April 11, 2018

Don Rucker, M.D.
National Coordinator
Office of the National Coordinator for Health Information Technology
330 C Street, SW
Floor 7
Washington, DC 20201

Dear Dr. Rucker,

On behalf of the more than 220 children’s hospitals across the country, the Children’s Hospital Association (CHA) is pleased to provide preliminary input into the development of voluntary certification criteria for pediatric health information technology (HIT) vendors. We believe that the establishment of a set of criteria for pediatric HIT and electronic health records (EHR) is an important step towards improving pediatric health care quality and safety.

Although they account for less than 5 percent of hospitals in the United States, children’s hospitals care for almost one half of children admitted to hospitals. Children’s hospitals are regional centers for children’s health, providing care across large geographic areas and serving the majority of children with serious illnesses and complex chronic conditions, and most children in need of major surgical services.

CHA would like to partner with the ONC in promoting EHR functions that focus on children’s health and improve pediatric clinical care; care coordination; information exchange between patients, families and providers, among providers, and with local, state, and federal agencies; and the overall quality of health care for children and their families. The development of pediatric-specific EHR certification criteria for vendors will help assure that the HIT products used by pediatric health care providers, including children’s hospitals, meet those goals and the unique needs of their child patients.

The nation’s children’s hospitals greatly appreciate the opportunities they have had to date to share their expertise through national pediatric HIT improvement efforts. We believe that the upcoming certification criteria should retain most aspects of the 2015 AHRQ Model EHR Format and Enhancement Recommendations. At the same time, there are a number of areas where the current format should be augmented to specifically address the small, but critically important, subset of issues unique to pediatric hospital care.

The lack of standardized EHR elements for the pediatric setting has resulted in resource-intensive “work-arounds” by children’s hospitals. Currently, it is not uncommon for a children’s hospital to have to spend time and resources to customize available EHR systems or use niche pediatric products that are then integrated into the children’s hospital EHR. For example, existing major EHR systems do not typically recognize the differences between adult cardiac care, which is focused on coronary artery and/or structural valve disease, and pediatric care, where providers must manage a wide array of anatomical and physiological abnormalities, primarily related to birth defects and genetic syndromes. The EHR that contains pediatric cardiac content including vital sign guardrails specific to the child’s diagnosis can provide safety reminders about certain standard interventions for adults, such as improving oxygen saturation, which could be life threatening for a child. In the absence of appropriate EHR systems, children’s hospitals must customize most of their pediatric cardiac clinical content as well as parent education modules that teach the parent/guardian how to optimize the child’s ability to feed, exercise and learn after discharge. These customizations can be burdensome for the hospital and detrimental to interoperability initiatives and strategies, given the lack of standardization.

Champions for Children’s Health
On the other hand, some customization capabilities are needed to accommodate unique workflows and communication channels that come with various pediatric specialties and subspecialties. The EHR system should have the appropriate backbone elements of functionality that clinicians can build upon under specialized circumstances when the standardized system cannot meet their needs. We urge ONC to work closely with the children’s hospital community to identify those specific EHR elements where some degree of customization should be allowed within a standardized framework for the pediatric hospital setting.

The following recommendations focus on needed pediatric EHR elements that will facilitate and support high-quality care throughout the care continuum with a focus on the children’s hospital setting.

- **Patient documentation**
  The documentation capabilities of the pediatric EHR system should allow for a standard patient identifier methodology that can match patients with their family/guardian but is not reliant on a social security number. The EHR should be able to capture parents'/guardians' legal names, along with additional demographic data, including telephone number, e-mail address, and gender. Family structure is changing and technology must be dynamic enough to capture less traditional identifiers. For example, not all children who receive care at a children’s hospital will have a social security number; others may have recently immigrated into the country.

  The system should allow providers to clearly flag children with special health care needs or complex conditions who may benefit from care management, tailored decision support tools, or social services. In addition, the EHR system should be able to proactively identify and notify families and the child’s provider when the child will soon need an immunization. The immunization data should be easily, and bi-directionally, interfaced with various state immunization registries to allow providers to see their pediatric patients’ updated immunization information as reported from all venues to the state.

  The EHR should be able to capture socioeconomic/social history items related to living arrangements, family, pets, grade in school, and other environmental and social issues that impact children’s health, in addition to the medical history. The EHR should allow this information to be documented discretely and easily visualized, and should facilitate the appropriate sharing of information with other providers, community agencies, etc. Knowledge of the life of the child – and the ability to share this information with others involved in the care continuum – is integral to the child’s health and well-being, particularly post-discharge when learning needs, housing or food instability, and personal psycho-social stressors must be addressed.

  Finally, we note that current EHR systems should facilitate the charting of children’s behavioral health visits. The systems must be designed to assure confidentiality for the older child patient, as well as parent/guardian access to data via self-service portals for the younger patients.

- **Decision support tools**
  Pediatric disease-specific decision support and workflow tools geared to the pediatric hospital setting should leverage accepted pediatric content to allow for more effective processes. These workflow tools can help reduce provider burnout and intensive resource utilization as well as improve outcomes. For example, the EHR should always require a child’s weight to be entered into the record, as the child’s weight is foundational to dosing of most medications. The Barton-Schmidt triage procedure is another example of a standardized process that should be incorporated into the EHR.

  In addition, the EHR must include condition-specific growth charts and vital signs as a standard component. Currently, hospital-based clinicians who care for a child with a complex condition, such as cerebral palsy, often must rely on paper growth charts because these children do not always fall into the set growth charts that are available in existing EHRs. Similarly, clinicians need decision support tools incorporated into the EHR for basic well-
child/preventive care and for primary care management for children with special health care needs or other chronic conditions.

Finally, we urge ONC to include pediatric risk scoring in the certification criteria for pediatric EHR systems. Most, if not all, of existing EHR-enabled scoring systems are adult-focused. Readmission risk in pediatrics is no less important than for the adult population, but the factors that influence readmission are vastly different for children.

- **Medication management**
  It is imperative that the pediatric EHR workflow allow for easily calculated weight-based dosing since children’s prescription drug doses are often based on the weight of the patient. The system must also allow for other dosing factors unique to pediatrics, such as chronological age or gestational age in highly vulnerable premature infants. The EHR should be able to calculate dose and volume for both individual and cumulative dosages and a dosage in reverse (i.e. dosage based on an entered volume). In addition, pediatric EHRs should facilitate safe prescribing for liquid medications of varying concentrations and the routine use of multiple products to achieve the intended dose, and provide automated medication instructions regarding dose tapers or increases. The system should also allow medications to be easily flagged “confidential” for adolescents.

  Current EHR usability related to pediatric medications is far from optimal and can lead to less than optimal care for the child. Available pediatric medication management workflows often do not account for the inability to use “unit dosing” in a population whose weight can vary widely (e.g. from <1 kg to >100kg), presenting serious safety concerns. Incorrect entry of patient information as a result of confusing screen layouts or designs and faulty calculations stemming from system design flaws can lead to overdosing and other medical errors. These errors will trigger systems’ built-in alarms, but the constant EHR alarms can cause some providers to sometimes ignore critical safety warnings.

  In addition to pediatric-appropriate medication management, the pediatric EHR must have the capability to manage and monitor nutritional supplementation for infants and children. We recommend that all pediatric-certified EHRs have technology that enables bedside identification of human breast milk, including identification of its source, as well as a system to track and monitor its administration to the infant. The EHR also should be able to track additives to the milk and have an inventory control mechanism.

  We also recommend that all pediatric-certified EHRs have a built-in Total Parenteral Nutrition (TPN) ordering process. TPN is a vital source of nutrients for sick or premature newborns, as well as older children who are unable, due to a gastrointestinal disorder, to otherwise get the nutrients they need. TPN is especially important for children and teenagers to help prevent developmental or growth delays. The EHR should be able to automate calculations of TPN formulations and streamline the order process from physician to pharmacist to patient.

- **Reporting requirements/capabilities**
  The EHR system should facilitate pediatric clinical, quality (including the reporting of adverse health events), and public health reporting to federal and state agencies, including the Centers for Medicare & Medicaid Services, disease registries, social services agencies and schools. Existing EHR systems often collect data points from pediatric providers that are the same as those collected from adult providers and are not relevant to the young pediatric patient (e.g., whether the patient has underlying coronary artery disease as a co-morbidity and if they smoke). As a result, many children’s hospitals must configure data as a custom metric for reporting, which requires ten-fold the effort and time. Others are unable to report key data elements to agencies and registries.

  To meet pediatric reporting needs, the EHR should include accepted pediatric quality measures with mechanisms for quick and easy reporting to relevant entities; enable reporting on the care of children with special health care needs
or other specific conditions/syndromes, including complex conditions; collect pediatric data points for submission to registries (e.g. newborn screening); and allow the provider to directly submit pediatric data to national and state pediatric registries. The certification criteria should be regularly updated to support the implementation of new pediatric quality measures when they are adopted, as well as new registry requirements. EHR systems themselves must be nimble enough to be modified in a timely manner as the measures and registry landscape evolves.

• **Functionality**
  We strongly recommend that the certification criteria address system functionality in order to improve and enhance the clinician experience. The use of simple standardized screens and workflows would reduce the administrative burden of the current documentation processes in most EHR systems. In particular, the technology should be capable of supporting patient or family/guardian direct entry of demographic data, including race, ethnicity, legal gender, and gender identification, as well as subjective data, which can then be verified and imported into the EHR by the clinician. The technology should also include standard pediatric developmental benchmark screens that pediatric providers (primary care and acute care) can use to monitor a child’s growth and development.

System functionality must also provide a mechanism to streamline proxy access for parents or guardians to their child’s electronic record, along with efficient tools to manage access when situations arise that require access to be discontinued, such as some circumstances related to the care of adolescents. We respectfully remind ONC that privacy and confidentiality functions are critically important aspects of the EHR, particularly in relation to the care of adolescents. There are some adolescent privacy issues (such as reproductive health, gender identity, drug use, and genetic issues) where parents’ involvement may need to be addressed. Portals and other patient and family-facing tools should allow for the ability to flag individual EHR components as confidential. In addition, EHRs should give providers some flexibility to adapt to the confidentiality needs of a patient’s particular situation, as well as specific state or local requirements. For example, states may have differing requirements and procedures related to the degree of confidentiality documentation (i.e.; which types of information can or cannot be shared with family members) and the point of care when an item is labeled as such.

• **Interoperability**
  Ensuring patient records, lab reports and other key pieces of data can be accessed and shared within the hospital, across a network of clinical and non-clinical providers, with patients and their families, and with outside agencies is essential in pediatric care. Interoperability capabilities enable pediatric providers (primary care through quaternary care) to have the most up-to-date health data about their patient in order to identify and appropriately address health concerns that may develop as the child grows. This exchange of information is especially important for children because their bodies may react differently from adults to a clinical condition, drug, or treatment plan. The more information about the pediatric patient that is accessible to a hospital, the better the outcome for that child.

Interoperability should begin with the birth of a child and should enable the linking or matching of EHRs and organizations related in any way to the care of newborns. For example, there currently is not a recognized newborn naming convention that assures that seriously ill newborns who are transferred to a children’s hospital from the birth hospital are correctly identified and that their records are appropriately transferred between the institutions. Interoperable technology should allow for queries, utilizing newborn naming conventions, of the birth hospital to identify and verify a newborn’s records prior to their import into the EHR. In addition, technology should be able to capture multiple birth status, including birth order, for use in patient identification.

Interoperability also can facilitate care collaboration and coordination, which can improve outcomes and overall quality of life for a child with special health care needs or a complex medical condition. Children with medical complexity are typically cared for by a number of pediatric specialists and subspecialists, who may be affiliated with one or more children’s hospitals. In fact, it is not uncommon for a child with multiple health issues to need care from several different children’s hospitals, given the regionalization of children’s specialty care. Robust
Interoperability capabilities are foundational to the effectiveness of care coordination efforts between a variety of institutions and to the child’s ability to meet their full potential. The child’s medical team must be able to utilize the data that is gathered in the home facility and by external organizations throughout the continuum of care in order to make more informed clinical and post-acute care decisions.

In addition to the interoperability elements that are needed to effectuate cross-provider collaboration and data exchange as the child grows, interoperability capabilities of the pediatric EHR should allow pediatric providers to work on pediatric quality improvement activities and tap into new technological innovations, such as telemedicine and smart medical devices. Interoperability in pediatrics should also enable communication between the pediatric provider and the child’s school nurse or counselor about issues that may impact the child’s health; have the capability to facilitate collaboration between the pediatric provider and the court, children’s services, law enforcement, and others on child welfare and social services issues affecting the child; and allow the provider to quickly give families information about their child’s condition and post-hospital care. Educational content for families on specific pediatric conditions and post-hospital care and concerns, including child welfare and other social services issues, should be standardized and built into the EHR. Currently, hospitals build their own content, pulling from a variety of established sources, such as the American Academy of Pediatrics’ Bright Futures. The standardized content should be available to providers across the care continuum to help ensure that families receive aligned information before, during, and after their child’s hospital stay.

In conclusion, we are pleased that the ONC is moving forward with the development of criteria for the voluntary certification of pediatric EHR systems. This effort is an important step toward improving the quality and safety of pediatric health care in all settings and affording all children, regardless of health status, the opportunity to grow and develop to their full potential. We look forward to working with you throughout the criteria establishment process. Please contact Jan Kaplan at 202-753-5384 with any questions.

Sincerely,

M. James Kaufman, PhD
Vice President, Public Policy