



AAP Headquarters

345 Park Blvd
Itasca, IL 60143
Phone: 630/626-6000
Fax: 847/434-8000
E-mail: kidsdocs@aap.org
www.aap.org

Reply to

AAP Washington Office
601 13th St NW, Suite 400N
Washington, DC 20005
Phone: 202/347-8600
E-mail: kids1st@aap.org

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April 15, 2024

Micky Tripathi, PhD, MPP

National Coordinator for Health Information Technology

U.S. Department of Health and Human Services

330 C St NW, Floor 7

Washington, DC 20201

Dear Dr. Tripathi:

On behalf of 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, I write to provide comments in response to the request for feedback on the recently released draft United States Core Data for Interoperability (USCDI) version 5.

The AAP appreciates the opportunity to provide comments on this draft USCDI version as USCDI sets the standard for health data classes and constituent data elements to help facilitate a nationwide interoperable health information exchange. While the Academy supports efforts to advance standards and functionality that promote the exchange of health data, as the USCDI advances the information which can be exchanged, there remain significant gaps in standards to exchange health information in a safe and effective manner. To advance the content, without having appropriate widely adopted and implemented standards of consent and sharing, and resharing, of sensitive information worsens the already occurring problem of unintended consequences and harm, especially to minors. The current exchange of data has significant gaps in functionality that are core to pediatric healthcare. As such, the AAP provides the following recommendations for additional data elements and considerations for implementation to address existing challenges and further build on the improvements included in this updated USCDI version.

Regarding new data elements, the AAP strongly supports the addition of "name to use" and "pronoun" in the USCDI v5. However, in implementing these new data elements, the AAP is concerned about the potential for unintended harm to minors of inadvertently disclosing these sensitive data elements to parents or other caregivers, particularly regarding adolescents and young adults. While the minor may disclose their preferences to their healthcare team, they may not understand that the recording of this information may lead to sharing with outside entities that may create secondary harm. For example, a minor may be comfortable disclosing their preferences to their primary care team and one parent, but not with a second parent or to other healthcare team members across the country. If the patient is visiting relatives and has the need to visit an emergency department, this information could be used to further disclose the sensitive information to outside parties which may cause ostracization or physical harm. Without the ability to tag this as sensitive data and having standards for consent to share this information, the Academy believes to implement this standard has the potential to cause harm to patients. The AAP recommends ensuring that these data elements, and other sensitive data elements, are able to be kept confidential, if requested by the adolescent, prior to implementation.

Regarding the proposed additions for observations, the unique challenges of advanced directives for minors have not been standardized to reflect parental rights, autonomy, and legal powers of attorney. The AAP recommends advancing appropriate standards for implementation to ensure that the wishes of children, guardians and families can be exchanged, and the information can be used in a meaningful way. Specifically, exchange of data within the element Sex Parameter of Clinical Use is concerning from the pediatric perspective. This information may be very sensitive in the pediatric population and may cause harm if shared or reshared without appropriate context and consent from the minor and guardians where appropriate. Currently there is no standard way to tag this information as sensitive and so it cannot be protected according to appropriate consent once shared. In addition, minors make healthcare decisions within the context of their developmental trajectory and may change their consent as they age or move to adulthood. Without standards to withdraw consent to exchange or redact shared data such as this, both emotional and physical harm may come to patients throughout their life course.

The addition of “interpreter needed” is an area that highlights the lack of pediatric functionality. An interpreter may be needed for one or more parent/caregiver and it may be a different language, in addition to an interpreter needed for a patient. The lack of multiple appropriate contacts that are associated with every pediatric patient, with individual need for contact information, preferred language, interpreter needs, etc. underscores the need to examine core functionality to be captured and shared to ensure that the pediatric population has the same robust access to health information exchange as the adult population. In addition, these needs change over the developmental lifespan of children and consideration must be given to how to update and validate this complex information.

The AAP supports the expansion of clinical notes to include emergency department notes and operative notes for a more complete reflection of exchanging important clinical data. Immunization lot number data is currently captured in electronic health records (EHRs) as discrete data and used in transmission of immunization information to Immunization Information Systems. Clarification regarding implementation of these elements should consider that immunizations entered as historical data may not contain this information. The AAP recommends including standardized implementation guidance on how to reflect immunizations administered versus historically entered immunization data so that appropriate clinical decisions can be made by the receiving entity.

Regarding the incorporation of the Test Kit Unique Device Identifier, consideration should be made to the additional burden of creating a new data field in existing EHR technologies, as many ambulatory EHRs are not currently capturing this data. In addition, as in-home testing is advancing with the opportunity for patients to test at home and submit results via patient portals, the AAP recommends exploring how to capture the evolving landscape of external data sources for maximum return on investment within this element.

Regarding the additions under data provenance, care team roles are complex and recording the role of non-provider care team members is not yet defined and robustly implemented within the EHR in a manner which reflects the care team. As team-based care is expanded to include integrated mental health workers, care coordinators, etc. the data set is not yet reflective of the emerging complexity of care teams both within the hospital, in the ambulatory setting and care at home. In addition, there are state and regional specifications on who can be the “author of record” which may be different from the person performing data entry and being part of the care team. As the complexity of the team-based care provided grows, having attributions to individual contributors of data is similarly complex and should be explored.

Thank you again for providing this opportunity to provide comments on the draft USCDI v5. We respectfully request a meeting with ONC leadership to further discuss these recommendations to ensure that updates and

additions to USCDI can be implemented successfully. The AAP looks forward to partnering with ONC to improve the implementation of USCDI to support healthcare professionals and the pediatric population.

Sincerely,

A handwritten signature in black ink, appearing to be 'B. Hoffman', with a long horizontal stroke extending to the right.

Benjamin D. Hoffman, MD, FAAP
President

BH/np