true, pervasive health data exchange in the United States. When I speak to folks from other countries they think we’re crazy; why can’t we just “do it?” Why doesn’t the Federal government mandate interoperability and everyone will follow suit? They never seem to get the Federal-state power sharing, or the influence of big business and big money, or our multi-payer insurance system. At least they understand our dysfunctional Congress....

Why is it so hard to reach consensus on even the basics of interoperability? Here are some potential reasons:

We can’t even agree on what Interoperability means. ONC put forth a modified IEEE definition of Interoperability in its January 2015 Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap,¹ and years ago I worked on an HL7 committee that examined hundreds of definitions and derived a master definition. The work of that group has gone largely unnoticed in the intervening years.² This is something I have stopped arguing about as the discussion becomes an end in and of itself. But clear definitions are still important to clear thinking.

It is hard to agree on scope. Even if we agreed on what interoperability means, we vacillate between the lure of all-inclusiveness and the reality of a phased-in approach. Should we restrict our initial implementations to clinical data? Should we also include administrative data? What about medical devices? Home health data? Data from personal health devices? How do we decide?

Multiple world views. Framing the problem as “interoperability” implies an acceptance of the current state of affairs in the US: fragmented data, fragmented systems, and an aversion to centralized data repositories. We purport to be interested in a “person-centric” Learning Health System (LHS) but our current reality is provider-centric largely because of the installed base of systems and power that are provider-centered (note that HITECH focuses on each person’s record, not each provider’s system). Others describe this as a tension between the needs of personalized care and population-based care. We have to decide as a nation just what our worldview should be, or concede that multiple, legitimate views are in play simultaneously, which require us to adjust our priorities accordingly.

Multiple audiences. When we talk and write about interoperability, we invariably have multiple audiences in mind, which causes the message to be muddled and the focus to become diffuse. The closer we get to “citizen” and even policy maker, the more background we need to provide; the closer to IT nerd, the less background is necessary. We need to find the middle ground, but admit to ourselves that not everything we think, say, or write is done so equally for everyone’s consumption.

We should measure interoperability outcomes not process or capability. Interoperability is not an end in and of itself – it is more important to measure what is achieved rather than the way it’s achieved. Measurement should also focus on the quality and not the quantity of what is exchanged. How do we balance the need to measure outcomes without it letting us off the hook in measuring anything about interoperability?

Lack of a compelling business case. Incentives cannot overcome the lack of a compelling business case to cooperate and not compete when it comes to sharing healthcare data. Similarly, technology solutions to interoperability need to be driven by business need, not the other way around. We have seen this issue come up numerous times with respect to HIEs (the noun), and it does feel like we are fighting a losing, uphill battle trying to make something happen without a compelling business need, and that if there was a compelling business need, interoperability would happen organically, as it has in the various IDN-centric and EHR vendor-centric private HIE networks.

Ambiguity over the role of HIEs (noun) and state government. We still do not seem to have a national strategy around HIE, certainly no agreed-upon “hub and spoke” scheme that to many seems natural given our size and complexity. With the end of the ONC State HIE Cooperative Agreement Program in 2014 states are on their own with little national direction about what they should mandate, support, encourage, or even just tolerate.

It is very hard to ignore self-interest. We need to ensure that what gets proposed
The pace of implementation will differ for different types of participants based on the use cases selected, the perceived benefits, and the investments made.

is the best for the system-as-a-whole and not one particular interest group, perspective, or part of the ecosystem. This is a very big challenge in an environment where money drives much of the decision-making and conflicts of interest are hard to avoid.

We tend to ignore the rest of the world. In the United States, we tend to think completely from a US-centric point of view, while most other countries consider internationally-developed standards and efforts, like ISO T215, critical to their planning. Do we really think that the need for interoperability stops at national borders any more than we think it stops at state borders?

We tend to reinvent the wheel. Whether you consider them a success, a failure, or something in between, our past efforts at organizing interoperability planning in the United States (AHIC, HITSP, HISPSc, NeHC, IHE, S&I Framework, and others) yielded high-quality artifacts that often go largely ignored when the next initiative begins. Some become building blocks of other efforts but more often than not, they just languish and collect dust. Shame on us all for failing to leverage this solid earlier work.

Our timelines are too aggressive. Or are they too lax? I read editorials that decry our rush to implementation given the complexity of it all. But there are those, including Congress, who just think we ought to “get on with it” and stop wasting time. Most organizations can only plan on a three-year horizon, and want only general direction beyond that. We need to craft strategy that strikes this balance well.

Different paces for different participants. The pace of implementation will differ for different types of participants based on the use cases selected, the perceived benefits, and the investments made. Intra-organizational interoperability often is a precursor to inter-organizational interoperability and also affects this pace. We need to speak clearly – and often differently – to early adopters, mainstream implementers, and laggards (see comments on audience above).

The tension between being too broad versus too granular. “Action plans” can be very practical and helpful, but when they are out of context – or simply have a voluminous number of steps and activities – they make us apoplectic. We need a better balance between clear and broad strategy and a limited, concise set of action steps we can all get behind.

Standards change too often. We have certainly seen just how long it takes to implement standards broadly, as well as how aggressively many of the SDOs work to improve and correct what they develop. Without backward compatibility this is a real structural problem. Introduce the notion of a paradigm shift in standards (like IHE Profiles/C-CDA to FHIR) and it feels paralyzing. Annual updates to standards are just too frequent. We should consider declaring standards and giving them a “freshness date;” so, for instance, a particular standard would be selected for 2016 with an explicit expected retirement in, say, 2020. We should also continue to insist on a separation of data format from transport in our standards articulation. FHIR, in an attempt to “simplify,” seems to have violated this rule. Finally, we should identify bundles of standards that fulfill specific use cases and promote them together.

A “common data set” has limited usefulness. It is more important to define...
appropriate data sets for specific use cases and ensure that the same data is represented the same way across these data sets. Our national strategy philosophically should be to align data formats (like CDA and HL7 messages) with the use cases they support based on a common data definition rather than a single common data set that satisfies no particular use case well. The notion of CDA and IHE profiles is that general-purpose data formats should be tailored to specific uses based on a common foundation. Let’s agree on the common foundation (whether it’s the HL7 RIM or FHIR resources) and leave it to the SDOs to define the specifics.

Monetization of data. Some EHR vendors are putting up financial barriers to access data that comes into the EHR even if the data originates within an organization – often referred to as “information blocking.” While the use by vendors of standards-based versus proprietary approaches to data access helps reduce some of these barriers, the strict use of standards by vendors does not guarantee that data will be accessible and available to the organizations that have already paid to capture and store it.

Some folks just don’t get it. Or do they? I have seen push-back from consumer-oriented groups on the whole notion of health data interoperability usually citing some unfavorably perceived characteristic of the Affordable Care Act or worry that this is all a nefarious plot to turn EHRs into public utilities that will allow the government to control information and invade our privacy. I can’t take seriously attitudes that completely misunderstand or misinterpret what is written in documents and plans. On the other hand, the world described in the LHS is so rich with data that I can understand this interpretation and am sobered by it.

Consent law differences are a bug to some, a feature to others. We continue to be unable to reconcile state and local consent-to-share data laws across the country which many consider to be a major barrier to interoperability. But to some, our attempt to harmonize and reduce state policy differences in this area is an attempt to squelch states’ rights and is offensive to them. And attempts to reinterpret HIPAA without actually changing it are unproductive and confusing.

Governance. Still. We continue to struggle with the role of government versus the market in the governance of health IT and interoperability in particular. Some feel the Federal government is ignoring the community activities already underway and advocate for a very light layer of government coordination and no more. Or worse, some fear that current initiatives are viewed by others in the ecosystem as a “problem to be solved” and not opportunities to be leveraged and resent the characterization. But will improved governance solve the basic issue of new standards being layered on old standards versus replacing them? Will it solve any of the intractable questions without leaving sizable minority opinions dissatisfied? Can it overcome inherent inconsistencies in State law? Should we just let the SDOs do their work and stay out of the way?

I’ve raised many issues here, and perhaps solved few of them. I don’t pretend these problems can be solved overnight. But we must as a nation (is that even possible?) make some decisions about how we will approach solving these issues. I propose we begin by

• Being skeptical of the notion of “consensus.” The best strategy might not be the most popular strategy. Some problems are in fact intractable. One critical role of leadership is to provide direction when the best choice is not obvious.
• Leveraging the past with an eye to the future. Enough of us have been around long enough to remember the successes and failures of past initiatives. We are at an inflection point: we must consider everything that has taken place up to this point before we charge on ahead.
• Recognizing that this is more about the pace of change than the substance of change. Our healthcare ecosystem is too large, complex, and fragmented to move lock-step. We need a broad vision within which early adopters, mainstream implementers, and laggards can all see a path forward. The details need to be tailored to each phase of implementation.

• In the meantime, focus on semantics. If we did nothing else over the next few years other than ensure that data in our various systems use standards terminologies and code sets, we will be far ahead of the curve when we are ready to really make interoperability happen. JHIM

REFERENCES
3. The saddest comment of all on this is that the wiki for the American Health Information Community (AHIC) is inaccessible due to an “expired subscription.”