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April 3, 2015

The Honorable Karen DeSalvo  
Office of the National Coordinator for Health Information Technology  
Attention: Interoperability Roadmap  
Hubert H. Humphrey Building, Suite 729D  
200 Independence Ave. SW.  
Washington, DC 20201

Dear Assistant Secretary DeSalvo:

The American Academy of Pediatrics (AAP), a non-profit professional organization of more than 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of all infants, children, adolescents, and young adults, appreciates the opportunity to comment on the Office of the National Coordinator for Health Information Technology's (ONC) "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Draft Version 1.0."

The AAP is committed to the meaningful adoption of health information technology (HIT) for improving the quality of care for children and commends the comprehensive approach being taken by the ONC to identify the essential elements that should be included in the new interoperability roadmap. There is tremendous potential for HIT to facilitate patient safety and quality improvement, specifically quality measurement and reporting through efficient data collection, analysis and information exchange.

The AAP has been involved in programmatic activities aimed to improve pediatric functionality in EHRs over the course of the last decade. We are one of the founding organizations of the Continuity of Care Record (CCR) effort that outlined pediatric specific requirements for ePrescribing as well as inpatient and outpatient HIT systems. The AAP also worked with Agency for Healthcare Research and Quality (AHRQ) and Centers for Medicare and Medicaid Services (CMS) as a subcontractor to develop the Model Pediatric EHR Format. We continue to be involved in subsequent ongoing work to identify and enhance critical pediatric EHR functionality outlined within the original format.

The AAP applauds the ONC's effort in producing this Interoperability Roadmap. The document is very comprehensive and covers a wide variety of topics that need to be addressed when examining ways to increase interoperability. We agree with much of what is contained in the document and support the overriding goal to achieve true interoperability throughout the nation's health care system. We believe that the stated goals in this document promise to make care for children more effective, safer, and less costly.

We also appreciate that, as Dr. DeSalvo states in her introductory letter to the document, “the Roadmap is intended to be a living document owned and guided in its evolution by all health IT stakeholders.” In that spirit, we offer the following suggestions to improve the Roadmap in order to aid the goal of achieving interoperability between providers, patients, hospitals, clinics, laboratories, immunization registries, and other stakeholders in the very diverse health care system.

## **Questions on the Roadmap:**

### **General**

The Roadmap begins by asking stakeholders to consider particular questions when reading the document. One of these questions asks what, if any, gaps need to be addressed. One area that the AAP views as a gap in this draft and that we hope to see in future versions is a focus on the unique needs of specific population groups like children, minorities, seniors, vulnerable populations, and others that have their own unique characteristics. True interoperability will not be achieved until it allows the capture, sending and receiving of data that addresses special needs of unique populations and helps reduce disparities in health outcomes between population groups.

Children are not just little adults. Pediatricians are trained to diagnose and treat the health care needs of children and need fully functional health IT systems that are able to facilitate the collection of unique data points for newborns, infants, children, adolescents and young adults. True interoperability will allow different health IT systems to “talk” to each other and exchange data – but there has to be a mechanism for capturing the right kind of data needed for the pediatric population. Any discussion of certification, standards, and data formats need to always focus on children and other population groups that have their own unique data needs. The AAP has researched and published extensively on specific data needs in child health. Any interoperability efforts must enable sharing of these pediatric specific data necessary to improve care in child health settings.

In addition, another “gap” that should be addressed in future drafts of the Roadmap is an emphasis on improving the affordability of acquiring and using health information systems. There are many providers who would like to purchase health IT systems to be able to interface and exchange information with other providers, as well as their own patients, but the cost of purchasing the system has become a significant barrier. Many pediatricians do not meet the Medicaid patient volume threshold to become eligible for participating in the Medicaid EHR Incentive program, and thus have to pay the full cost for purchasing a health IT system in his or her practice. In order for interoperability to allow providers to communicate with each other, providers first need to have a system that allows them to send and receive important data to and from other stakeholders in the health care system. But as a recent article in *Pediatrics* found, 61 percent of pediatricians who do not use electronic health records in their practice identified cost as the largest barrier to attaining one. Again, it is incredibly important to continue to work on certification, standards and data formats, but providers actually have to have the technology in their offices to utilize the information and become part of an interoperable health care system.

In addition to help in identifying gaps, the Roadmap also asks stakeholders whether they thought the timing of the specific actions in the Roadmap is appropriate. In our view, we think the planned timeline laid out in the document may be much too ambitious, especially because there are too many critical action items in the first two years of the plan, making it much more likely to fail at least partially.

For example, we are one-third of the way through 2015 and we feel that the goals of getting existing communities to agree on coordinated governing practices, as well as establishing common rules of the road, will not be completed by the end of the 2015 calendar year as suggested. Many local health information exchanges (HIEs) have been working on community governance process for years, and many have no results to show thus far. In addition, the 2015 CEHRT NPRM was just released, so it is very unlikely that it will be in all vendor products by 2017, particularly given the experience with the 2014 certification requirements. We have also seen the different stages of Meaningful Use moved backed by several years as well. As such, we would recommend a much more spaced out timeline than is currently suggested.

### **Questions on the Roadmap: Priority Use Cases**

As requested, the AAP has chosen three priority interoperability use cases that should inform priorities for the development of technical standards, policies and implementation specifications. Our three selections are:

- (2) Clinical settings and public health are connected through bi-directional interfaces that enable seamless reporting to public health departments and seamless feedback and decision support from public health to clinical providers.
- (27) Data for disease surveillance, immunization tracking and other public health reporting are exchanged automatically.
- (45) Care providers have electronic access to the information they need for the detection of domestic violence or child abuse.

In addition to commenting on these general questions and priority use cases, we also would like to share our thoughts on the following sections contained in the Interoperability Roadmap.

### **Executive Summary: Critical Actions for Near Term Wins**

On page 11 of the report, under the section “Critical Actions for Near Term Wins,” the draft report states:

*“The four most important actions for public and private sector stakeholders to take to enable nationwide interoperability of electronic health information through health IT in the near term are: (1) establish a coordinated governance framework and process for nationwide health IT interoperability; (2) improve technical standards and implementation guidance for sharing and using a*

*common clinical data set; (3) enhance incentives for sharing electronic health information according to common technical standards, starting with a common clinical data set; and (4) clarify privacy and security requirements that enable interoperability.”*

The AAP suggests that a discussion about how to reconcile data inconsistencies be included here. For example: if documentation exists that a patient is allergic to penicillin in one electronic health record (EHR), but not in another, it is impossible to reconcile such contradictory information reliably through automated algorithms.

Similarly, problems exist when merging problem lists and other patient-level data, such as gender. Many Health Information Exchanges (HIE) currently present the requestor with inconsistencies; however, that does not solve the issue of which record is correct. A suggestion could be to “tag” data with a predicted accuracy factor. Then there should be a way for this inaccurate data to be suppressed when it is being retrieved. Otherwise, the record will be inaccurate and potentially harmful. Patient (or their surrogate) ownership of their data must be a priority to ensure the accuracy of these records.

Also, information that is exchanged is only useful if it can be integrated in the receiving EHR in a manner that it can be indexed and searched for. Transmitting scanned documents that cannot be indexed only exposes the receiving party to potential liability (i.e., “the biopsy results were sent to you”) due to information that is contained in the EHR but hidden to providers due to the lag of appropriate metadata and search-ability.

In addition, this section also contains a footnote in reference to the near term action of “improving technical standards and implementation guidance for sharing and using a common clinical data set” that states:

*“Vitals in particular should be expanded to include – patient’s body height, body weight measured, diastolic and systolic blood pressure, heart rate, respiratory rate, body temperature, oxygen saturation in arterial blood by pulse oximetry, body mass index (ratio). Vitals should also include date and time of vital sign measurement or end time of vital sign measurement and the measuring- or authoring-type source of the vital sign measurement.”*

The AAP would like to emphasize the importance of ensuring that these vitals include child-specific measures, for instance, like head circumference. It is crucial to the health and safety of children that their different needs are accommodated in any data collected to be included in a patient’s record.

### **A Shared Nationwide Interoperability Roadmap: Rules of Engagement and Governance**

The Academy appreciates the fact that the Interoperability Roadmap asserts that shared governance of policy and standards is a key building block that enables interoperability. We

certainly feel that, because of the diverse HIT ecosystem, numerous stakeholders will need to make collective decisions between competing policies, strategies, and standards in a manner that does not limit competition or innovation.

However, while we acknowledge that coordinated governance helps identify common policies and standards to support services that enable interoperability, and can provide a mechanism for establishing trust across electronic health information stakeholders, we still feel this section could lay out more of a path forward than it currently does. In particular, this section of the Roadmap should lay out the “curves of the road” and the “green lights” ahead and elaborate more on how future governance entities should be started, and by whom.

**A Shared Nationwide Interoperability Roadmap:  
Supportive Business, Clinical, Cultural and Regulatory Environments  
A Supportive Business and Regulatory Environment that Encourages Interoperability**

This portion of the draft Roadmap, which extols the need to migrate policy and funding levers to create the business imperative and clinical demand for interoperability and electronic health information exchange, includes a discussion of how the Federal government, State governments, private payers, and purchasers can help accelerate the speed of achieving true interoperability. The AAP appreciates this discussion and strongly supports giving incentives to providers, hospitals and other health care organizations to share the data they have. Vendors have acknowledged that sending patient data requires resources and have translated this into a charge per transmission. Epic for example charges \$2.35 for sending data for a patient to another provider. No considerations have been made to explore the efforts and additional work required from a physician’s office to assure that data get exchanged in a timely and accurate manner. We would encourage further exploration of payment models that cover the cost of sharing data for both the sending and receiving of data. Payments that are dependent on health care organizations actually sharing their data can help make this part of a business model that speeds up interoperability.

In addition, this section also includes Table 2, “Critical Actions for a Supportive Business and Regulatory Environment that Encourages Interoperability.” The table includes the category B2, “State Action,” which includes the following provision:

*1. Call to action: All states should have an interoperability roadmap articulated in their health-related strategic plans (included in their Annual Medicaid Health IT Plan).*

The AAP is supportive of state-level engagement and coordination for interoperability. However, we believe it is critical that the ONC ensures some level of uniformity throughout the States. Though we should be careful not to stifle innovation, it is also important that we do not inadvertently create 50 different interoperability maps that are incompatible with one another. Meaningful use made pediatricians eligible under Medicaid, which added significant burdens both in eligibility hurdles and reporting requirements, in addition to withholding of payments through some State governments as outlined in a recent paper in Pediatrics. It would be a

significant mistake to let local variations in requirements and standard create similar burdens for HIEs. In addition, we would also like to note that children with complex or chronic diseases frequently get care across State lines and lack of uniformity across States will severely interfere with their care. As such, the ONC should ensure that geography does not become a barrier to the exchange of data.

### **A Shared Nationwide Interoperability Roadmap: Privacy and Security Protection for Health Information**

AAP appreciates that the draft includes this section that highlights the fact that a health information system is highly dependent upon reliable mechanisms to ensure a secure network infrastructure and patient privacy. However, we must also note that this section and the rest of the Roadmap does not discuss the special privacy and security protections required for adolescent patients who, in some instances, have the right to consent to their own treatment. Under these circumstances, there are times where an adolescent would be able to specify that no one else, including their parents, have access to that medical information. Page 63 contains some mention of this by noting the possibility of, “managing and communicating an individual’s choice preferences regarding the use and disclosure of health information.” The AAP is pleased to see this inclusion, but we strongly believe that the roadmap would benefit greatly from specifically acknowledging the special circumstances of adolescent privacy protections. This issue is of paramount importance when considering the proper care for the adolescent population.

### **A Shared Nationwide Interoperability Roadmap: Privacy and Security Protections for Health Information Consistent Representation of Permission to Collect, Share and Use Identifiable Health Information**

The LHS requirement for this section states:

*“G. Consistent representation of permission to collect, share, and use identifiable health information: Though legal requirements differ across the states, nationwide interoperability requires a consistent way to represent an individual's permission to share their electronic health information, including with whom and for what purpose(s).”*

Though the AAP commends the notion of consistent permissions for the exchange of data, there are already varying levels of requirements that will require standardization. Many providers find it difficult to share data because of this lack of standardization, particularly in terms of opting-out versus opting-in with exclusions. For example: some providers have different permissions in different HIEs and even within the HIE if permissions are kept in the EHR. The AAP encourages the ONC to recognize that all of a patient’s data must be in a single location with a single set of permissions, and preferably patient controlled. This would solve a good deal of permissions problems.

**A Shared Nationwide Interoperability Roadmap:  
Core Technical Standards and Functions:  
Consistent Data Formats and Semantics**

The Academy appreciates the fact that the Roadmap includes a section on technical standards, including a focus on consistent data formats and semantics. However, we think this section should have included more of a focus on the ownership of the data format itself. In order for interoperability to truly be achieved, there needs to be a direct commitment to open, free, and published data. This means that the data cannot belong to any one company or to even a consortium of companies.

**A Shared Nationwide Interoperability Roadmap:  
Core Technical Standards and Functions:  
Accurate Individual Matching Data and Reliable Resource Location**

The AAP appreciates that the document covers the challenge involved with individual data matching. For children particularly, accurate data is absolutely crucial because children often cannot relay patient history or confirm accuracy of particular pieces of information in a medical record. It is imperative that appropriate algorithms are developed to ensure accurate matching. Though the given data elements listed on page 93 may be comprehensive for adults, the AAP suggests that the ONC ensure that this starting point for standardization is adequate for identifying and matching children's records including records of siblings and multiple births.

In addition, the identity of a patient can be hard to track because of a plethora of changes in life and living situations: divorce, moving across town or across state lines, changing insurance providers, placement in foster care, emancipation as a minor, and so on. As the AAP has suggested in the past, we believe that in order to truly achieve interoperability of patient data, there needs to be a National Patient Identifier (NPI) that would be assigned immediately at the time of birth and be linked to the child as she ages and grows into adulthood, as well as while she changes providers who deliver her care. So far, this type of NPI has not been achieved—in part due to the restrictions placed by the Federal government—but it is a necessary step in creating a truly function EHR environment and would tremendously help the nation achieve true interoperability.

As such, while we appreciate the focus on accurate individual matching data and reliable resource location, we were disappointed that these sections did not include any mention of a National Patient Identifier. Both of these tasks could be significantly helped and accelerated with the introduction of an NPI. We strongly urge the ONC to explore ways of working on this issue without violations of applicable language that has been included in the past 15 appropriations bills for the Departments of Labor, Health and Human Services, and Education. However, should this remain impossible, we encourage the ONC to look at the basic demographic data

requirements already outlined in the certification criteria for EHRs as a core set for patient matching data requirements.

The AAP appreciates the opportunity to provide comments on the ONC's "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Draft Version 1.0." The Academy is committed to the meaningful adoption of HIT for improving the quality of care for children and looks forward to continuing to work with the ONC to ensure that interoperability is implemented in a way that promotes the goals of improving the quality, safety and cost-effectiveness of care. If we may provide further information or assistance, please contact Patrick Johnson in our Washington, DC office at (202) 347-8600 or [pjohnson@aap.org](mailto:pjohnson@aap.org).

Sincerely,

A handwritten signature in black ink that reads "Sandra G. Hassink, MD, FAAP". The signature is written in a cursive style.

Sandra G. Hassink, MD, FAAP  
President

SGH/pmj