October 1, 2018

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The Honorable Don Rucker, MD
National Coordinator for Health Information Technology
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
330 C Street, SW
Floor 7

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Lisa A. Cosgrove, MD, FAAP Merritt Island, FL **RE: 2018 Interoperability Standards Advisory**

Dear Dr. Rucker:

Washington, DC 20201

The American Academy of Pediatrics (AAP), a non-profit professional organization of more than 67,000 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) 2018 Interoperability Standards Advisory (ISA).

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 examined when considering nationwide interoperability. 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, and the AAP believes that interoperability standards measurement is key to realizing this potential.

The AAP applauds the ONC's effort in encouraging interoperability and is pleased to see that it is seeking feedback on the 2018 Interoperability Standards Advisory. As the ONC notes, there are both opportunities and barriers to implementing interoperability standards, and that AAP is pleased to provide feedback focusing on the pediatric perspective.

The AAP is providing the following answers to the proposed questions:

18-1: In what ways has the ISA been useful for you/your organization as a resource? ONC seeks to better understand how ISA is being used, by whom, and what type of support it may be providing for implementers and policy-makers.

Pediatricians have numerous demands on their time and thus have limited time and resources to digest and learn the "formal definitions" reflected in the ISA, which

could be more user friendly. Additionally, many of the ISA code sets lack pediatric functionality that is needed and demanded by pediatricians.

While the AAP is aware of the Office of the National Coordinator's effort in the pediatric certification of EHRs and is looking forward to commenting on the pending regulations, we are concerned that the ISA lacks a pediatric focus.

18-2: Over the course of 2018, some new functionality has been added to the ISA, with more enhancements expected through 2018 and 2019. Are there additional features or functionality that would enhance the user experience?

The AAP suggests that the ONC develop tools that allow pediatricians to review, filter, and select code sets to help determine which code sets are specifically geared to pediatricians. Any additional guidance specifically geared towards pediatricians would be appreciated as well. The AAP would perceive as helpful any information on the prevalence of the adoption of Electronic Health Records (EHRs), and the degree to which they conform to the standards.

18-4: Are there additional informative or educational resources that can be provided to help stakeholders better understand the ISA, health IT standards, interoperability, etc.?

The complex nature of the ISA can be difficult for the average physician to understand. As mentioned before, pediatricians have many demands on their time and attention, most importantly in caring for children, and they lack the time to digest ISA codes and their implications. The AAP suggests that the ONC work to develop a more user-friendly interface with more easily digestible guides to the ISA.

Additionally, the AAP provides the following feedback on the ISA as a whole:

Though the AAP recognizes the importance of the ISA, we want to emphasize that there is much more to interoperability than standards. Lack of incentives to participate in exchange of health information is the major barrier. Pediatricians have faced significant challenges navigating health exchange, including health system level barriers that continue to be an issue with many pediatricians who are not part of large health systems and are being left out of interoperability all together. The AAP has voiced frustration with large pediatric centers not participating in Direct Messaging, which many pediatricians are ready and prepared to do.¹

Additionally, even when the larger systems are willing to engage, effective data exchange is costly. Small, independent or practices with significant Medicaid case load simply cannot afford to pay the cost associated to setting up effective exchange, and there is a lack of state level programs willing to support the pediatric exchange of data. Finally, when pediatricians can engage health systems to meaningfully exchange data with them, the interaction is often one-sided. Many health systems are willing to send pediatricians Admit/Discharge/Transfer (ADT)

¹ Lehmann CU, Kressly S, Hart WWC, Johnson KB, Frisse ME. Barriers to Pediatric Health Information Exchange. Pediatrics. 2017 May;139(5). pii: e20162653. doi: 10.1542/peds.2016-2653. PubMed PMID: 28557727.

information but refuse to accept referral information. Many also cite the barrier of an inability to collect and route electronic data from the multitude of vendors.

Often, pediatricians have little influence on the standards that are incorporated into their EHRs and how they are used. In many cases pediatricians are unaware of the data sets included. Despite SNOMED being the standard for problem list items, many vendors have versions of their software running in pediatric offices that are still using ICD. The problem lists of many software products were never mapped from ICD 9 to ICD 10. While the pediatrician's EHR might be certified, there may be versions of the software running in pediatric offices that vary greatly in their capabilities. Compounding this problem is the fact that fifty percent of pediatricians did not receive Meaningful Use incentives. Since much of the quality reporting is Medicare driven, many pediatricians were left without the same robust meaningful usability experienced by our colleagues who care for adults.

Unfortunately, despite the new standard, there is a lack of agreement in the medical community about how to handle much of the exchanged medical information. As one example, there is still a question of whether non-medication items should be put in an "allergy section" or on the problem list as a non-medication allergy with the appropriate SNOMED code. There are also questions raised about where vaccine reactions should be logged—in the allergy section, or perhaps in a separate table for vaccines? Different EHRs store the same data and information in various places with varying nomenclature. While this is frustrating for providers, more importantly it is a safety concern as providers and staff navigate between EHR systems and expect them to behave in the same way, when in fact that is not occurring.

Lack of funding is also a barrier to the ISA. For example, while the updated specifications for bidirectional immunization information exchange do exist, many states lack the funds to implement integration with every vendor, and many still mandate end-to-end connections and verification for every practice. Again, this negatively affects smaller, independent practices, who cannot afford to fund these updates.

Another large problem is the need to hold all entities accountable to using code sets appropriately and collectively troubleshooting issues. For example, laboratories and state Immunization Information Systems (IISs) are not certified. While the EHR may have to adhere to the latest standards, no entity is certifying or testing them. In many places, numerous organizations have tweaked the standards to include or exclude additional information, which makes it impossible for vendors to support across all fifty states.

Coupled with this is the problem of retrofitting information. In places where there were inadequate code sets or no specific answers to a problem, many EHR vendors created their own solution, which led to new standards. Now that ONC has focused on the new ISA standard, going back and retrofitting current systems is anticipated to be onerous.

The AAP is still deeply concerned about adolescent privacy and sees this as a major concern for patients aged 13 to 18. Health systems have made choices regarding how to protect their information internally but cannot ensure that their privacy decisions are maintained with fidelity on the adult side.

Further, the AAP is concerned that many advancements are being made without considering usability. There is no standard in the industry on how to display to users the data providence or pedigree. Providers and staff are overwhelmed with information and do not know how to navigate the confusion. For example, a pediatrician may be asking herself: How can I be sure which SNOMED codes for asthma on the problem list are the most accurate? Are these the codes that I have in my EHR? Are these the codes that the allergist sent me when they saw this child six months ago? How can I identify the source of the information and decide how to harmonize the data to reflect what is most accurate? These challenges are cumbersome for providers and staff, and ultimately leads to more burden for pediatricians. As this administration is focused on reducing regulation and governmental burden, these issues should be concerning to the ONC.

The AAP appreciates the opportunity to provide comments on the ONC's 2018 Interoperability Standards Advisory. The AAP 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 you have any questions, please contact Patrick Johnson in our Washington, DC office at 202/347-8600 or pjohnson@aap.org.

Sincerely,

Colleen A. Kraft, MD, MBA, FAAP

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President, American Academy of Pediatrics

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