

Extracts from

NHIN RFI Response

Submitted by Apelon, Inc.

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Apelon is the world's leading supplier of medical terminology software and services. For more than sixteen years Apelon has helped government agencies, professional societies, care providers, and industry create, maintain and leverage healthcare terminology. This work has given us an intimate view of the challenges and opportunities to be addressed by a NHIN (National Health Information Network). Our responses to this RFI derive from the successes of our customers, and are focused on the aspects of the RFI with which we have direct experience.

In summary, we propose that:

- the NHIN be a “soft” asset: standards and frameworks that facilitate the effective exchange and analysis of the nation's health information, and
- the NHIN be built incrementally and be undertaken as soon as possible in a way that yields short term benefit and at the same time supports graceful evolution

Standards define the interfaces by which the various “instruments” of the national health infrastructure, (e.g., electronic medical record systems, registries, directories, indexes, and analysis systems) exchange information.

We envision the NHIN as a set of standards and protocols, encompassing both transaction and data (content) areas, defining how healthcare information is transmitted, accepted, understood, and analyzed by both human and machine recipients.

More specifically, given the consent of a patient and his or her caregiver, an NHIN should support the secure retrieval of health information about the patient for timely and productive use by the caregiver, including the computer systems used by that caregiver.

Implicit in this view are beliefs that:

- health information about the patient is controlled and preserved by the patient's prior caregivers, the patient's agent, or the patient him/herself, and

- the prime requirement of the retrieved information is that it be readable by the current caregiver and organized for his or her productive use.

Experience has shown that healthcare information can be standardized productively – examples include HL7 transactions, NCPDP SCRIPT, LOINC, and SNOMED.

Apelon's customers are investing in a future wherein the patient information retrieved via a NHIN empowers computers, as well as humans, through the use of standards for structured information.

While many standards are required to create an effective NHIN, terminology standards are particularly important for consistent, repeatable automated analysis, and offer the greatest potential for quality improvements and cost savings through applications such as data mining, decision support, and point-of-care clinical guideline support.

Standard terminology means that both human and computer consumers of NHIN-transmitted information can use medication lists, lab test results, problem lists, procedure names, diagnoses and other relevant units of information with the confidence that the meaning is the same for both creator and consumer. Structured terminology supports enhanced comparability of these units.

For example: viral and bacterial hepatitis are hepatic diseases, h. pylori infections can be detected by an antigen or antibody tests, and certain prescription and over-the-counter medications can contain acetaminophen. Without such structure computers, and perhaps humans, cannot link different kinds of hepatitis, prompt that a test for h. pylori was positive, or help caregivers and patients consume safe levels of acetaminophen.

An NHIN might be useful without the use of standard terminology or structured terminology or even structured information, but it will be much more valuable with such technology. We encourage the transformation of an NHIN that supports only the transfer of human-readable health information into an NHIN that leverages structured information based on normalized data standards.

An obvious barrier to this approach – starting with something simple that is specifically designed to evolve gracefully – is today's lack of a complete set of appropriate standards.

Of equal challenge is that parts of healthcare – such as the availability and use of new medications and new lab tests - emerge frequently and rapidly, so the NHIN technology framework must change equally rapidly in ways that ensure that nothing important is thrown away.

Current healthcare IT processes and development cycles sometimes inhibit evolution; NHIN processes will need to accelerate evolution. Consequently, maintenance costs

will exceed creation costs. It is not enough to create standards, they must be continuously maintained by appropriate independent standards organizations.

A key enabler of an NHIN is a set of evolving, compatible standards that span an appropriate range of functions. This enabler will be more powerful, and have a more immediate effect, if it focuses on simple, reliable, broad-based services. The latter can serve as an infra-structure for rapid evolution of more sophisticated services. Again, the requirement is a focus on standards that enable orderly, timely evolution.

An NHIN should not be built using a single model; instead it should make use of an evolving sequence of models in analogy with contemporary communication protocols. Such protocols specify how data units – such as bits or characters - are to be transmitted, and how such units are to be combined in a computer processable and human readable piece of information on the receiving end.

Just as modems “negotiate” with one another to agree on the fastest communication protocol that each can support when connected to the other at any given time, two communicating NHIN computers can negotiate the protocol by which patient information is to be transmitted most effectively.

The lowest common denominator protocol can make use of secure email; that is, in the absence of a faster, more functional protocol, any piece of NHIN-eligible patient information should be NHIN-transmissible using NHIN-defined secure email. In this way, regional health providers can leverage faster or more efficient intra-region protocols as engineering investment dictates, and yet still support the inter-region transfer of information with any other NHIN “peer” regardless of engineering investment. Analogously, the format of the information transmitted should also have a lowest common denominator definition, such as an HL7 CDA (Compound Document Architecture) specification, and each named element of this format should be represented in a NHIN information model.

The portions of a format – or other organization of health information about a given patient – should all be defined and maintained in a standard way consistent with NHIN-standard information models, including the use of standard terminology.

For example, the portion of a NHIN transmitted record that contains demographics and a medication list should be clearly identified relative to a reference model of such records. The model specifies what it is that a computer can rely upon and what must still be interpreted by humans, and it does so in a way that permits more sophisticated approaches if desired by both sender and receiver.

Again, in analogy with email, an NHIN-transmitted record might be extremely simple in structure, as much early email was – but no simpler than some defined limit – or it might be more sophisticated, and include heterogeneous information elements – such as an image. Regardless, it should be processable in a specified lowest-common denominator way, and this processability should be sustainable as the NHIN evolves.

Just as standard interface formats and terminology are maintained and extended over time, NHIN record elements can evolve over time using the same mechanisms. Using this model, simple information can be displayed and used in more complex environments, and complex information can still be displayed and used in simple environments to the degree practical. For example, ASCII devices cannot easily display an x-ray, but they can display the radiology report and note that an image is available.

The latter recommendation is an example of a deeper engineering principle – homogeneity of representation – namely, that the portion of a NHIN-transmissible unit of information that is understandable by an NHIN-computer be represented consistently relative to other such units. The National Cancer Institute (NCI) uses this principle to define its standard objects; each object name, sub-field name, and defined value are all “terms” with formal definitions that are accessible in the NCI Thesaurus. The NCI objects are defined in the same human- and computer-empowering way as the names for cancers, investigational agents, animal models and biologic processes.

These ideas – and models – are neither new nor complex, but they require discipline to implement and deploy. The same processes and technology that created the Web can be used to create the necessary specifications and definitions. Deployed examples of everything required already exist.

The key is the vertical compatibility described above -- a well defined lowest-common denominator, such as secure email transmission of an NHIN-CDA record that everyone can use and build on. Building enhancements on top of such functionality will be what attracts private investment, and market forces can sort out those that are sustainable.

If the government pays for even part of a healthcare encounter, it should provide incentives and eventually mandates that a description of the key elements of that encounter be described in an NHIN-compatible form. As with DRGs, other major players will align themselves rapidly.

To the extent that an aspect of the NHIN is well understood and desirable it can be mandated by the government. Otherwise, the government should pay for function, use, and performance – to the extent these things can be measured. This is the fastest way to get interoperability standards and policies to converge.

Numerous RHIO initiatives have demonstrated the difficulty of negotiating the varying statutory and regulatory aspects of health information sharing among State and federal laws. Some simplification, or consolidation, of these issues should be addressed.

Nonetheless, the only way to discover the real barriers is to start creating and using NHIN functionality. Some anticipated barriers will disappear and unanticipated ones will appear. In this way resources can be focused on the barriers that matter the most.

Start with the secure email, CDA approach recommended, and plan for the orderly introduction of standard, structured information as would be natural and useful in an important context (eg: e-prescribing).