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Micky Tripathi, Ph.D.
National Coordinator
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
330 C Street, SW
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Dear Mr. Tripathi,

The Children's Hospital Association (CHA) appreciates the opportunity to comment on the Office of the National Coordinator for Health Information Technology (ONC) 2024-2030 Federal Health IT Strategic Plan. We share the goal of ensuring the exchange of safe and timely information to promote health and wellness, enhance care delivery, accelerate research and innovation, and connect health systems with health data, and want to work with you to ensure that the health information technology (HIT) infrastructure meets the needs of children and their specialized providers.

The appropriate exchange of health information enables pediatric patients and their families/caregivers, as well as their providers, to have timely access to needed health care information to ensure the best possible health outcomes. These types of communications can help empower families of children with medical complexity to address changes in their child's condition and avoid frequent visits to the emergency department, thus reducing costs and stress to the family.

While the plan presents a comprehensive approach to improving the access and exchange of health information, we strongly urge you to consider the pediatric-specific implications for HIT development and innovation. We recommend that:

- Federal agencies set voluntary cybersecurity performance goals for all facets of the health care sector and help pediatric providers prepare for and respond to cyber threats.
- Predictive analytics be used to anticipate pediatric supply chain disruptions.
- Actionable pediatric-specific social determinants of health (SDOH) data should be included in children's electronic health records (EHRs) to optimize care delivery.

The 200+ children's hospitals across the country are dedicated to the health and well-being of our nation's children and advance child health through innovations in the quality, cost, and delivery of pediatric care. We are regional centers for children's health, providing highly specialized pediatric care across large geographic areas, and as such, are especially attuned to the value and need of strong interoperability and HIT infrastructure to support high-quality care across pediatric settings. Although they account for less than 5% of hospitals in the United States, children's hospitals care for almost one-half of children admitted to hospitals and serve the majority of children with serious illnesses and complex chronic conditions.

Champions for Children's Health

Our detailed response to relevant aspects of your strategic plan highlights the ways that your proposals can better meet the unique needs of our pediatric patients.

Artificial Intelligence

We appreciate the draft's proposal to promote the safe and responsible use of AI tools so that health care providers and patients experience streamlined and efficient care delivery. We urge the ONC to work with pediatric health care providers to identify ways to ensure that the pediatric-specific implications of AI development, adoption and use are addressed as AI advancements are made.

For example, AI models and tools can provide the most accurate diagnoses or treatment options by accruing large, comprehensive data sets. This can make the development and applicability of these models in pediatrics challenging given that there may be only few samples or data points for certain pediatric conditions that affect small numbers of children, such as for children with rare or other complex health conditions. To address these challenges, data experts and researchers at children's hospitals are working to make data sets interpretable for computerized learning. Efforts to advance AI should incorporate these types of learnings and experiences from frontline pediatric providers.

Furthermore, pediatric medical data may be more complex that adult data, which presents unique challenges for their use in AI. For example, in most adult medical files, there are only notes from the patient and the clinician. In contrast, pediatric medical files may include notes from parents, other caregiver clinicians, the children themselves, numerous subspecialists and even teachers, social workers or other community members engaged in the care of children. Merging these data sources together makes it more difficult to provide accurate predictions for diagnosis or treatment.

Cybersecurity

We appreciate the strategic plan's goal of providing guidance and resources to help health care organizations integrate high-impact cybersecurity practices. Children's hospitals may be especially vulnerable to cyberattacks since some cybercriminals may consider children's health care data to be a more lucrative target, given the longevity of the data and the difficulty in detecting cybercriminal activity until pediatric patients become adults. Therefore, cybersecurity is especially critical to ensuring that children's hospitals can provide safe, high-quality care.

While we remain committed to responsible cybersecurity practices, we oppose mandatory cybersecurity requirements without a framework to provide financial incentives for children's hospitals. Hospitals and health systems have invested billions of dollars and taken many steps to protect patients and defend their networks from cyberattacks that can disrupt patient care and erode privacy by the loss of personal health care data. It is critical that ONC consult with children's hospitals to ensure that they have the specific tools needed to prepare and respond to cybersecurity threats.

To that end, we recommend that ONC work with Congress and other agencies to strengthen federal coordination and help pediatric providers prepare for and respond to cyber threats. We recommend setting federal voluntary cybersecurity performance goals for all facets of the health care sector (including providers, payers, suppliers, etc.) and identifying resources to support the achievement of those goals. For example, investments in employee

education, system patching, strong access controls, and monitoring and response practices would help protect children's hospitals' critical clinical assets.

Cyberattacks may pose immediate risks for pediatric patients' care and safety, especially patients with complex medical conditions who depend on timely health care services. For example, one of our hospitals experienced a cyberattack that caused the suspension of its phones, email access, and electronic health records for more than a month. As a result of this attack, it was difficult for patients' families to communicate with their health care providers, keep appointments for checkups and procedures, and refill prescriptions. It is critical that future cybersecurity guidance incorporate the perspective of children's hospitals to prevent and mitigate the negative impacts of these cyberattacks on children and their families.

Drugs and Medical Devices

We appreciate the proposal's support of standards and technologies for improved adverse events detection and reporting of drugs and medical devices. We urge ONC to consider children's unique challenges in accessing needed medications and devices when developing these critical tools. Because there are fewer sick children as compared to adults, the data surrounding the pediatric supply chain often does not rise above even minimally used adult therapies, therefore pediatric-specific supplies are often not prioritized in a crisis.

HIT is an important tool to advance the maintenance of supplies and devices needed for pediatric patient care through investments in robust inventory management systems. The use of predictive analytics can be particularly helpful in anticipating supply chain disruptions and volumes of pediatric patients in a hospital. For example, a children's hospital has launched a system that integrates the facility's supply chain with electronic medical records, providing real-time alerts on pediatric supplies. Furthermore, many children's hospitals have found that HIT technology can assist in forecasting demand for pediatric use cases, combining historical utilization with seasonal illness trends.

Health Equity

We applaud the plan's promotion of HIT interventions that address health disparities so that researchers and technology developers can generate insights on how to support health care needs across the socioeconomic landscape. We know that childhood poverty poses serious risks to children's healthy physical, emotional, and cognitive development and long-term development. In particular, childhood food and housing insecurity have serious implications for children's health and stability and must be considered in future federal HIT strategies that address health equity.

To that end, we urge the ONC to explore strategies for including actionable pediatric-specific SDOH data in children's EHRs to optimize care delivery. For example, Child Opportunity Index (COI) data could be incorporated into EHRs to examine how a child's environment impacts their overall development. Neighborhood context, as measured by the COI, looks at different features of children's neighborhood environments, including air pollution, quality of housing, access to transportation, proximity to primary care providers and community economic

resources. Data from the COI has shown that children who come from lower-income families are more likely to experience asthma, migraines/severe headaches, and ear infections, after controlling for other factors.[1]

Furthermore, we recommend that the ONC incentivize a technology infrastructure that makes it easier to exchange pediatric-specific SDOH information and support capacity building across sectors and within and across states. In particular, states should be incentivized to build an HIT infrastructure that links various data sets and promotes a closed loop referral system. In addition, all data should be stratified by race/ethnicity and disability to assess equity implications and be reported by age. When a state is not routinely and accurately capturing race/ethnicity and disability data—and some are not—the state will be limited in its ability to pursue health equity reforms that could improve children's health outcomes.

Pandemic and Emergency Preparedness

We appreciate the plan's proposal to strengthen emergency and disaster preparedness efforts through the use of interoperable HIT standards. Disruptions in health care, trauma, social isolation, food and housing insecurity, and grief associated with a disaster or pandemic can have a significant negative impact on children's mental and physical health.[2] HIT standards should incorporate strategies that ensure children and their families can readily access child-appropriate physical and mental health care during a public health emergency.

To that end, we recommend targeting the collection and dissemination of pediatric-specific health data to enhance emergency preparedness, and standardizing the collection of pediatric public health data and their public displays from state to state. The federal government should be required to collaborate with a range of pediatric stakeholders to build out a national data infrastructure capable of efficiently sharing important public health information, including pediatric-specific information, among providers and federal and state agencies. This would enable collaborative local, state, and regional emergency preparedness and resource-sharing for pediatric populations affected by disasters in their communities.

In particular, a real-time surveillance data network that includes available pediatric data (from hospital inpatient, outpatient and emergency departments, as well as school and other relevant community-based settings) is needed. This network must have the capability to connect pediatric-specific data with other already existing data resources for better insight into pediatric cases.

For example, some children's hospitals use public health data tools that incorporate a variety of publicly available resources to enhance their coordinated pandemic and emergency preparedness and enable analyses by researchers. PEDSnet, for instance, is a multi-specialty network that conducts observational research across multiple children's hospital health systems, and the Observational Medical Outcomes Partnership Common Data Model is designed to standardize the structure and content of observational data.

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[1] Molly K. Krager, MD; Henry T. Puls, MD; Jessica L. Bettenhausen, MD; Matt Hall, PhD; Cary Thurm, PhD; Laura M. Plencner, MD; Jessica L. Markham, MD, MSc; Clemens Noelke, PhD; Andrew F. Beck, MD, MPH, American Academy of Pediatrics. The Child Opportunity Index 2.0 and Hospitalizations for Ambulatory Care Sensitive Conditions. Aug. 1, 2021

[2] CHA Publishes National Blueprint for Pediatric-Specific Readiness in Pandemics and Disasters (childrenshospitals.org)

Privacy

We appreciate the plan's proposal to protect the privacy and security of electronic health information by developing educational resources for choosing and using technologies that incorporate privacy protections. It is critical that these efforts address the privacy and confidentiality, proxy and safety issues that are unique to pediatrics. We urge that federal policies ensure that providers have the flexibility to adapt to the confidentiality needs of a pediatric patient's particular situation, including restricting access to some personal health information (PHI), when developing and implementing new digital technologies.

For example, children's hospitals work with—and obtain proxy consent from—parents, legal guardians, or other authorized representatives when providing care to minor children and before extending an invitation for portal access. It is not unusual for a hospital to receive a request from a parent, non-guardian, foster parent, or temporary court-ordered care provider—i.e., extended family, friends, etc.—who does not have authority to receive the child's PHI.

Furthermore, pediatric providers who serve large Medicaid populations, such as children's hospitals, often run into a disproportionately higher number of difficult-to-address guardianship disputes, non-traditional family structures, primary caregivers who have not received formal legal authorizations, undocumented children, or other related situations. Providing PHI access to the person with parental rights for a child who may have been subjected to abuse or neglect could cause further harm to the child and would be inappropriate.

Telehealth

We appreciate the plan's support for the expanded use of secure telehealth services, including audio-only, so that health care providers and patients can easily access and use telehealth to reduce disparities in health care access and outcomes. Telehealth services are complementary and synergistic to in-person care and, in many cases, have enhanced pediatric care delivery.

At the same time, certain pediatric-specific privacy and security issues must be considered and addressed. For example, states may have differing requirements and procedures related to the degree of adolescent confidentiality when telehealth services can be provided across state lines. Most states allow adolescent patients to seek and consent for medical care for certain conditions (e.g., mental health check-ins) on their own without permission or awareness of their parents or legal guardians, but states may have different parameters for the age thresholds for those adolescent confidentiality protections and the types of information that is protected.

Furthermore, pediatric telehealth advancements will depend on the adoption and use of common standards for interoperability amongst a range of provider types to enable secure data exchange and access. Children's hospitals often work with many community-based providers that may not have adopted telehealth platforms or may not have compatible pediatric-specific systems. In addition, children with medical complexity are typically cared for by a number of pediatric specialists, subspecialists, and other clinical providers who may be affiliated with one or more children's hospitals. The integration of telehealth through secure interoperability systems is critical for children's hospitals' provision of telehealth services for services that range from behavioral health to neurology care.

Additional Considerations

We strongly recommend that the strategic plan offer more detailed information about timelines and measurable targets (including pediatric-specific targets) for achieving the desired health care outcomes, as well as specifics about how the various strategies and initiatives will be resourced and monitored. The absence of this information may make it challenging to track and evaluate progress, especially when addressing complex pediatric health care challenges. Furthermore, it is important to acknowledge that the success of the plan is partly dependent on factors outside the federal government's direct control. Therefore, the ONC should plan for different scenarios around industry adoption, technological advancements, and broader societal changes in pediatric health care.

In conclusion, we share the agency's commitment to improving access to health data through stronger interoperability systems in order to strengthen care coordination and quality health care and urge you to consider the unique implications for the pediatric population. We look forward to working with you to collaboratively advance a pediatric HIT infrastructure that can efficiently and effectively allow for health information exchange that supports child patients, their providers, and their families and caregivers. Please contact Natalie Torentinos at natalie.torentinos@childrenshospitals.org or (202) 753-5372 should you need more information.

Sincerely,

Aimee C. Ossman
Vice President, Policy
Children's Hospital Association