

**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

**Executive Committee****President**

Benjamin D. Hoffman, MD, FAAP

**President-Elect**

Susan J. Kressly, MD, FAAP

**Immediate Past President**

Sandy L. Chung, MD, FAAP

**Secretary/Treasurer**

Margaret C. Fisher, MD, FAAP

**CEO/Executive Vice President**

Mark Del Monte, JD

**Board of Directors****District I**

Patricia Flanagan, MD, FAAP

**District II**

Jeffrey Kaczorowski, MD, FAAP

**District III**

Margaret C. Fisher, MD, FAAP

**District IV**

Patricia Purcell, MD, MBA, FAAP

**District V**

Jeannette "Lia" Gaggino, MD, FAAP

**District VI**

Dennis M. Cooley, MD, FAAP

**District VII**

Susan Buttross, MD, FAAP

**District VIII**

Greg Blaschke, MD, MPH, FAAP

**District IX**

Yasuko Fukuda, MD, FAAP

**District X**

Madeline M. Joseph, MD, FAAP

**At Large**

Angela M. Ellison, MD, MSc, FAAP

**At Large**

Kristina W. Rosbe, MD, FAAP

**At Large**

Joelle N. Simpson, MD, FAAP

May 28, 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 Office of the National Coordinator for Health Information Technology's (ONC) request for feedback on the draft 2024-2030 Federal Health IT Strategic Plan.

The AAP is committed to the meaningful adoption of Health IT for improving the quality of care for children, and appreciates the efforts being taken by ONC and other federal agencies to ensure thoughtful coordination around interoperability of health information. As such, the Academy largely supports the strategic plan's guiding mission to improve the health and well-being of individuals and communities using technology and health information that is accessible when and where it matters most, while envisioning a system that uses information to engage individuals, lower costs, deliver high quality care, and improve individual and population health.

Overall, the AAP applauds the plan's focus on equity and the expansion of broadband as critical to ONC's mission and vision. However, on slide six, to advance ONC's federal health IT principle of data-led decision making, the AAP encourages ONC to consider adding the use of Fast Healthcare Interoperability Resources (FHIR) to connect centralized knowledgebases (such as CDC immunization rules) instead of every vendor or local health system having to create the knowledge themselves. The AAP believes this resource should be fostered and encouraged to decrease the administrative burden that exists currently. Additionally, as part of the principle to increase health equity across all populations, the AAP recommends including the need to address equity and social drivers of health, not just represent them.

In addition, to further the goal of making healthcare more transparent, accountable, and accessible, the AAP would like to again note that privacy protection and data segmentation policies are essential for safe healthcare administration. Both concerns are particularly important for pediatricians, as they are trained to develop relationships with the patient directly, in addition to the caregivers or family members. In general, pediatricians try to respect confidentiality requests unless they have reason to believe that the patient poses a serious risk to themselves or others. This may be related to mental health, gender identity, risk-taking behavior (i.e., sexual activity, substance use), or other health concerns. The physician may work with the patient to arrive at a place where they are comfortable sharing information with

caregivers, but to break that confidence prematurely may permanently damage the patient-doctor relationship, family relationships, and future trust in the healthcare system.

The Academy encourages ONC to recognize this priority in the 2024-2030 Federal Health IT Strategic Plan and we encourage ONC to promote and incentivize, particularly through new funding mechanisms, the development of electronic health record (EHR) systems that allow true data segmentation to better allow for protection of sensitive patient data. The Academy encourages ONC to fund and mandate data tagging and segmentation for sensitive data elements so that pediatric providers can safely share pediatric data with the correct parties.

In addition to these general observations, the Academy urges ONC to consider the following comments to goals 1, 2, 3 and 4 from the draft 2024-2030 Federal Health IT Strategic Plan.

#### Goal 1: Promote Health and Wellness

The AAP supports the objective to ensure that individuals are empowered to manage their health, and it is important to ensure that this is inclusive of children and adolescent populations. Striving to help parents/guardians have access to information about their children and establishing and driving strategies for adolescent privacy has been a significant area of concern with recent regulatory efforts regarding information blocking and the balance with privacy. The AAP is concerned that sensitive data is not being equally protected by organizations not covered by HIPAA and that there is potential for data to be used in punitive ways and have unintended consequences. In an effort to further ensure data privacy, the AAP recommends protecting the privacy and security of electronic health information (EHI) in circumstances beyond those addressed by all applicable federal and local regulations and statutes by closing the gaps that exist in regulations and statutes in addition to ensuring individuals are better informed about how their information will be used. The Academy believes this can be achieved by developing standards on not just technical sharing of information, but on how to tag and protect sensitive data to ensure that it cannot be used in unintended ways that may harm patients. Assuring specific consideration for pediatric populations is also vital and the AAP recommends including language to support pediatric populations within this objective.

The AAP also supports the objective to ensure that individuals and populations experience modern and equitable health care and recommends including the use of diverse platforms to further strengthen this effort. Although many populations in the United States have access to mobile devices, there are many who do not or who do not have phones with internet access. Therefore, it would be beneficial to include language within the strategy around diverse platforms that would facilitate access for people who have hearing or vision impairments, language barriers, etc.

In advancing the health and safety of communities, the Academy suggests adding environmental data as part of this objective. Environmental data has many implications for health, and information such as pollution, housing quality, food deserts, and transportation availability is available for many communities. There are significant gaps in public health data and wide variation across the country, so it is important to leverage all available environmental data in this strategy as these factors drive widespread inequity in health care access and outcomes.

#### Goal 2: Enhance the Delivery and Experience of Care

To advance the objective of delivering safe, equitable, high-quality, and improved care, the AAP recommends including stronger language around interoperable information to work towards implementing federally mandated standards for all EHR vendors to follow. This would help advance standardization and interoperability of social determinants of health data as well, as outlined by the strategic plan, and advance equity.

Additionally, to use health IT to support payment for high-quality, value-based care as described in this objective, appropriate health IT functionality and support for high-quality pediatric care that can advance pediatric-specific alternative payment models is essential. Current models only support Medicare-based payment models that serve adults, but do not address the unique needs of children and the pediatric care team.

The AAP also supports efforts to increase transparency and understanding of health data that goes into algorithm-based decision tools. Transparent policies and transparency regarding the development and use of the technology that does not prevent assessment, comparison, and versioning would be helpful, particularly in knowing the extent of training data for contracted development. The Academy encourages ONC to ensure that tools are applied to appropriate patients based on the underlying data sets incorporated and that these tools both include and specify appropriate age-based datasets crucial for appropriate pediatric applications. Additionally, ONC should collect and review unintended consequences for those who perceive negative impacts of this technology and ensure that there is accountability for any harm caused by AI-enabled tools or services.

In order to truly put patients first, the Academy also continues to strongly recommend the development of a unique patient identifier for each child at birth as a long-term solution to patient matching and to better support interoperability of patient-specific data. Without implementation of a national patient identifier, there will continue to be additional costs to the system and errors in patient matching that will be difficult to eliminate.

The AAP appreciates the acknowledgement of the regulatory and administrative burden that providers experience, and recommends adding language to streamline processes in addition to standardizing data and processes related to electronic prior authorizations to allow for increased automation.

As part of leveraging health IT expertise from different health care settings, as mentioned previously, the AAP recommends adding the use of FHIR to connect centralized knowledgebases.

### Goal 3: Accelerate Research and Innovation

The AAP appreciates the focus on advancing opportunities for individuals, researchers, technology developers, and other health IT users to accelerate scientific discovery and innovation. As part of efforts to achieve this, the Academy recommends accelerating research on where tools can safely and appropriately automate functionality so that health care teams can most efficiently use tools, especially in a workforce shortage. Similarly, research on the implications of health IT tools in either contributing to or alleviating the burnout and turnover currently affecting the health care workforce would be beneficial in optimizing ways to utilize health IT to support health care, public health, and provider workflows more broadly.

Additionally, it is essential to implement and improve standards and mitigations for interrupted connections. As interdependency on data sharing increases, downtime due to cybersecurity issues and other threats are becoming increasingly problematic. It is critical to innovate and improve mitigation strategies, including alternative technological strategies instead of reverting to paper claims and records when outages may last for weeks at a time. Similarly, research on patient care, health care access, and outcomes as a result of downtime and outages is important to inform mitigation efforts.

As information is increasingly being shared electronically, clinical teams are increasingly receiving duplicative detailed information that can negatively impact the ability to make timely decisions and manage the flow of important information. In alignment with ONC's objective to ensure appropriate access to health data, the

AAP recommends that ONC invest in innovative ways to deduplicate and harmonize information without putting the entire burden on the clinical team to review this information individually.

Goal 4: Connect the Health System with Health Data

In developing clear and shared expectations for data sharing, it is crucial to promote information sharing practices that balance privacy with important health information to minimize information blocking. It is important for ONC to consider that there are many details related to the segmentation of data that are unique to pediatrics. For example, maternal data is included in the birth history section of a child's notes, and family member data is included in the family history section. If a mother decides that she does not want to share her medical history of substance abuse, for example, then her doctor may know to block that information. However, in the child's chart, that information is likely present because it is medically relevant to the child's medical care. Currently, there is no way to block maternal data in a child's chart from being shared. This capability is critically important now with increasing interoperability and a landscape where there is growing mistrust and misuse of information related to sensitive topics like reproductive health, mental health and gender-affirming care. There are countless examples similar to this that make pediatric data privacy a complicated issue, and as such, pediatricians should be consulted as regulations related to patient privacy and granular segmentation of data are considered and implemented.

Additional Comments:

The AAP notes that the improvements outlined in this plan will come with a financial cost and encourages ONC to directly address who will bear the costs, as it could impact some of the most underserved populations and areas of the country. It is becoming increasingly difficult for small and independent provider practices to continue to innovate, and the AAP urges ONC to ensure that these costs are not directly or indirectly placed on individual providers and practices. When more stringent, costly requirements related to physician use of technology are implemented, it can force smaller provider practices to make incredibly difficult financial decisions or close. Ultimately, this may leave patients without care.

Thank you again for providing this opportunity to provide comments on the 2024-2030 Federal Health IT Strategic Plan. If we can be of further assistance, please contact Pat Johnson in our Washington, DC office at [pjohnson@aap.org](mailto:pjohnson@aap.org).

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/ncp