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Response to “Achieving a Nationwide Health Information Infrastructure: A New Approach”

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In the March, 2009 issue of *Health Lawyers News* [now *AHLA Connections*], the health law analysis titled, “Achieving a Nationwide Health Information Infrastructure: A New Approach”¹ suggests largely dropping the efforts pursued to date to develop the Nationwide Health Information Network (NHIN) and starting over with a “simple, bare-bones system that is interoperable from the very beginning.” While we agree with the merits of some of the author’s ideas and suggestions, as counsel to a participant in the NHIN, we believe that the article mischaracterizes the NHIN and recommends some approaches that appear counter-productive.

The author derides the progress of the NHIN since 2004, as though the NHIN had been an active record exchange since that time. The NHIN, a federal program involving numerous entities including Regional Health Information Organizations (RHIOs), state and federal entities, and personal health records, has successfully exchanged “test” (i.e., anonymized) data. Phase 1 of the NHIN addressed “Architectural Prototypes,” which tested different approaches, and the lessons learned from that effort serve as the foundation for Phase 2 - Trial Implementations. The current NHIN II project plans to exchange “live” data, including protected health information (PHI), beginning this year. As such, if there is a target to the author’s criticism, it theoretically should be at various RHIOs and other entities including federal agencies participating in the NHIN. The NHIN itself is developing and has made great progress.

The author points to four reasons for the alleged “lackluster” progress toward the NHIN. First, the author argues that “financial incentives for interoperability are lacking.” Admittedly, the track record of proven financial benefit of RHIOs is mixed. Nonetheless, as the health community’s experience with RHIOs matures, so too will the varying financial models for RHIOs. Ultimately, we believe that the sustainability of RHIOs will be helped by the need for the dissemination of missing information at the point of decision making. Having such information should decrease the number of unnecessary tests and the resources wasted on obtaining information in archaic, time-consuming, and expensive ways. These benefits will lead to improved and more cost-effective healthcare. There is significant evidence that better information leads to improved care and outcomes and lower costs for those who are paying for care. Rebalancing the investments required and the

financial benefits is one of the challenges to a sustainability model. Through trial and error will hopefully emerge models for the financial sustainability of RHIOs. The blanket statement that “neither providers nor payors appear to believe that interoperability will improve their profits enough to justify the expenditure of the time and money that interoperability entails” is too broad. Regardless of whether their efforts have succeeded or stalled, private providers and payors have, in fact, been investing in the development of RHIOs and the push toward interoperability. By further aligning their interests, we firmly believe that sustainability can be attained and the focus solely on short term profitability appears to us to be misguided. Private payors and providers presumably see the overall benefits from RHIOs and the NHIN, such as improved quality of patient care and reduction in medical errors, as long term benefits that will result in tangible gains in the future.

Second, the author argues that “existing health data exchange projects are too different to be interoperable.” It is true that having varying technical and systematic approaches to data exchange poses a barrier to an efficient NHIN, which is why there are ongoing efforts to develop standards for data exchange. For example, the Health Information Technology Standards Panel (HITSP) has developed standards utilized by CCHIT (Certification Commission for Healthcare Information Technology) and the NHIN. HL-7 standards also are broadly and currently used for exchange of data. Not only are exchanges possible, but the NHIN has demonstrated, in real life, actual exchanges among NHIN participants in their local communities—where exchange is most vital. Focusing on the lack of interoperability among the numerous health information exchange projects around the country not only ignores current achievements but misses the greater purpose they serve. Certainly, there will have to be some standardization for the NHIN to succeed, which is where organizations such as HITSP, HL-7, and CCHIT come into play. Among the numerous barriers, technology is not foremost. One barrier we do see to the NHIN is education and familiarization with health information exchange. While varying health information exchange projects may not yet be turn-key ready for universal interoperability, many are through programs such as CCHIT.

The third argument for dropping the efforts to date for the NHIN is that “[o]nline medical records are too complex to form the basis of the NHIN.” We understand that populating

a complete electronic medical record may be complex, but it is essential to the ultimate goal of improved patient care—so why not tackle the challenges now? First, the challenge is not insurmountable. While the number of possible data entries is infinite (e.g. variations in patient histories, possible diagnosis and treatments, etc.), the number of fields to be populated with such data is finite. There is a definable and manageable scope to a medical record. To demonstrate this concept, Microsoft's HealthVault program has created a limited number of data entry fields. Based on these fields, a potentially infinite number of personal health record systems may utilize the HealthVault accounts. The author suggests that the NHIN should provide a quick "snapshot" of the patient's overall health status, not a history of prior treatment. Such an approach is needlessly limited, as software capable of exchanging a broad range of data is not only possible, but *already developed and operational*.

Finally, the author argues that "[p]roviding patient access to their online health information is too complicated for the early days of the NHIN." We agree that this is a difficult task. Varying state laws regarding access by minors, augmentation or deletion of information from medical records, and other privacy and security concerns mentioned by the author are legitimate. Such an observation, however, only raises the issue of how the legal community needs a more unified approach to health information exchange and not why there has been lackluster progress toward the NHIN. Issues regarding patient access to records will exist regardless of what approach the nation takes toward developing the NHIN. Regardless of how the NHIN is developed, absent legal reform, each provider will have to abide by the individual state laws applicable to such provider. In fact, the Office of the National Coordinator for Health Information Technology (ONC), through the NHIN, is currently drafting a Data Use and Reciprocal Support Agreement (DURSA) addressing many of the concerns voiced by the author. Further, the ONC has also funded the Health Information Security and Privacy Collaboration (a collaborative of 44 states and territories) (HISPC) that is addressing the various barriers to the exchanges of health information. One product of the HISPC is a collaborative analyzing differences in state laws. A second collaborative has drafted form agreements currently being used in pilots for the exchange of data across state lines, which forms are intended to work around many of the legal barriers to exchange.

The author's "new approach to NHIN" is laudable and should be explored, but to ignore the efforts put into the NHIN to date would be a mistake. No one can say with absolute certainty what route the nation should take. The idea of a centralized repository for protected health information has faced extreme resistance among privacy advocates and governmental bodies. Achieving a fully interoperable NHIN with true nationwide reach will take some time, but would only be slowed, we believe, by the author's approach. The author's new approach also will require an overarching organization or body to head the efforts, which lacks the flexibility of the NHIN and could hinder efforts towards patient-



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centered approaches to health exchange.

The author focuses largely on technical and practical considerations and interoperability barriers to the NHIN. Prefaced with the disclaimer that we are by no means technical experts, it is our understanding that there are few who actually believe that technology is the most significant barrier. The problem that we believe to be a cause for delayed progress toward the NHIN is the law. In a race to the NHIN, IT engineers are ready for the last 100 meter sprint to the finish line, while the law and lawyers are still trying to figure out on which track and in which stadium they are running. From a provider standpoint, one of the biggest fears of interstate health information exchange is uncertainty about variances in state privacy and security laws. A coordinated effort by the health and law communities to push for adoption of uniform privacy and security laws would provide the biggest benefit to achieving the NHIN. The basic structure of the NHIN, in our opinion, is not the problem.

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Endnotes

- 1 Deborah L. Drexler, *Achieving a Nationwide Health Information Infrastructure: A New Approach*, HEALTH LAWYERS NEWS, (Mar. 2009), available at www.healthlawyers.org/News/Health%20Lawyers%20News/Documents/2009/HLN0903.pdf.