

Databound Healthcare Solutions' Commentary on the Nationwide Interoperability Roadmap

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At Databound Healthcare Solutions, we agree with the vision of the Nationwide Interoperability Roadmap and its importance to the future of healthcare in this country. We are impressed by the quality of the Roadmap and the obvious thoughtfulness that went into it, and express our gratitude to the ONC for their leadership on this important topic. Our comments that follow focus on our perspective of how progress towards this vision may be achieved through specific actions to create a supportive business culture. We believe the Roadmap can be improved by prioritizing the scenarios where the cost of the necessary infrastructure and patient data management is aligned to the generation of revenues and the improvement of patient care.

Challenges and Gaps

The US healthcare ecosystem is huge, involving well-established stakeholders with differing motivations, few of which are currently focused on driving a shift to patient-centric healthcare. Providers are paid when the transaction of giving care is delivered and typically, the more urgent and complicated the need the greater the fees involved. Given this transactional focus as well as the limited focus placed on holistic patient wellness there have been limited revenues and infrastructure applied towards reaching the ultimate goal of patient-centric care. One significant gap in the roadmap is an absence of focus on why ecosystem participants should make the needed changes and how they will be motivated to make them.

Supportive Business Culture: Motivating change through standards and vertical integration

The "Questions on the Roadmap" asked "*How* can private health plans and purchasers support providers to send, find or receive common clinical data across the care continuum through financial incentives?" The more important question to ask is "*Why* will they want to do this?" Motivating change in such an environment is most effective when it can be done at the lowest level where the patient is seeking service and then propagated throughout the system.

In short, care providers will want to prioritize building such data continuum if it helps them compete more effectively for patients, reduces internal costs, accelerates reimbursements, and enables doctors to spend more time with patients and less time on paperwork. The business participants most likely to lead this change, those most likely to benefit from it, are those who make up the "vertical provider chains": the networked groups of primary care physician, labs, and specialists, of regional hospital systems and the pharmacies and payers who support their patients. Therefore, the first actions should be focused on care scenarios involving these groups. We would encourage development of incentives within these networks that support the building of the needed IT infrastructure, thereby aligning the ongoing cost of the necessary infrastructure and patient data management to the generation of revenues.

Prioritized Use Cases

Of the 56 use cases identified in Appendix H, we chose the following four in prioritized order, with additional comments on each.

26. All providers in a care team will have unique access, authorization and auditing functionality from health IT systems necessary to fulfill their role on the care team.

- Expand to include Use Case 41. Providers and patients receive electronic laboratory results from laboratory information systems (LISs) inside and outside their organization
- Expand to include Use Case 3. The status of transitions of care should be available to sending and receiving providers to enable effective transitions and closure of all referral loops.

56. Individuals exercise their choice for consent and consent management policies and procedures are in place to enable the private and secure electronic exchange of behavioral health data.

- The method for consent should be a defined standard for all participants of the exchange, and a core function of the REST API.
- This will require robust identity management and security to insure the person providing consent is the true owner of the PHI record.

35. Individuals have electronic access to an aggregated view of their health information including their immunization history

- Expand to include fitness and other wearable device, patient-created data in the defined data and API standards. Given the tremendous growth in demand of such devices, and the expectation that such demand will continue for some time, consumer's desires to see their clinical data side-by-side with their fitness and other health data will help accelerate progress of the roadmap deployment. Coincidentally, Care Providers will be able to create new offerings of value, and potentially more accurate diagnoses for the patient through the potential to include such data.

31. Payers use integrated data from clinical and administrative sources to determine reimbursement in support of payment reform

- Expand to include Use Case 22. Those who pay for care use standardized transactions and interoperability to acquire data needed to justify payment

Core technical standards and functions

The development of data standards and availability should govern all exchanges between provider entities and data should be made available to and manageable by the patient. For the avoidance of doubt, the regulations of data under HIPAA and related governing laws should clarify that Protected Health Information is owned by the patient and the care provider is the custodian of it. Data should be available immediately and electronically upon request. This ensures all providers have increased insight, and the patient has transparency about their care, prognosis, and follow-up. This will also align well with the medical data privacy standards which are developing in Europe, and will ease the technical burdens of healthcare IT companies that develop solutions for the worldwide market. In the US, we will need to start with the vertically connected scenarios mentioned above, paving the way for horizontal exchange of information secondarily.

The data standards should provide for not just clinician generated data, but also the integration of tele-medicine supportive data, including patient-generated data from the growing class of wearable devices available on the commercial market so that the patient and care provider can see a more complete picture of the patient's health. The rapid growth of these devices in the market is an indicator of the powerful force the consumer can create through their demand for monitoring their health. Standards that include managing and transmitting activity data (steps per day, run/walk/ride distances and times, moving time vs. sleeping time) would be useful.

Governance

Given the tangential and even opposing motivations that exist when managing health data, it could be helpful to develop a governance model similar to that used to manage the ever evolving web standards (the W3C consortium). ONC's sponsorship and administrative assistance in creating, selecting members, running the meetings and publishing findings would be instrumental to the initiative.

Accurate Individual Data Mapping

A unique identifier for each person is the most effective way to match a person to their record. We suggest utilizing a multi-identification system, which could include various types of identification, such as Social Security Number, State issued drivers licenses, Passports, etc) as a short term, common, key data element. In the future, other options such as hashed biometric and/or genetic data could be used. The creation of an identification scheme will bring with it the need for a master data management strategy for both standards and the identity lists themselves. While we do not think HHS or another Federal agency should be in the position of maintaining PHI, they could be the most appropriate custodian of the identity lists itself.

We recommend studying the field of digital marketing automation software companies and customer relationship management software vendors like Marketo, Eloqua (Oracle Marketing Cloud), ExactTarget (Salesforce Marketing Cloud), Siebel, Constant Contact, and Blackbaud. These vendors must "de-duplicate" their databases regularly of records from customers or constituents that have been duplicated due to multiple solicitations, multiple channel responses, and other sources. Over the years they have developed effective and sometimes complex algorithms to support matching a new person's record to their existing one in the database.

Conclusion

We believe that the vision of the Nationwide Interoperability Roadmap can best be achieved by focusing on the vertical integration of healthcare providers first. We believe the Roadmap standards should focus on supporting the ecosystem with data portability, availability, and security guidelines that allows the patient to conveniently grant consent amongst providers who are naturally motivated to cooperate in order that they can deliver better service and reduce their own internal costs. By incorporating patient's non-clinical and ever-increasingly demanded fitness and other health data from wearable devices and other home monitoring systems, patient demand will accelerate provider's adoption of these systems.

Paul Martin (pmartin@databound.com)

Eric de Jager (edejager@databound.com)

Databound Healthcare Solutions (<http://www.databoundhealthcare.com>)