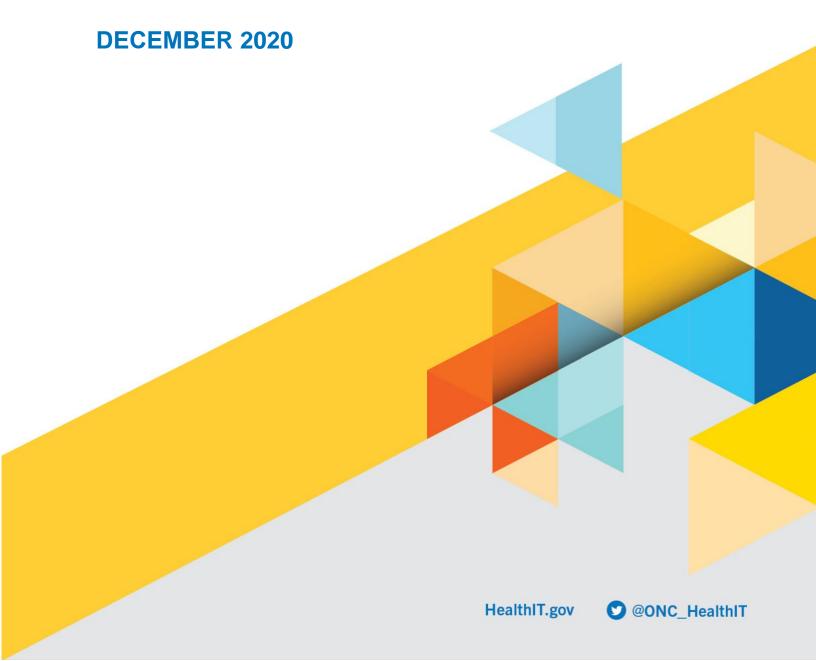


# Pediatric Health Information Technology: Pediatric HealthCare Provider Informational Resource



Office of the National Coordinator for Health Information Technology (ONC)

# PEDIATRIC HEALTH INFORMATION TECHNOLOGY: PEDIATRIC HEALTHCARE PROVIDER INFORMATIONAL RESOURCE

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**General Resources** 

### **Quick Start – All Recommendations**

Use Biometric-Specific Norms for Growth Curves and Support Growth Charts for Children	Compute Weight-Based Drug Dosage
Ability to Document All Guardians and Caregivers	Segmented Access to Information
Synchronize Immunization Histories with Registries	Age- and Weight-Specific Single-Dose Range Checking
Transferrable Access Authority	Associate Maternal Health Information and Demographics with Newborn
Track Incomplete Preventative  Care Opportunities	Flag Special Healthcare Needs

### **Learn More**

Fast Healthcare
Interoperability
Resources (FHIR)

Applications (Apps)

Clinical Decision Support (CDS)

**Privacy** 

Pediatric Health Information Technology: Developer Informational Resource

### **Foreword**

The development of this resource was guided by recommendations from the Health Information Technology Advisory Committee (HITAC) Notice of Proposed Rulemaking (NPRM) Task Force [1] and the Pediatric Technical Worksheets [2] included as an appendix in the 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program Proposed Rule. Other relevant materials are referenced in the *Works Cited* section of this document.

### INTRODUCTION AND PURPOSE

The Office of the National Coordinator for Health Information Technology (ONC) is making available this Healthcare Provider Informational Resource (Healthcare Provider IR) to support the implementation of health information technology (IT) products used by clinicians that provide healthcare for children. In this resource, for purposes of streamlining, the title "healthcare provider" is intended to capture any clinician or clinical site dedicated to providing healthcare for infants, children, and adolescents. Healthcare providers have an important role to play in this implementation. As users of electronic health records (EHR) and health IT, their input and direction to developers implementing recommended practices in clinical settings is critical. Incorporating healthcare provider insights to health IT development efforts can help to maximize the quality of children's healthcare and enhance coordination of services.

The Healthcare Provider IR serves as a complement to ONC's Pediatric Health Information Technology Developer Informational Resource (Developer IR). The Developer and Healthcare Provider IRs identify ONC's ten recommendations for health IT for pediatric care [3], [4], relevant certification criteria within the ONC Health IT Certification Program (Program), and other information to support the implementation of health IT products to support the safe and effective healthcare of children. The Healthcare Provider IR is intended to help healthcare providers work with their health IT developers to implement these ten recommendations.

To develop this document ONC engaged in a collaborative approach to incorporate input on clinical priorities from a variety of stakeholders involved in supporting pediatric care settings. <sup>a</sup> The ten recommendations in this document are informed by American Academy of Pediatrics (AAP) clinical priorities and build upon federal and stakeholder activities to date, including efforts supported by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS).

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<sup>&</sup>lt;sup>a</sup> More information on ONC's work related to health IT for pediatric care and practice settings can be found at: <a href="https://www.healthit.gov/topic/health-it-pediatric-care-and-practice-settings">https://www.healthit.gov/topic/health-it-pediatric-care-and-practice-settings</a>.

ONC also conducted a technical analysis to evaluate how relevant resources could be used by developers to support the health IT needs for pediatric care and sites of service.

The Developer and Healthcare Provider IRs are part of a broader ONC effort to promote the availability of certified health IT for medical specialty care providers and care settings. [3] ONC's approach to supporting the advancement of interoperable health IT across the care continuum has been applied here for pediatric care and settings. [3]

### **HOW TO USE THIS MATERIAL**

This document provides thorough reviews of the resources and considerations for each of ONC's ten recommendations for pediatric health IT. For healthcare providers who prefer to go directly to items for discussion with their developers, Part 1 provides an abbreviated version of each recommendation and relevant questions.

Introductory material on several specific topics— Fast Healthcare Interoperability Resources® (FHIR®), applications, clinical decision support, and privacy—follows this Foreword. Part 2 presents the central content focused on each recommendation.

The structure of each recommendation contains the following information:

- **Description –** a brief description of the recommendation.
- How Health IT Supports This Recommendation an overview of the functionality that supports the implementation of the recommendation in practice.<sup>b</sup>
- Considerations and Challenges common barriers to implementation of the recommendation or areas in which a healthcare provider may need to work or consult with a health IT developer at the beginning of implementation.
- Suggested Questions for Discussion with Your Health IT Developer
- For Further Reading Where Can I Find More Information?

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Note: Specific details about technical standards relevant to this recommendation, including references to the HL7 Child Health Functional Profile requirements (<a href="https://www.hl7.org/implement/standards/product\_brief.cfm?product\_id=468">https://www.hl7.org/implement/standards/product\_brief.cfm?product\_id=468</a>), reference implementations, and technical papers, can be found in the Developer IR (<a href="https://www.healthit.gov/sites/default/files/page/2020-06/Pediatric-Health-IT-Developer-IR-06102020.pdf">https://www.healthit.gov/sites/default/files/page/2020-06/Pediatric-Health-IT-Developer-IR-06102020.pdf</a>).

### **GENERAL APPROACH AND LIMITATIONS**

The functionalities identified in this document reflect commonly accepted features of current technical standards. ONC recognizes that the standards for all the recommendations may not be at full maturity. By referencing them in this document, ONC does not intend to limit progress, innovation, or flexibility to improve technical capabilities and guidelines. To optimize care for pediatric patients, healthcare providers and health IT developers are encouraged to work together to integrate functionality into workflow design specific to healthcare providers' sites of practice and to update systems to keep pace with best practices in EHR design. The Developer and Healthcare Provider IRs do not offer specific workflows or comprehensive solutions for healthcare providers; they are first steps. The recommendations expressed in this document are not intended to be prescriptive.

Care for the pediatric population largely occurs in two distinct care settings: the inpatient hospital and ambulatory care. The health IT needs of these and other relevant settings, such as emergency medical services, may be different for select recommendations discussed in this document. The scope of healthcare for children also involves community-based telehealth modalities. The existing standards and ONC certification criteria identified in this document could inform how health IT can support these recommendations in telehealth delivery. For example, the United States Core Data for Interoperability data standard could support telehealth visits by making key information available prior to a visit for a child receiving care outside an integrated network system. Future work could explore examples such as this for recommendations for the telehealth use case. <sup>c</sup> Healthcare providers may wish to prioritize specific recommendations in practice based on the care setting for which the product is designed and implemented.

ONC disclaimer: The Healthcare Provider IR is not intended to serve as legal advice, medical advice, or as recommendations for a healthcare provider's specific circumstances. We encourage healthcare providers to seek expert advice when evaluating changes to their EHR systems.

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C Healthcare providers may find additional telehealth resources at *Telehealth: Health Care from the Safety of Our Homes* (<a href="https://telehealth.hhs.gov">https://telehealth.hhs.gov</a>) and a telehealth toolkit from the Centers for Medicare & Medicaid Services (<a href="https://www.cms.gov/newsroom/press-releases/trump-administration-releases-covid-19-telehealth-toolkit-accelerate-state-use-telehealth-medicaid">https://www.cms.gov/newsroom/press-releases/trump-administration-releases-covid-19-telehealth-toolkit-accelerate-state-use-telehealth-medicaid</a>).

## **General Resources**

In addition to the resources and information contained in this document, healthcare providers may find the following resources useful to review when contemplating needs and opportunities for the implementation of health IT in support of the care of pediatric patients. <u>Appendix 1</u> includes additional background discussions on FHIR, application programming interfaces (API), Clinical Decision Support (CDS), and privacy considerations.

Resource	Description
Human Factors Guide to Enhance EHR Usability of critical user interactions when supporting pediatric care (NISTIR 7865)	This NISTIR guide (2012) highlights critical user interactions that can help increase the functionality of EHRs supporting the care of children and prioritize patient safety. <a href="https://www.nist.gov/publications/nistir-7865-human-factors-guide-enhance-ehr-usability-critical-user-interactions-when">https://www.nist.gov/publications/nistir-7865-human-factors-guide-enhance-ehr-usability-critical-user-interactions-when</a>
Bright Futures™: Guidelines for Health Supervision of Infants, Children, and Adolescents, 4th Edition	The AAP developed a common framework for pediatric preventive care screenings and well-child visits. This framework serves as a foundation of healthcare supporting the care of children in the US and will be supported by the recommendations outlined in this informational resource. <a href="https://brightfutures.aap.org/Pages/default.aspx">https://brightfutures.aap.org/Pages/default.aspx</a>
Certified Health IT Product List (CHPL) (ONC)	A comprehensive and authoritative listing of all certified health IT which has been successfully tested and certified by the ONC Health IT Certification program. The CHPL also catalogues details of each individual certification criterion, including such things as the types and numbers of user-centered design testers, for every certified EHR. Providers can search the listing to see if their EHR or health IT module are certified or specifically search for those certification criteria aligned with pediatric EHR requirements. <a href="https://www.healthit.gov/topic/certified-health-it-products-list-chpl">https://www.healthit.gov/topic/certified-health-it-products-list-chpl</a>
Children's EHR Format (AHRQ)	The Children's Electronic Health Record Format (2015) expands on the hierarchy created by Health Level Seven International® (HL7®) for the EHR-System Functional Model [5] and incorporates the HL7 Child Health Functional Profile [6] to help bridge the gap between functions present in most EHRs, and functions that would provide optimal support for the care of children. <a href="https://ushik.ahrq.gov/mdr/portals/cehrf?system=cehrf">https://ushik.ahrq.gov/mdr/portals/cehrf?system=cehrf</a>
Core Functionality in Pediatric Electronic Health Records (AHRQ)	This technical brief (2015) describes the state of practice and literature around core functionalities for EHRs supporting the care of children. The brief describes current practice and provides a framework for future research. <a href="https://www.ncbi.nlm.nih.gov/books/NBK293626/">https://www.ncbi.nlm.nih.gov/books/NBK293626/</a>
EHR Contracts Untangled: Selecting Wisely, Negotiating Terms, and Understanding the Fine Print (ONC)	A guide (2016) to equip providers with questions to ask when selecting an EHR, and to better communicate their requirements to potential developers while managing the expectations of both developers and providers. The guide offers specific strategies to help providers as they

Resource	Description
	plan for the purchase of an EHR system and negotiate key terms with their health IT developers. <a href="https://www.healthit.gov/sites/default/files/EHR_Contracts_Untangled.pdf">https://www.healthit.gov/sites/default/files/EHR_Contracts_Untangled.pdf</a>
EHR Selection, Purchasing & Implementation Resource Sets (HITEQ)	Resources to help providers select and implement health IT. The collection of resources is organized into two primary sections: Selection (EHR selection guides, needs analysis, workflow evaluation, and migration analysis) and Contracting (the ONC guide to EHR Key Contract Terms and supplemental issue briefs that address concerns specific to the FQHC environment). <a href="http://hiteqcenter.org/Resources/EHR-Selection-Implementation">http://hiteqcenter.org/Resources/EHR-Selection-Implementation</a>
Electronic Health Records for Pediatricians: A Shopper's Guide (AAP)	This guide for pediatric providers when selecting or implementing an EHR or other health IT tools includes information on health IT certification, important questions to consider when thinking about EHR functionality for the pediatric population, and links to AAP and other resources related to selecting and using EHRs. <a href="https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Informatics/Pages/ehrs-for-pediatric-care.aspx">https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Informatics/Pages/ehrs-for-pediatric-care.aspx</a>
Health IT Playbook (ONC)	A tool for administrators, physician practice owners, clinicians and practitioners, practice staff, and other with strategies, recommendations, and best practices on how to leverage health IT. Providers can learn how to optimize the safety and use of electronic health records and be equipped to protect the security of patient information and ensure patient safety. <a href="https://www.healthit.gov/playbook/">https://www.healthit.gov/playbook/</a>
Pediatric Aspects of Inpatient Health Information Technology Systems (AAP)	A technical report outlining pediatric-specific concepts, child health needs and their data elements, and required functionalities in inpatient clinical information systems that may be missing in adult-oriented HIT systems. https://pediatrics.aappublications.org/content/135/3/e756
Interoperability Standards Advisory (ISA) (ONC)	The ONC Interoperability Standards Advisory (ISA) is a process by which ONC coordinates the identification, assessment, and public awareness of interoperability standards and implementation specifications that can be used by the health care industry to address specific interoperability needs (including clinical, public health, and research purposes). The ISA includes standards and specifications required by ONC's certified health IT certification program, but also includes other emerging standards. <a href="https://www.healthit.gov/isa/">https://www.healthit.gov/isa/</a>
Social Determinants of Health (ONC)	Many of the pediatric health IT recommendations in this document involve aspects of social determinants of health. In certain recommendations, specific resources are identified. While this document is not intended to provide a comprehensive overview of social determinants of health, this ONC webpage provides more information on their connection with health IT. <a href="https://www.healthit.gov/topic/health-it-health-care-settings/social-determinants-health">https://www.healthit.gov/topic/health-it-health-care-settings/social-determinants-health</a>

# Part 1: Quick Start – All Recommendations

# RECOMMENDATION 1: USE BIOMETRIC-SPECIFIC NORMS FOR GROWTH CURVES AND SUPPORT GROWTH CHARTS FOR CHILDREN

This recommendation supports the accurate assessment and characterization of growth by encouraging health IT systems to incorporate visual displays of growth charts that plot selected growth parameters, such as height, weight, head circumference, and BMI percentiles over time on standardized Centers for Disease Control and Prevention/World Health Organizations (CDC/WHO) growth curves as appropriate.

Implementing this recommendation benefits pediatric care by:

- Facilitating age and sex-specific weight, height/length, head circumference measurement and body mass index (BMI) percentile calculation
- Allowing assessment of normal or abnormal growth patterns to evaluate nutritional and general health status.

### ONC Certification Criteria and Data Standard Supporting This Recommendation

- Standardized API for Patient and Population Services
- Clinical Decision Support
- Demographics

Data Standard: United States Core Data for Interoperability (USCDI)

	Suggested Questions for Discussion with Your Health IT Developer:	
	Underlying Data	
	Will the health IT account for adjusted gestational age for premature infants and specialized growth charts for children with special healthcare needs?	
	On what data sources will this functionality rely and are they in the public domain?	
	Will the health IT display an author or citation and/or a hyperlink to the source for the algorithm or standard used to present growth data compared to norms?	
	Will a BMI percentile ICD-10 code be automatically generated when the BMI percentile is computed?	
Data Visualization		
	Will the health IT allow healthcare providers to visually display longitudinal growth information with automatic calculation of growth patterns? If so, what will these displays look like, and can they be manipulated at the point-of care?	
	Will the health IT provide visual comparisons of a child's growth compared to established norms? If so, what will these displays look like and can they be manipulated at the point-of care?	
Alerts / CDS		
	What alerts could be available to inform healthcare providers of significant changes in the weight or height of a child?	
	Can healthcare providers customize alerts if they wish?	
Patient Access		
	Will patients or their authorized representatives be able to access their growth information? If so, how?	

## RECOMMENDATION 2: COMPUTE WEIGHT-BASED DRUG DOSAGE

Accurate and recently recorded height/length and weight is a key input to dose calculation for pediatric patients when the medication dose varies based on these factors.

Implementing this recommendation benefits pediatric care by:

- Facilitating accurate weight-based dosing, which has been shown to reduce errors and patient harm.
- Enabling independent, redundant calculation verification.

# ONC Certification Criteria and Data Standard Supporting This Recommendation Electronic Prescribing Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:
What medication databases are used in the EHR for medication ordering and e-prescribing? Are they pediatric-specific? How often are they updated?
How does the health IT round the recommended weight-based medication dosage? What rounding rules apply to the dose?
Are there alerts or safeguards against using outdated weight information to compute a weight-based medication dose?
Can the health IT support lifelong cumulative dose range checks?
How are medications managed for patients with special conditions?
How can a balance be achieved between alert fatigue and using health IT tools optimally to improve patient safety?
How are medical dosing errors tracked and how is this feedback incorporated back into the system?

## RECOMMENDATION 3: ABILITY TO DOCUMENT ALL GUARDIANS AND CAREGIVERS

Maintaining an accurate and structured record of a patient's care team has been identified as a critical component of an EHR supporting pediatric patients. The care team may include caregivers and guardians such as biological parents, foster parents, adoptive parents, surrogates, custodians, siblings, or case workers.

Implementing this recommendation benefits pediatric care by:

- Allowing accurate understanding of the social context influencing a patient's health and wellbeing.
- Better manage who needs access to the patient's record and who has authority to make decisions for the patient.

ONC Certification Criteria and Data Standard Supporting This Recommendation	
Standardized API for Patient and Population Services	
Security Tags - Summary of Care - Send	
Security Tags - Summary of Care - Receive	
Care Plan	
Transitions of Care	
Demographics	
Data Standard: United States Core Data for Interoperability (USCDI)	

Suggested Questions for Discussion with Your Health IT Developer:	
	What information can I document about a caregiver or guardian?
	What roles can I assign to the different care team members for a single EHR record?
	How are non-clinician viewers of the EHR designated in the record?
	Is there any limit on the number of names that can be added to the guardians and caregivers list?
	Am I able to view the decision-making authority of care team members?
	How can I archive caregivers who are no longer involved with the child?
	Can historical care team members be reactivated?

# RECOMMENDATION 4: SEGMENTED ACCESS TO INFORMATION

This recommendation addresses the need for privacy of certain services by tagging electronic health information and providing or limiting electronic access to specific segments of the record to specific users. While identifying and controlling sensitive information, such as sexual health, mental health, and social history, is challenging for patients of all ages, it is a particular challenge for adolescent populations as they mature and develop increasing capacity for their own health communication.

Implementing this recommendation benefits pediatric care by:

- Enabling access controls to sensitive information.
- Building trust with adolescent patients.

# ONC Certification Criteria and Data Standard Supporting This Recommendation Standardized API for Patient and Population Services Security Tags - Summary of Care - Send Security Tags - Summary of Care - Receive Transitions of Care Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:	
Data Segmentation	
How can I use my EHR to mark, tag, or identify health information as sensitive or private?	
Will the health record show that parts of the record have been marked private and are not visible?	
How does the health IT support setting preferences for access to sensitive health data?	
Can the EHR document additional consents for the access of segmented health information? How will this information be exchanged with other EHRs?	
Can clinical decision support tools scan tagged, sensitive information?	
Can I specify the length of time segmented data can be accessed?	
How can the EHR help me account for state-specific laws when tagging data?	
Can I add Consent2Share software to my EHR?	

# RECOMMENDATION 5: SYNCHRONIZE IMMUNIZATION HISTORIES WITH REGISTRIES

This recommendation supports up-to-date bidirectional pediatric immunization information for healthcare providers by encouraging health IT systems to support, update, and reconcile a child's immunization record with information received from Immunization Information Systems (IIS).

Implementing this recommendation benefits pediatric care by:

- Identifying immunizations given elsewhere
- Reducing duplicate immunizations
- Using immunization forecasting
- Making it possible to schedule appropriate follow-up visits around immunizations

# ONC Certification Criteria and Data Standard Supporting This Recommendation Standardized API for Patient and Population Services View, Download, and Transmit to Third Party Transmission to Immunization Registries

Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:		
	Registries	
	Can the health IT transmit data to state and territory registries so other healthcare providers can see the immunization data from my patient's visit?	
	Can the health IT query state and territory registries for a patient's complete immunization history?	
	Can immunization data in a patient's EHR be compared with registry information?	
Decision Support		
	Will alerts be available to inform healthcare providers of immunization needs for patients?	
	What alerts could be available to inform healthcare providers of potential over-vaccination?	
	How will EHR-based tools promote maintaining the rules that drive immunization clinical decision support?	

	Suggested Questions for Discussion with Your Health IT Developer:	
	Functionality	
	Will healthcare providers be able to produce reports? If so, what data elements will be included in these reports?	
	How will the health IT incorporate state-specific immunization requirements for schools, camps or childcare facilities?	
Patient Access		
	Will patients and/or their guardians be able to access their immunization data? If so, how?	
	Will patients and/or their guardians receive alerts on required immunizations?	
	Will patients and/or their guardians be able to electronically share their immunization data with third parties?	

### RECOMMENDATION 6: AGE- AND WEIGHT-SPECIFIC SINGLE-DOSE RANGE CHECKING

Weight-based dosing has been shown to reduce medication errors for pediatric patients, but medication errors may still occur when a single medication dose falls outside of accepted maximum and minimum reference ranges for pediatric dosing. EHRs supporting the care of children can support medication single-dose range checking by leveraging existing pediatric drug database references or tools and displaying normal pediatric ranges for reference and weight-based dose calculations.

Implementing this recommendation benefits pediatric care by:

- Assisting with weight-based dosing calculations
- Detection of a drug dose falling outside the minimum-maximum range based on patient age, weight, and maximum recommended adult or pediatric dose for a single dose of the medication

# ONC Certification Criteria and Data Standard Supporting This Recommendation Standardized API for Patient and Population Services Clinical Decision Support Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:		
	What drug database is being used? Does it support pediatric dosing?	
	Are single-dose alerts available for minimum or maximum single doses? Maximum daily doses? Is this customizable?	
	Do single-dose alerts suggest a dose range?	
	How can a balance be achieved between alert fatigue and using health IT tools optimally to improve patient safety?	
	How are medical dosing errors and overriding of dose range checking tracked, and how is this feedback incorporated back into the system?	
	How are healthcare provider workflows and user-centered design factored into system design?	

# RECOMMENDATION 7: TRANSFERRABLE ACCESS AUTHORITY

The care team members allowed to access a pediatric patient's health record may change over time due to changing family dynamics (e.g., foster care, adoption, and divorce). This recommendation manages access authority and changing circumstances of pediatric patients.

Implementing this recommendation benefits pediatric care by:

- Ensuring appropriate and current caregivers and/or guardians are given the correct permissions to a minor's health record.
- Providing an ability to make changes to caregiver/guardian access based on changes in caregivers, guardians, or circumstances.

ONC Certification Criteria Supporting This Recommendation	
Standardized API for Patient and Population Services	
Security Tags - Summary of Care - Send	
Security Tags - Summary of Care - Receive	
View, Download, and Transmit to Third Party	

Suggested Questions for Discussion with Your Health IT Developer:		
	How are different permissions for my patients' caregivers or guardians documented?	
	Can roles be edited or deleted if circumstances change or errors are found?	
	What information in the patient's record is available to be identified/selected for access control?	
	Can the EHR distinguish between permission to access the patient record and medical decision-making authority?	
	Is there a way to document any disagreements between caregivers or guardians and their desired decision-making priority?	
	How can this functionality be used to enable the transition of care from pediatrics to other specialties?	

## RECOMMENDATION 8: ASSOCIATE MATERNAL HEALTH INFORMATION AND DEMOGRAPHICS WITH NEWBORN

Point-of-care access to maternal health and demographic information is critical for the care of a newborn patient. Important health information may include but is not limited to maternal infections, immunizations, blood type, maternal substance use that can affect babies (tobacco, alcohol, opiates), behavioral health disorders, and heritable genetic conditions

Implementing this recommendation benefits pediatric care by:

- Allowing access to maternal information at the point of decision making necessary for the care of an infant.
- Ensuring maternal information does not need to be input by hand, decreasing risk of error.

# ONC Certification Criteria and Data Standard Supporting This Recommendation Standardized API for Patient and Population Services Care Plan Transitions of Care Demographics Family Health History Social, Psychological, and Behavioral Data Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:		
Associate		
How will the EHR associate information when the mother and newborn are treated at different hospitals?		
How will the EHR associate information when the mother and newborn are treated in the same hospital?		
How can maternal information be associated when the newborn is cared for in the ambulatory setting?		
How will sources/provenance of information be identified?		
How will maternal information be displayed in the newborn record?		
Can the healthcare provider select the maternal information that is associated with the newborn record?		

	Suggested Questions for Discussion with Your Health IT Developer:	
	Family Members	
	What options are there to incorporate information from the maternal record that relates to other family members (such as family history)?	
	Can information be flagged as being from a surrogate mother versus a genetic mother?	
Privacy		
	Can the maternal information incorporated into the pediatric record be tagged as sensitive data for maternal privacy when the child reaches a certain age or a specific milestone?	
	Can a mother request that maternal information incorporated into the pediatric record be tagged as sensitive data and shielded from the child's view?	
	Can a copy of maternal consent to share information be included in the pediatric record?	

## RECOMMENDATION 9: TRACK INCOMPLETE PREVENTATIVE CARE OPPORTUNITIES

Identifying preventive care that is overdue or expected soon is key to maintaining a pediatric patient's health. Pediatric clinical guidelines such as Bright Futures Guidelines and the Bright Futures Periodicity Schedule (2020) provide age-specific preventive care recommendations for the frequency and content of well-child visits, including screenings, assessments, immunizations, and anticipatory guidance.<sup>d</sup>

Implementing this recommendation benefits pediatric care by:

- Leveraging the EHR to detect the absence of well-child visits or age-appropriate screenings.
- Integrating notifications into the clinical workflow to close gaps while the patient is in the office for other reasons.
- Generating lists of patients who have missed preventive services.

# ONC Certification Criteria Supporting This Recommendation Standardized API for Patient and Population Services Clinical Quality Measures Clinical Decision Support

	Suggested Questions for Discussion with Your Health IT Developer:	
	Patient Missed Visits	
	Can a report be run on demand that creates a list of all patients who have missed a well child visit? Can the list be sorted by age, type of visit (e.g., 2 month, 12 month), or other factors?	
	Are there alerts if a patient misses a scheduled visit or is due for a specific intervention?	
	Can alerts be turned off or limited for patients who have missed more than one visit? Are there other ways to mitigate healthcare provider alert fatigue?	
Clinical Guidelines		
	If clinical guidelines from more than one organization or program are needed, how are they differentiated in the EHR?	
	Can different guidelines be matched to different subpopulations (e.g., children with special healthcare needs)?	

d See <a href="https://brightfutures.aap.org/Pages/default.aspx">https://brightfutures.aap.org/Pages/default.aspx</a> and <a href="https://downloads.aap.org/AAP/PDF/periodicity-schedule.pdf">https://downloads.aap.org/AAP/PDF/periodicity-schedule.pdf</a>.

Suggested Questions for Discussion with Your Health IT Developer:		
	How and when will newly implemented guidelines be incorporated into the EHR?	
	How can guidelines that need to be implemented into an EHR be prioritized and communicated? How can updates to those guidelines be executed?	
	Can the FHIR-based APIs available to me reference external sources?	
Social Determinants of Health		
	Can relevant social determinants of health be captured in an EHR?	

# RECOMMENDATION 10: FLAG SPECIAL HEALTH CARE NEEDS

Children and youth with special healthcare needs are defined as at increased risk for chronic physical, developmental, behavioral, or emotional conditions, or that require health or health-related services of a type and amount beyond that required generally. [7] Practices may subjectively identify such patient populations. This recommendation allows such a designation to be communicated in a clear and intuitive manner.

Implementing this recommendation benefits pediatric care by:

- Ensuring appropriate and current caregivers and/or guardians are given the correct permissions to a minor's health record.
- Providing an ability to make changes to caregiver/guardian access based on changes in caregivers, guardians, or circumstances.

# ONC Certification Criteria and Data Standard Supporting This Recommendation Standardized API for Patient and Population Services Clinical Quality Measures Clinical Decision Support Data Standard: United States Core Data for Interoperability (USCDI)

Suggested Questions for Discussion with Your Health IT Developer:	
	Can the health IT implement existing screening tools, such as the Children with Special Health Care Needs Screener <sup>e</sup> , in the EHR?
	How can a patient with a special healthcare need be designated so that a healthcare provider looking at the record knows right away that the patient has special needs?
	Can the health IT implement a screening tool in such a way that it triggers an alert if certain criteria are either missing, not met, or met?
	Can the health IT capture social determinants of health relevant for the patient?
	Can patients be unflagged?
	Can alerts or flags be designed by healthcare providers to signal specific needs or interventions?
	Can a flag be shared between EHR systems to ensure that a recipient system "understands" the patient has special healthcare needs?

<sup>&</sup>lt;sup>e</sup> See <a href="https://www.cahmi.org/projects/children-with-special-health-care-needs-screener/">https://www.cahmi.org/projects/children-with-special-health-care-needs-screener/</a>.

# Part 2: Recommendation Descriptions

**Note:** There may be numerous criteria, technical standards, and other technical resources that can support implementation of the recommendations, depending on the comprehensiveness of those resources and their maturity. In addition, developers may need healthcare providers to share information and specifics about their practice to effectively implement health IT pursuant to this and other recommendations. For more information on the certification criteria, visit ONC; for other technical resources that support this recommendation, visit the Developer IR (<a href="https://www.healthit.gov/sites/default/files/page/2020-06/Pediatric-Health-IT-Developer-IR-06102020.pdf">https://www.healthit.gov/sites/default/files/page/2020-06/Pediatric-Health-IT-Developer-IR-06102020.pdf</a>). See also the 21st Century Cures Act Final Rule and ONC guidance for information on effective dates, sunset dates, and other information on the certification criteria impacted by the 2015 Edition Cures Update (<a href="https://www.govinfo.gov/content/pkg/FR-2020-05-01/pdf/2020-07419.pdf">https://www.govinfo.gov/content/pkg/FR-2020-05-01/pdf/2020-07419.pdf</a>). The Pediatric Technical Worksheets Appendix from the 21st Century Cures Act Proposed Rule discusses in detail how select certification criteria support each recommendation (<a href="https://www.healthit.gov/sites/default/files/page/2019-03/PediatricHealthITWorksheets.pdf">https://www.healthit.gov/sites/default/files/page/2019-03/PediatricHealthITWorksheets.pdf</a>).

# RECOMMENDATION 1: USE BIOMETRIC-SPECIFIC NORMS FOR GROWTH CURVES AND SUPPORT GROWTH CHARTS FOR CHILDREN

### **Description**

Age and sex-specific weight, height/length, head circumference measurement, and body mass index (BMI) percentile calculation are important for assessing normal or abnormal growth patterns to evaluate nutritional and general health status. [8] This recommendation supports the accurate assessment and characterization of growth by encouraging health IT systems to incorporate visual displays of growth charts that plot selected growth parameters, such as height, weight, head circumference, and BMI percentiles over time on standardized Centers for Disease Control and Prevention/World Health Organizations (CDC/WHO) growth curves as appropriate. [9], [10]

User-friendly displays providing longitudinal information, that automatically calculate growth patterns, and that automatically calculate comparison with normal velocity are critical components of an EHR supporting care of children. Implementation of this recommendation allows proactive visualization of a child's growth pattern and the ability to provide alerts for body measurements that fall outside a growth standard. [9] This recommendation also allows for displayed values to reference correct data sets.

### How Health IT Supports This Recommendation<sup>f</sup>

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Clinical Decision Support	
Demographics	
Data Standard: United States Core Data for Interoperability (USCDI)	New

Standardized API for Patient and Population Services is replacing the existing certification criterion Application Access – Data Category Request as part of the 2015 Edition Cures Update. USCDI is replacing the Common Clinical Data Set.

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Healthcare providers are advised that there may be numerous steps to implement these recommendations beyond availability of some supportive certification criteria, technical standards, and other technical resources depending upon the comprehensiveness of those resources and their maturity. In addition, developers may need healthcare providers to share information and specifics about their practice to effectively implement health IT pursuant to these recommendations.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Display of user-friendly longitudinal information with automatic calculation and display of growth patterns;
- Comparisons with normal velocity based on or informed by established growth norms;
- Use and reference of evidence-based data sets for growth;
- Accounting for adjusted gestational age and/or specialized growth charts; and
- Enable patients and their authorized representatives to electronically view, download, and transmit their height, weight, and related growth information to a third party. [4], [9]

#### Health IT can also include functions that:

- Incorporate CDS at the point of care when growth measurements are being recorded and when healthcare providers are using height and weight data to guide clinical decision-making for weight-based dosing.
- Add alerts that could indicate deviations from established norms. Healthcare providers who want to add alerts are encouraged to work with their developers to ensure that the alerts are in an acceptable format and are useful to inform
- acceptable format and are useful to inform decision-making.
- Display the source of the growth standard (e.g., WHO or CDC) or the algorithm
  underlying the presentation of growth data to assist evaluation of the displayed values.
  Once sources are identified, healthcare providers could recommend ways to display
  the author or citation in a manner that is useful. [9]

### **Considerations and Challenges**

Availability of Normative Datasets and Standardized Formats. Recommendation 1 describes visual display of growth charts for pediatric patients based on biometric-specific norms. Some growth charts (particularly specialized growth charts) may require a license for access and use which can add cost or administrative burden. [11] Healthcare providers could work with their health IT developers to base the functionality on data in the public domain where possible. For example, healthcare providers could request that developers implement functionality based on the growth charts and public data sets recommended by the CDC and WHO.

### Applicable Children's EHR Format Requirements

- Req-2009: Allow Unknown Patient Sex
- Req-2019: Record Gestational Age Assessment and Persist in the EHR
- Req-2042: Support Growth Charts for Children
- Req-2044: Use Biometric-Specific Norms for Growth Curves

Lack of standardized formats for growth charts may add time and effort to the development and implementation process. [4] Health IT developers may also need healthcare providers' assistance to determine which data and calculations are most relevant to a healthcare provider's practice.

Sources of Data. Valid, reliable data is important for visual displays of growth, growth curves, and growth charts. Specialized growth charts, however, may be based on small sample sizes or have other limitations. Healthcare providers are encouraged to work with their developers to verify that the underlying data informing this recommendation's functionality comes from a reliable source and is cited in the system for provider reference. CDC's website serves as a resource for reliable reference data for use in health IT systems, and may be shared with developers implementing this recommendation.

### **Example in Practice: Applications**

Boston Children's Hospital SMART Pediatric Growth Chart, a SMART® on FHIR application, demonstrates a high-performance, concise, minimal click presentation of a child's growth over time.

https://apps.smarthealthit.org/app/growth-chart

Boston Children's Hospital also developed an app for iOS that includes official growth charts from the WHO and CDC.

https://apps.smarthealthit.org/app/pediatric-growth-chart-for-ios

The Prairie Byte Solutions Growth Chart and Immunizations is a SMART® on FHIR application designed for parents and clinicians, provides a visual display of growth based on CDC recommendations.

https://apps.smarthealthit.org/app/growth-chart-and-immunizations

Suggested Questions for Discussion with Your Health IT Developer:		
	Underlying Data	
	Will the health IT account for adjusted gestational age for premature infants and specialized growth charts for children with special healthcare needs?	
	On what data sources will this functionality rely and are they in the public domain?	
	Will the health IT display an author or citation and/or a hyperlink to the source for the algorithm or standard used to present growth data compared to norms?	
	Will a BMI percentile ICD-10 code be automatically generated when the BMI percentile is computed?	
Data Visualization		
	Will the health IT allow healthcare providers to visually display longitudinal growth information with automatic calculation of growth patterns? If so, what will these displays look like, and can they be manipulated at the point-of care?	
	Will the health IT provide visual comparisons of a child's growth compared to established norms? If so, what will these displays look like and can they be manipulated at the point-of care?	

<sup>&</sup>lt;sup>9</sup> CDC, Frequently Asked Questions About the 2000 CDC Growth Charts, https://www.cdc.gov/growthcharts/growthchart\_faq.htm

h CDC, National Center for Health Statistics, Growth Charts at <a href="https://www.cdc.gov/growthcharts/index.htm">https://www.cdc.gov/growthcharts/index.htm</a>

Suggested Questions for Discussion with Your Health IT Developer:	
	How will EHR-based tools promote maintaining the rules that drive immunization clinical decision support?
Alerts / CDS	
	What alerts could be available to inform healthcare providers of significant changes in the weight or height of a child?
	Can healthcare providers customize alerts if they wish?
Patient Access	
	Will patients or their authorized representatives be able to access their growth information? If so, how?

### For Further Reading – Where Can I Get More Information?

- PediTools is a publicly accessible website of clinical calculators (<a href="https://peditools.org">https://peditools.org</a>).
   This article assesses the implementation of electronic calculators for growth charts using the lambda-mu-sigma parameterization method, with examples of their use for patient care delivery, clinical research, and quality improvement projects. [12]
- In A Comparison of Existing Methods to Detect Weight Data Errors in a Pediatric Academic Medical Center, the authors describe a method for developing a machine learning algorithm to detect weight entry errors and abnormal weight values, which may help healthcare providers who wish to implement algorithms to provide alerts signaling abnormal weight and height values. [13]
- A case commentary in A Weighty Mistake recommends, "As pediatric providers continue to adopt EHRs with computerized provider order entry (CPOE), they should consider strongly implementing automated CDS at the critical moment of data entry. [14] The EHR software can calculate expected weight in a variety of ways, most commonly by placing a reasonable range (e.g., plus or minus 10%) around the most recent previously entered patient weight. Software can also be programmed to compare entered weight to age-adjusted norms according to standardized growth charts."
- The article, Specialized Pediatric Growth Charts For Electronic Health Record Systems: the example of Down syndrome, describes how growth charts specific to children with Down syndrome were developed and met requirements for EHR implementation, [11] and which may help healthcare providers seeking to implement subpopulation-specific growth charts into their health IT systems.

Resource	Description
From the CDC:	CDC's website serves as a central resource for healthcare providers and developers to access clinical growth charts, individual growth charts, data tables, educational materials, computer programs, and reports that may be useful for implementing the functionality outlined in this recommendation. <a href="https://www.cdc.gov/growthcharts/index.htm">https://www.cdc.gov/growthcharts/index.htm</a>
	CDC recommends that healthcare providers (1) use the WHO growth standards to assess growth for pediatric patients aged 0 to 2 years of age <a href="https://www.cdc.gov/growthcharts/who_charts.htm">https://www.cdc.gov/growthcharts/who_charts.htm</a> ; and (2) use the CDC growth charts for pediatric patients aged ≥2 years <a href="https://www.cdc.gov/growthcharts/cdc_charts.htm">https://www.cdc.gov/growthcharts/cdc_charts.htm</a> .
	CDC's Growth Chart Training provides information on using the WHO Growth Charts, an overview of the CDC growth charts, information on using BMI-for-age growth charts, and additional growth chart resources. <a href="https://www.cdc.gov/nccdphp/dnpao/growthcharts/index.htm">https://www.cdc.gov/nccdphp/dnpao/growthcharts/index.htm</a>
	CDC maintains growth charts for children with Down syndrome. Healthcare providers could work with developers to implement these growth charts into their EHR or other health IT system to make it easier to monitor growth of children with Down syndrome. https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growthcharts.html
Other Resources:	The Fenton Preterm Growth Chart provides preterm growth chart applications supporting the WHO growth standard to reflect actual age instead of completed weeks. <a href="https://ucalgary.ca/resource/preterm-growth-chart/preterm-growth-chart">https://ucalgary.ca/resource/preterm-growth-chart</a>
	The WHO Anthro R Package Ages 0 to 5 Years provides WHO child growth standards (Z-scores) with confidence intervals and standard errors around the prevalence estimates. <a href="https://cran.r-project.org/web/packages/anthro/index.html">https://cran.r-project.org/web/packages/anthro/index.html</a>
	The Olsen 2010 Growth Calculator for Preterm Infants, which leverages growth curves from Olsen, et al., [12], [15] is a web interface with data entry, used to report percentiles and Z-scores for preterm infants, with an integrated gestational age calculator and decision support. <a href="https://peditools.org/olsen2010/">https://peditools.org/olsen2010/</a>

Access to the specialized growth chart for Down Syndrome or other specialized growth charts may require a license.

# RECOMMENDATION 2: COMPUTE WEIGHT-BASED DRUG DOSAGE

### **Description**

Displaying a calculated medication dose as well as displaying how the calculated dose was determined supports safe medication prescribing for pediatric patients by enabling independent, redundant checking. [9] Accurate and recently recorded height/length and weight is a key input to dose calculation for pediatric patients when the medication dose varies based on this factor. [16]

Pediatric patients are at higher risk of medical errors than adults. Children and infants are particularly vulnerable populations because of: [16]

- A wide range of permissible body weights (less than 1 kg to more than 100 kg) for which medications may be prescribed;
- High frequency of off-label use of medications; and
- An often narrower therapeutic window.

Pediatric patients may also be unable to communicate adverse effects. [17]

These risks can pose a concern across different pediatric care settings. Weight-based dosing has been shown to reduce errors and potential patient harm in continuous infusions and nutrition orders as well as regular medications. [16] For example, in the ordering of chemotherapy medication with narrow therapeutic windows, both weight-based dosing and weight-based dosing alerts may be effective. Medication ordering tools with prepopulated dosing recommendations can support standardization, reduced prescribing errors, and increased safety to pediatric patients. [18]

### **How Health IT Supports This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Electronic Prescribing	New
Data Standard: United States Core Data for Interoperability (USCDI)	New

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Allow entry and display of only metric measurements of patient height (or length) (cm only) and patient weight (kg only [or grams for low-birth-weight infants]), and provide a field to document the date the height and weight were collected;
- Use milliliter-based dosing when prescribing and administering liquid medications;

- Include or connect to a pediatric-specific medication database with pediatric medication information and formulation options;
- Contain weight-based dosing calculators built into the EHR and/or e-prescribing system; and
- Display the weight-based dosing strategy directly on the prescription (when applicable) to further prevent dosing errors by allowing the filling pharmacist to check the prescribed dosage. [19], [16], [17]

#### Health IT can also include functions that:

- Allow weight-based doses to be rounded and expressed in the volume of drug to be administered;
- Assure integrated calculators do not round to more than what is measurable using a syringe;

### Applicable Children's EHR Format Requirements

- Req-2012: Medication Management,
   Compute Weight-Based Drug Dosage
- Req-2035: Medication Management, Rounding for Administrable Doses
- Transmit the patient weight to the pharmacy with e-prescribing so that pharmacies can perform the dose-range checks to provide independent confirmation;
- Allow for the use of weight and height/length to calculate dose using the patient's body surface area for medications when appropriate;
- Allow for dosing alerts based on the dose per weight, total daily dose per weight, dose
  per surface area, total daily dose per surface area, total dose and total daily dose, and
  maximum dose per administration/ per single dose (see Recommendation 6); and
- Provide medication order tools with prepopulated dosing recommendations. [9], [19],
   [20] [16], [21]

### **Considerations and Challenges**

**Lifelong Cumulative Dose Range Checks.** Perform lifelong cumulative dose range checks for pediatric patients undergoing certain long-term therapies, such as chemotherapy. [16]

Use of Computerized Provider Order Entry (CPOE) with the Incorporation of CDS. CPOE along with the addition of CDS tools can reduce errors and improve patient safety. For example, CDS tools can encourage healthcare providers to "second check" their medication selection, [14] or can prompt users to enter up-to-date patient weight information as required for the population and height/length information as appropriate for the medication. [18] Tools may be included to inform healthcare providers of medication dosing concerns, such as exceeding the recommended dose, prescribing below the recommended dose, frequency outside of the recommended, outside range for indication, duration outside recommended length of dose, and order sentences. They can also leverage standardized medication dose range concentrations at the system/EHR level to prevent calculation errors. [16] CPOE and CDS tools may be designed to consider clinical workflow, human factors design principles, and usability standards. More information is found in the Appendix section Clinical Decision Support.

#### **CDS Tools in Practice**

Researchers funded by AHRQ conducted nine group randomized controlled trials at 15 pediatric practices and measured dosing errors related to the use of CDS tools. "The intervention we used had both an active and a passive decision aid. The active decision support aid requests the user to choose a total daily dose (mg/kg) and, based on a weight the computer uses from elsewhere in the child's record, the computer provides the correct calculated dose. The passive component simply displayed the total daily dose the child will receive given the dose that the user selected. In addition, often the appropriate dose sometimes varies by age and weight (in addition to indication). For example, a neonate may require XX mg per kg of an antibiotic to treat pneumonia while a toddler may require YY mg per kg of the same antibiotic for the same condition. In addition, liquid preparations come in predetermined combinations so that exact weight based dosing may result in difficult amounts for a parent to dispense (e.g., 1.35 teaspoons). The weight based dosing CDS...addressed both of these issues." [22]

Ginzburg, R., et al. evaluated integration of a tool for calculating dosage into EHRs. "Dosing errors were defined as overdosage of strength, overdosage of regimen, underdosage of strength, under-dosage of regimen, and incomprehensible dosing directions. An automated weight-based dosing calculator integrated into an EHR system in the outpatient setting significantly reduced medication prescribing errors for antipyretics prescribed to pediatric patients." [23]

**Obese Patients.** Obesity can result in physiologic alterations that may be important to medication absorption and metabolism. Dosing recommendations for children with obesity remain limited, which can lead to variability in prescribing practices for children with obesity and pose risk of under- or over-dosing of medications. [20]

**Patients Not Within Age-Specific Norms.** Alerts to a healthcare provider may be of value when, for example, the patient's weight or height is not within age-specific norms. [16] Alerts could serve as an additional check or pause during ordering or prescribing for pediatric patients to alert healthcare providers that the patient may require special considerations when it comes to medication dosing.

Suggested Questions for Discussion with Your Health IT Developer:	
What medication databases are used in the EHR for medication ordering and e-prescribing? Are they pediatric-specific? How often are they updated?	
How does the health IT round the recommended weight-based medication dosage? What rounding rules apply to the dose?	
Are there alerts or safeguards against using outdated weight information to compute a weight-based medication dose?	
Can the health IT support lifelong cumulative dose range checks?	
How are medications managed for patients with special conditions?	
How can a balance be achieved between alert fatigue and using health IT tools optimally to improve patient safety?	
How are medical dosing errors tracked and how is this feedback incorporated back into the system?	

### For Further Reading – Where Can I Get More Information?

- SafeDose® Enterprise by eBroselow is a web-based application with an acute care
  focus that presents the correct dosing units by form, weight, and indication. Please
  note that this tool, and others by eBroselow to aid clinicians in safe medication
  prescribing, require a subscription. https://www.ebroselow.com/safedose-enterprise/
- In Computerized Dose Range Checking Using Hard and Soft Stop Alerts Reduces Prescribing Errors in a Pediatric Intensive Care Unit, the authors describe an enhanced dose range checking system that incorporates "soft" and "hard" alerts. [24]
- AHRQ funded the tool Safety Through Enhanced e-Prescribing Tools (STEPSTools):
   Developing Web Services for Safe Pediatric Dosing which focused on enhancing e prescribing and various aspects of medication management via web services.
   STEPSTools supported various aspects of medication management. The AHRQ e prescribing grant project included an algorithm for rounding medication doses and a
   compounded medication knowledgebase.

https://www.healthit.gov/techlab/ipg/node/4/submission/2101

ONC does not endorse any particular application or vendor product, but has included examples in this IR for healthcare providers to see what tools and functionalities may be possible to integrate into a health IT system.

# RECOMMENDATION 3: ABILITY TO DOCUMENT ALL GUARDIANS AND CAREGIVERS

### **Description**

Due to the unique caregiver and guardianship scenarios for pediatric patients, maintaining an accurate and structured record of a patient's care team has been identified as a critical component of an EHR supporting pediatric patients. [16]

A care team includes all of the people, teams, and organizations who participate in the coordination and delivery of care for a patient. [25] The care team may include caregivers and guardians such as biological parents, foster parents, adoptive parents, surrogates, custodians, siblings, or case workers. Documentation of a patient's guardians and caregivers and their contact information is especially important for managing the care of pediatric patients who are in changing guardianship scenarios. [16], [26]

The composition of a care team is dynamic and could change over time. [27] Accurately capturing guardian and caregiver members of a child's care team can be critical to understanding the family and social context influencing a child's health and wellbeing, as well as to promoting care coordination. [26]

Use of a structured format to capture information ensures that guardian and caregiver information is not comingled with patient data. [26] Additionally, structured documentation of guardians and caregivers may allow healthcare providers to designate or better understand who may have access to some or all of a child's electronic health information or have authority to make some or all medical decisions. Recommendation 7 contains further discussion on health information access for care team members and their permissions related to the patient's medical care.

Technical standards exist for adoption in an EHR support for structured care team member definition. Each care team member would be identified with a participant role, such as healthcare provider, patient, relative, friend, guardian, or organization. [16] This allows for the care team documentation to reflect that the care team can be dynamic over time and can clarify which team members have authority for decision-making. The structured nature of care team members established by this recommendation supports the privacy and security features discussed in <a href="Recommendation 4">Recommendation 4</a> and <a href="Recommendation 7">Recommendation 7</a>.

### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Security Tags - Summary of Care - Send	Revised
Security Tags - Summary of Care - Receive	Revised
Care Plan	Revised
Transitions of Care	Revised
Demographics	
Data Standard: United States Core Data for Interoperability (USCDI)	New

Standardized API for Patient and Population Services is replacing the existing certification criterion Application Access – Data Category Request as part of the 2015 Edition Cures Update.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Document multiple care team members;
- Document contact information for each care team member, including the option to document multiple phone numbers and email addresses for each member;
- Include individuals who provide care or support to the patient and who may be part of a dynamic or extended network of family and friend caregivers; and
- Indicate the role of each care team member and the member's relationship to the child.
   [9]

### Health IT can also include functions that:

- Allow a system to document all/unlimited care team members for a patient;
- Document a caregiver's role in a structured way;
- Document start and end date for a care team member;
- Keep a record of historical roles denoting very clearly the difference between active and historical roles;

## Applicable Children's EHR Format Requirements

- Req-2006: Ability to Access Family
   History, Including All Guardians and
   Caregivers
- Req-2016: Record Parental Notification of Newborn Screening Diagnosis
- Req-2032: Authorized Non-Clinician Viewers of EHR Data
- Document decision-making authority of care team members as a structured list with an option for supporting notes; and

 Document notifications provided to caregivers or guardians and permission/consent given by caregivers or guardians. [9]

### **Considerations and Challenges**

Standard documentation of decision-making authority. Standardized terminology and structured data are not widely available to support documenting the decision-making authority of each caregiver or guardian. This may lead to inconsistent use in terms and challenges when this information is exchanged electronically. [27], [26] healthcare providers will need to select standard terms and definitions to use for each role to provide consistency and help the clinical care team understand the roles and status of caregivers associated with each patient. This may also mean providing limited access to child welfare agencies for children in custody of foster care: "For children in foster care or other custodial arrangements, inpatient health information systems must be able to capture routinely during the admission process (when possible) information on who is permitted to make medical decisions and can consent to care, who is permitted or not permitted to see the child's health information, and who may or may not visit." [16], [27]

**Standard documentation of start and end dates for each caregiver.** Some EHRs may not provide a standard or structured way to document start and end dates for the caregiver or guardian, so a healthcare provider may not know if a caregiver or guardian is actively part of the patient's care team. This could result in care coordination challenges. Therefore, healthcare providers may need to determine and share a preferred format for documenting caregiver start/end dates so they can be applied to the implementation. [16]

**Financial responsibility data.** A parent or guardian may not be financially responsible for the child depending on the care team structure and other factors. [28] A system that allows identification for the guardians financially responsible for the child among care team members may be useful.

Suggested Questions for Discussion with Your Health IT Developer:		
	What information can I document about a caregiver?	
	What roles can I assign to the different care team members for a single EHR record?	
	How are non-clinician viewers of the EHR designated in the record?	
	Is there any limit on the number of names that can be added to the guardians and caregivers list?	
	Am I able to view the decision-making authority of care team members?	
	How can I archive caregivers who are no longer involved with the child?	
	Can historical care team members be reactivated?	

## For Further Reading – Where Can I Get More Information?

In Data Standards for Interoperability of Care Team Information to Support Care
 Coordination of Complex Pediatric Patients, authors assessed the adequacy of
 available health information exchange data standards to support the information needs
 related to care coordination of complex pediatric patients. [29]

# RECOMMENDATION 4: SEGMENTED ACCESS TO INFORMATION

#### **Description**

This recommendation addresses the need for privacy of certain services by tagging electronic health information and providing or limiting electronic access to specific segments of the record to specific users. [9] While identifying and controlling sensitive information, such as sexual health, mental health, and social history, is challenging for patients of all ages, it is a particular challenge for adolescent populations as they mature and develop increasing capacity for their own health communication. [27] Ensuring privacy of health data allows for open communication with their healthcare providers about these sensitive topics. [16]

Adolescent privacy is further confounded by variations in state and local laws related to access to medical care without consent of a guardian. State and local laws also vary in what information can be kept private. [4] For example, adolescents may be allowed by law to sequester access to information, such as sexual and behavioral health history, in their health record. Some jurisdictions require sequestering a child's record of sexual history or abuse.

Data segmentation includes capabilities for tagging healthcare data and allows for certain documents, messages, or individual data elements (entries) to be marked as sensitive or private without restricting access to information in the whole EHR. Security tagging enables computer systems to recognize the existence of sensitive elements in data and properly protect the privacy and security of the data by ensuring that only the appropriate individuals and entities can access it. [3] Tagging of documents is not a fully automated segmentation of the record but rather a first, technological step or tool to support healthcare providers to replace burdensome manual processes for tagging sensitive information. Segmented access to information is critical to protecting the privacy of all patients. When information cannot be appropriately protected, disparities in care may result, and there is a risk that adolescents may not seek services if they cannot trust that their health information will be kept private. [30] Data segmentation capabilities do not compromise the availability or comprehensiveness of health information available for treatment or research purposes; rather, they enable appropriate access controls in accordance with existing policies, governance, and applicable laws. [3]

The implementation of this recommendation supports healthcare providers with the ability to tag healthcare data in order to keep information, particularly about specific minor consented services, private and distinct from other content of the record so that it is not exposed to parents or guardians without the minor's authorization. [9]

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Security Tags – Summary of Care – Send	Revised
Security Tags – Summary of Care – Receive	Revised
Transitions of Care	Revised
Data Standard: United States Core Data for Interoperability (USCDI)	New

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Support for the secure exchange of health information and security tags applied to documents, messages, or individual data elements;
- Document any limits on the use of information and handling instructions;
- Allow a user to tag items that they determine should be protected; and
- Prevent data identified as sensitive from appearing in a discharge summary, portal, or exit note given to another healthcare provider without consent. [3], [9]

#### Health IT can also include functions that:

 Record a patient's choices to permit or deny identified recipients or recipient roles to perform one or more actions within a given policy context. A patient's desire to have control over what information is accessed in their EHR suggests the need for user interfaces that allow patients to

## Applicable Children's EHR Format Requirements

- Req-2039: Problem-Specific Age of Consent
- Req-2041: Segmented Access to Information

make decisions on what information can be shared with a specific recipient group; [31]

- Record a care team member's choice to permit or deny identified recipients or recipient
  roles to perform one or more actions within a given policy context in cases where
  applicable (i.e., minor patient);<sup>k</sup>
- Record when a patient's EHR was accessed by or shared with a member of the care team;
- Improve the transmission and sharing of data, and level of granularity involved with tagging data elements for inclusion or exclusion;
- Provide the ability to access and apply legal guidelines on consent requirements for reference, where available, to meet privacy and consent standards consistent with state laws; and
- Limit information sent out relevant to dependents on family-based insurance communications (e.g., billing information). [9], [31]

k See additional discussion in the 21st Century Cures Act Final Rule. https://www.federalregister.gov/d/2020-07419/p-760 "Though the updated criteria would support a more granular approach to tagging the sensitive information, we recognize that this will not solve the whole problem of how to manage data segmentation for privacy and consent management...However, we emphasize that health care providers already have processes and workflows to address their existing compliance obligations for State and Federal privacy laws, which could be made more efficient and cost effective through the use of health IT, rather than relying on case-by-case manual redaction and subsequent workarounds to transmit redacted documents. We believe this tool may be one part of innovative solutions to support health IT enabled privacy segmentation in care coordination workflows to significantly reduce the burden of these manual processes currently in practice."

#### **Examples in Practice**

Following up on the standards and guidelines developed from the DS4P Initiative (<a href="https://archive.healthit.gov/providers-professionals/ds4p-initiative">https://archive.healthit.gov/providers-professionals/ds4p-initiative</a>), SAMHSA sponsored the development of Consent2Share (C2S), an open source tool for consent management and data segmentation. (<a href="https://bhits.github.io/consent2share/downloads/3.4.0/C2S">https://bhits.github.io/consent2share/downloads/3.4.0/C2S</a> Provider User Guide 3.4.0.pdf). The C2S tool will enable patients to have more meaningful choice when sharing their health information and supports the exchange of sensitive behavioral health information in compliance with diverse federal and state privacy regulations.

The C2S architecture is comprised of two major components:

- Patient Consent Management (PCM) a front-end, patient-facing user interface which allows
  patients to define their privacy policy and provide informed consent.
- Access Control Services (ACS) a backend control system designed to integrate with EHRs and HIEs and provide privacy policy configuration, management, decision-making and policy enforcement.

Data segmentation relies on models that specify what categories of health information are sensitive. "The technical challenge is to come to a consensus on a standard method that will support the automatic management and implementation of data segmentation policies driven by patients or required by law." [18] A pilot evaluation studied the accuracy of C2S data categorizations compared to those of healthcare providers. The study concluded the capability to determine the sensitivity of medical record items strongly depends on the content of the value sets and the decision rules implemented. [32] For more information on C2S, see the section in Appendix 1 on <a href="Privacy">Privacy</a>, as well as ONC's discussion of consent of behavioral health consent management. <a href="https://www.healthit.gov/topic/health-it-health-care-settings/behavioral-health-consent-management">https://www.healthit.gov/topic/health-it-health-care-settings/behavioral-health-consent-management</a>

The Institute for Family Health developed an adolescent patient portal in compliance with New York state's laws and regulations. The Institute considered the appropriate minimum age for portal access and limitations for a third-party caregiver to interact with the portal. In cases where a minor may have complex medical problems, caregivers are allowed full proxy access. Other important considerations for this pilot portal are discussed in *Electronic Access to Adolescents' Health Records: Legal, Policy, and Practice Implications*, <a href="https://www.aafp.org/fpm/2015/0300/p11.pdf">https://www.aafp.org/fpm/2015/0300/p11.pdf</a>.

#### **Considerations and Challenges**

**Improve Data Categorization.** Healthcare providers can also work with health IT developers to help validate data sets which are used to automate data segmentation. Structured data from the EHR can be coded using clinical terminologies. If the data is found to be classified as sensitive in the data set used for coding, the structured data can automatically be marked. Automated tagging software needs further validation from healthcare providers to ensure the correct data is segmented and classified. [32]

**State Differences in the Evaluation and Treatment of Minors.** Applicable state and local laws can affect if and when minors can consent to treatments or testing. [20], [4]. States may permit certain categories of minors, such as emancipated or pregnant minors, to consent to their own healthcare. Other states may allow all minors to consent to certain types of care, such as reproductive care or mental healthcare. Some

states specifically establish legal principles, such as the concept of mature minor, which allows minors that demonstrate cognitive maturity to give informed consent.

Healthcare providers can work with their developers to identify and implement health IT solutions that can manage variations in state-specific privacy and consent laws. [33] For example, healthcare providers can identify treatments and tests subject to regulation and work with the health IT developer to test automated data segmentation rules. Additional confidentiality considerations for healthcare providers caring for minors are available in the ACOG Committee on Adolescent Health Care's 2020 publication *Confidentiality in Adolescent Health Care*. [30]

Consent for Reproductive Health Services. For an overview on state consent laws for reproductive health services, the Guttmacher Institute provides recent information on state laws and policies. These resources and others may assist healthcare providers in identifying what health information should be kept private based on their practice locations. [34]

**Billing and insurance.** Sequestering patient-selected information from parental, billing, or insurance communications may aid in protecting a pediatric patient's privacy.

- Several states have developed solutions to address these issues. For example,
   California requires insurers to provide confidential communications if requested by the dependent. [35]
- Some states have considered policy-level solutions to protect patients' privacy while meeting the disclosure requirements for health insurance communications. [36]

Suggested Questions for Discussion with Your Health IT Developer:
What information can I document about a caregiver?
What roles can I assign to the different care team members for a single EHR record?
How are non-clinician viewers of the EHR designated in the record?
Is there any limit on the number of names that can be added to the guardians and caregivers list?
Am I able to view the decision-making authority of care team members?
How can I archive caregivers who are no longer involved with the child?
Can historical care team members be reactivated?

Paid resources, such as the Center for Adolescent Health & the Law's <u>State Minor Consent Laws</u> are available. <a href="http://www.cahl.org/state-minor-consent-laws-a-summary-third-edition/">http://www.cahl.org/state-minor-consent-laws-a-summary-third-edition/</a>.

#### For Further Reading – Where Can I Get More Information?

- The Patient Choice Technical Project is a 2018 pilot project that seeks to develop technical standards for implementing and sharing individual consent for health information sharing.
  - https://oncprojectracking.healthit.gov/wiki/display/PATCH/The+Patient+Choice+Technical+Project+Homepage
- The 2011 DS4P Initiative produced six pilots that demonstrated how standards can be used to support current privacy policies for sharing sensitive health information across organizational boundaries.<sup>m</sup> <a href="https://archive.healthit.gov/providers-professionals/ds4p-initiative">https://archive.healthit.gov/providers-professionals/ds4p-initiative</a>
- The draft HL7 FHIR implementation guide Consent2Share FHIR Profile Design describes how Consent2Share (C2S) application and associated access control solution uses FHIR resources to represent and persist patient consent for treatment, research, or disclosure.
  - https://gforge.hl7.org/gf/download/frsrelease/1259/16175/Consent2Share FHIR Profile Design.docx
- The Consumer Partnership for eHealth published an issue brief that lays out key
  factors to consider in protecting sensitive health information in an electronic context. It
  includes a discussion of the definition of sensitive health information and provides a set
  of principles, based on widely accepted Fair Information Practices, and some
  examples of how they can be applied through policy and technical solutions. [37]
- Several case studies discuss ethical challenges related to visit notes:
  - The Catch to Confidentiality: The Use of Electronic Health Records in Adolescent Health Care (2018) [38]
  - Ethical Challenges Raised by OpenNotes for Pediatric and Adolescent Patients (2018) [39]

For additional data segmentation for privacy resources, see the Health Information Technology Advisory Committee (HITAC) task force transmittal, page 59. <a href="https://www.healthit.gov/sites/default/files/page/2019-07/2019-06-03">https://www.healthit.gov/sites/default/files/page/2019-07/2019-06-03</a> All%20FINAL%20HITAC%20NPRM%20Recs 508-signed.pdf

Resource	Description
From ONC:	Patient Consent Decisions:  https://www.healthit.gov/topic/health-information-technology
	Patient Consent and Interoperability: https://www.healthit.gov/topic/interoperability/patient-consent-electronic-health-information-exchange-and-interoperability
	State consent laws: <a href="https://www.healthit.gov/topic/interoperability/state-consent-laws">https://www.healthit.gov/topic/interoperability/state-consent-laws</a>
	Health Information Privacy Law and Policy: <a href="https://www.healthit.gov/topic/health-information-privacy-law-and-policy">https://www.healthit.gov/topic/health-information-privacy-law-and-policy</a>
	Health IT Privacy and Security Resources for Healthcare Providers: https://www.healthit.gov/topic/privacy-security-and-hipaa/health-it-privacy-and-security-resources-providers
From the AAP:	The Adolescent Sexual Health: Confidential Health Care Services website from the AAP provides other resources including clinical guidance for healthcare providers and helpful resources for adolescents and families. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/adolescent-sexual-health/Pages/Confidential-Health-Care-Services.aspx
	Electronic Communication of the Health Record and Information with Pediatric Patients and Their Guardians (2019): This AAP policy statement discusses the need for segmenting functionality capabilities in EHRs for adolescent privacy and confidentiality and limitations in EHR systems. [27]
	Standards for Health Information Technology to Ensure Adolescent Privacy (2012): This AAP policy statement contains recommended standards for health IT developers, including the ability to filter data. [40]

# RECOMMENDATION 5: SYNCHRONIZE IMMUNIZATION HISTORIES WITH REGISTRIES

#### **Description**

Access to accurate and up-to-date pediatric immunization information is critical for comprehensive, age-based, preventive care. [4] This recommendation supports up-to-date bidirectional pediatric immunization information exchange by synchronizing the EHR with Immunization Information Systems (IISs) and encouraging health IT systems to update and reconcile a child's immunization record with information received from an IIS. [9]

EHR synchronization with IISs is necessary to confirm current immunization status both during and between visits to avoid unnecessary and missed immunizations. Interoperability with IISs allows EHRs to take advantage of the immunization forecasting features provided by many of the state registries. This feature removes the burden from developers of health IT modules to maintain immunization forecasting rules. [41], [42] Healthcare providers benefit because this feature allows them to leverage the IIS to identify immunizations that may have been given elsewhere, which allows providers to reduce duplicate immunization, take advantage of immunization forecasting, and schedule appropriate follow-up visits around immunization. [9], [41]

Messaging standards established through Meaningful Use requirements remain in place to confirm bidirectional communication and reconciliation functions with IISs or other Health Information Exchanges (HIEs), which further supports the implementation of this recommendation into EHR systems certified under the ONC certification program. [9], [43]

The goal of this functionality is to have the right information related to immunization history in front of the right healthcare provider at the right time. Display of the patient's complete immunization history in an easy-to view manner at the point of care can help drive informed decision making. Synchronizing immunization histories with state registries allows healthcare providers to better leverage immunization clinical decision support such as evaluation and forecasting.

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
View, Download, and Transmit to Third Party	Revised
Transmission to Immunization Registries	
Data Standard: United States Core Data for Interoperability (USCDI)	New

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Send data to IIS:
- Receive immunization data from IIS:
- Request, access, and display immunization history and immunization forecasting; and
- Allow patients and patients' authorized representatives to electronically view, download, and transmit their health information to a third party. [9]

#### Health IT can also include functions that:

Produce reports of a child's immunization history for use for camp, school, or childcare documentation purposes, however state laws and regulations may vary on acceptance of these documents; state IIS may also have their own means for patient access to reports or information. The following elements can be included in such reports: child's name, date of birth

## Applicable Children's EHR Format Requirements

- Req-2011: Synchronize Immunization
   Histories with Registry
- Req-2027: Produce Completed Forms from EHR Data
- Req-2028: Use Established Immunization Messaging Standards

and sex, date the report was produced, antigen administered, date administered, route of administration (when available), and an indication of whether a vaccine was refused or contraindicated. [4], [9]

#### **Examples in Practice**

ONC, in partnership with CDC, began pilots to gain additional information regarding implementation of IISs and consumer access to immunization records, and cross jurisdictional data exchange between public health agencies. A Report to Congress reflects work completed on the pilots between 2013 and 2017. [44]

In a 2019 presentation on the Immunization Information System Landscape, Myerburg and Larson note that "in Rhode Island, as data became more complete, the school nurses now use the IIS almost exclusively to monitor compliance with school immunization requirements – reducing the frequency of contacts with provider offices for the information." <a href="https://www.izsummitpartners.org/content/uploads/2019/05/0pre-a-1-iis-landscape-larson-myerburg.pdf">https://www.izsummitpartners.org/content/uploads/2019/05/0pre-a-1-iis-landscape-larson-myerburg.pdf</a>

The Synchronized Immunization Notifications Project (2019) in New York aims to assess the impact of EHR reminders integrated with immunization data and forecasting from a regional IIS on receipt of recommended vaccines. This project is also assessing the impact of integrated EHR reminders that incorporate patient medical conditions on receipt of immunizations in children with chronic medical conditions. https://healthit.ahrq.gov/ahrq-funded-projects/sinc-synchronized-immunization-notifications

#### **Considerations and Challenges**

**Comparison Across Registries/Systems.** Given systems will include information from the child's EHR, and an IIS or other HIE, healthcare providers may request developers build functionalities that allow them to compare immunization information from each system for a given patient. Because some EHRs consume

messages from registries and do not display them, or only display them to an administrator, clinical staff are recommended to ensure they have access to the registry data at point of care for complete patient information.

Clinical Decision Support. Healthcare providers could request their health IT developers to implement clinical decision support for immunizations to alert which immunizations a patient needs both at the point of care and in advance of a patient's visit. [16] Additionally, healthcare providers could work with their developers to implement alerts in the EHR that signal potential over- or under-vaccination.

#### **State-by-State Variations**

- Immunization registries. This recommendation supports bidirectional interoperability between EHRs and jurisdictions. Immunization registries and requirements may vary by state; there is not a single standard used by all jurisdictions for immunization data, and state registries may not be able to communicate with each other. [4] The lack of standardized immunization registries can result in missed immunization opportunities or over-vaccinating due to the lack of consolidated information and reduced efficiency of information systems. [4] Healthcare providers are advised to work with their health IT developers to understand the unique features of their state's immunization registry and to implement standards and best practices that support the sharing of immunization data across state registries. For example, healthcare providers could request that developers implement EHR-IIS queries at the point of care and develop features that allow for the comparison of information in the EHR and IIS records. [9] Healthcare providers who practice along state borders and interact with more than one registry may have additional implementation considerations to discuss with their health IT developer.
  - The IZ Gateway project, led by the HHS Office of the CTO, in partnership with the CDC, provides a centralized technical infrastructure that facilitates the flow of immunization data through an intelligent message router between IISs, large multi-jurisdictional provider organizations to IIS, and from IIS to consumers. <a href="https://www.hhs.gov/cto/initiatives/public-health-innovation/provider-iis-interoperability-project/index.html">https://www.hhs.gov/cto/initiatives/public-health-innovation/provider-iis-interoperability-project/index.html</a>
- Required immunizations for school entry. States generally require a minimum set of immunizations for school entry; however, the type of vaccines and number of doses can vary. In addition, not all states require an official certificate of immunization status for school, camp, or childcare entry. [9] Healthcare providers are encouraged to work with their health IT developers to develop queries or other health IT functionalities that allow healthcare providers to easily determine state-specific school vaccination requirements, receive alerts when immunizations are needed, and develop reports outlining a child's immunization history. [9]

Suggested Questions for Discussion with Your Health IT Developer:
Registries
Can the health IT transmit data to state and territory registries so other healthcare providers can see the immunization data from my patient's visit?
Can the health IT query state and territory registries for a patient's complete immunization history?
Can immunization data in a patient's EHR be compared with registry information?
Decision Support
Will alerts be available to inform healthcare providers of immunization needs for patients?
What alerts could be available to inform healthcare providers of potential over-vaccination?
How will EHR-based tools promote maintaining the rules that drive immunization clinical decision support?
Functionality
Will healthcare providers be able to produce reports? If so, what data elements will be included in these reports?
How will the health IT incorporate state-specific immunization requirements for schools, camps or childcare facilities?
Patient Access
Will patients and/or their guardians be able to access their immunization data? If so, how?
Will patients and/or their guardians receive alerts on required immunizations?
Will patients and/or their guardians be able to electronically share their immunization data with third parties?

#### For Further Reading - Where Can I Get More Information?

- The Give Teens Vaccines Study is an AHRQ funded project from 2012 that evaluated the impact of clinician-focused and patient/family-focused health information interventions on HPV vaccination rates among adolescents. https://digital.ahrq.gov/ahrq-funded-projects/give-teens-vaccines-study
- FluAlert: Influenza Vaccine Alerts for Providers in the Electronic Health Record is an AHRQ funded project from 2013 that evaluated the impact of tailored healthcare provider influenza alerts on pediatric influenza vaccine delivery and coverage rates. <a href="https://digital.ahrq.gov/ahrq-funded-projects/flualert-influenza-vaccine-alerts-providers-electronic-health-record">https://digital.ahrq.gov/ahrq-funded-projects/flualert-influenza-vaccine-alerts-providers-electronic-health-record</a>

Resource	Description
From the CDC:	The CDC authored Immunization Information System Functional Standards, V4.0 (2017) describes the operations, data quality and technology needed by IIS to support immunization programs, healthcare providers and other stakeholders. Healthcare providers may consider leveraging this resource for additional information when working with health IT developers to implement this recommendation. https://www.cdc.gov/vaccines/programs/iis/functional-standards/func-stds-v4-0.pdf
	The CDC provides a comprehensive set of resources ( <a href="https://www.cdc.gov/vaccines/schedules/index.html">https://www.cdc.gov/vaccines/schedules/index.html</a> ) on immunizations for healthcare providers, including an updated child and adolescent immunization schedule as well as links to information on vaccine administration, storage and handling, safety, and other guidance. <a href="https://www.cdc.gov/vaccines/schedules/hcp/resources.html">https://www.cdc.gov/vaccines/schedules/hcp/resources.html</a>
	CDC's national immunization quality improvement program promotes and supports implementation of healthcare provider-level strategies designed to help increase on-time vaccination of children and adolescents. Strategies include: Schedule the next immunization visit before the patient leaves the office; leverage IIS functionality to improve immunization practice; give a strong vaccine recommendation (include HPV vaccine if healthcare provider has adolescent patients); and customize the strategy based on state or local public health priorities. <a href="https://www.cdc.gov/vaccines/programs/iqip/at-a-glance.html">https://www.cdc.gov/vaccines/programs/iqip/at-a-glance.html</a>
From the Federal Advisory Committee on Immunization Practices:	The Federal Advisory Committee on Immunization Practices (https://www.cdc.gov/vaccines/hcp/acip-recs/index.html) offers resources to assist healthcare providers with implementing and leveraging Clinical Decision Support for Immunizations (CDSi) in their practices. More information can be found in the CDSi Mini Guide (https://www.cdc.gov/vaccines/programs/iis/downloads/CDSiminiGuide.pdf) or on the CDC Immunization Information Systems website (https://www.cdc.gov/vaccines/programs/iis/cdsi.html).
From the AAP:	AAP's policy statement, <i>Immunization Information Systems</i> , expresses support for the development and implementation of IISs for the benefit of children, pediatricians, and their communities. [45]
From Other Resources:	The Immunization Integration Program is a program implemented by the Healthcare Information and Management Systems Society to assure that clinicians and IISs have timely access to complete and accurate data to improve clinical decision-making and management, increase vaccination coverage, and reduce vaccine-preventable diseases. https://www.himss.org/initiatives/immunization-integration-program

### RECOMMENDATION 6: AGE- AND WEIGHT-SPECIFIC SINGLE-DOSE RANGE CHECKING

#### **Description**

Pediatric patients are at an increased risk of medication errors, especially overdosing. Meight-based dosing has been shown to reduce medication errors for pediatric patients, but medication errors may still occur when a single medication dose falls outside of accepted maximum and minimum reference ranges for pediatric dosing. [18] EHRs supporting the care of children can support medication single-dose range checking by leveraging existing pediatric drug database references or tools, providing alerts where appropriate, and displaying normal pediatric ranges for reference and weight-based dose calculations.

This functionality provides medication dosing decision support that detects a drug dose that falls outside the minimum-maximum range based on the patient's age, weight, and maximum recommended adult dose (if known) or maximum recommended pediatric dose (if known), for a single dose of the medication. [9] It is crucial to have accurate patient measurements documented in the EHR. [14] The implementation of this recommendation allows the system to alert if the maximum recommended adult or pediatric (based on weight or body surface area dose for a single dose or for a total daily dose of the medication) is exceeded.

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Clinical Decision Support	
Data Standard: United States Core Data for Interoperability (USCDI)	New

Standardized API for Patient and Population Services is replacing the existing certification criterion Application Access – Data Category Request as part of the 2015 Edition Cures Update.

<sup>&</sup>lt;sup>n</sup> For a discussion of factors that contribute to a higher risk of medical errors among pediatric patients, please refer to Recommendation 2.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Record and transform/display a patient's age in meaningful units;
- Allow the entry and display of only metric measurements of patient height (in cm only) and patient weight (in kg only [or grams for low-birth-weight infants]), and provide a field to document the date the height and weight were collected;
- Include pediatric-specific medication databases with pediatric drug information and formulation options;
- Include weight-based dosing calculators built into the EHR and/or e-prescribing system; and
- Allow the opportunity to implement weight-based dosing alerts for single doses falling outside of dosing ranges. [9], [4], [46], [47], [19]

#### Health IT can also include functions that:

- Display the age- and weight-based dosing strategy directly on the prescription;
- Display the data source for reference ranges (when applicable);

## Applicable Children's EHR Format Requirements

- Req-2037: Age- and Weight-Specific
   Single Dose Range Checking
- Transmit the patient age and weight to the pharmacy with e-prescribing so that pharmacies can perform the dose-range checks to provide independent confirmation;
- Offer medication order tools with prepopulated dosing recommendations;
- Assure integrated calculators do not round to more than what is measurable using a syringe; and
- Use milliliter-based dosing when prescribing and administering liquid medications. [17],
   [19], [9], [16], [21]

#### **Considerations and Challenges**

**Obesity.** Obesity can result in physiologic alterations that may be important to drug disposition. Dosing recommendations for hospitalized children with obesity remain limited, which can lead to variability in prescribing practices for children with obesity and pose risk of under- or over-dosing of medications. [20]

**Minimum dose range alert.** Minimum dose range alerts have been shown to have limited value to clinicians. [48] This may be an important point of discussion with a health IT developer as to what is useful in a healthcare provider's practice.

**Other CPOE and CDS Tools.** With care to avoid factors contributing to errors, CPOE and CDS tools can further support patient safety, [18] including:

- Incorporate CDS tools that encourage users to "second check" their drug selection;
   [14]
- Prompts to enter or confirm up-to-date patient clinical parameters (height, weight, etc.);
   [18]
- Standardization of medication dose range concentrations at the system/EHR level to prevent calculation errors; and [16]
- Design of CPOE and CDS tools to factor in workflow, human factors design principles, and usability standards (see also the section in the Appendix, <u>Clinical Decision</u> <u>Support</u>).

Suggested Questions for Discussion with Your Health IT Developer:
What drug database is being used? Does it support pediatric dosing?
Are single-dose alerts available for minimum or maximum single doses? Maximum daily doses? Is this customizable?
Do single-dose alerts suggest a dose range?
How can a balance be achieved between alert fatigue and using health IT tools optimally to improve patient safety?
How are medical dosing errors and overriding of dose range checking tracked, and how is this feedback incorporated back into the system?
How are healthcare provider workflows and user-centered design factored into system design?

#### For Further Reading – Where Can I Get More Information?

- The SCRIPT Implementation Recommendations guide (2020) provides requirements
  and best-practice guidance for implementation when transmitting National Council for
  Prescription Drug Programs (NCPDP) SCRIPT transactions, including specific
  guidance for prescribing in pediatric populations. [21] The NCPDP indicates that the
  use of industry drug database products is recommended in conjunction with its
  requirements and guidance.
- SMART Health IT Medication Management Applications is a catalog of SMART on FHIR applications that focuses on medication management. <a href="http://apps.smarthealthit.org/apps/category/medication">http://apps.smarthealthit.org/apps/category/medication</a>

- epocrates is a commercial medical reference app of that provides information, dosing calculators, and clinical guidelines to support medication dosing.
   https://www.epocrates.com/
- AAP's Pediatric Drug Lookup system provides a continually updated list of all essential pediatric and neonatal drugs and drug maximums.
   <a href="https://pediatriccare.solutions.aap.org/drug-lookup.aspx">https://pediatriccare.solutions.aap.org/drug-lookup.aspx</a>

ONC does not endorse any particular application or vendor product but has included examples in this IR for healthcare providers to see what tools and functionalities may be possible to integrate into a health IT system.

# RECOMMENDATION 7: TRANSFERRABLE ACCESS AUTHORITY

#### **Description**

The care team members allowed to access a pediatric patient's health record may change over time due to changing family dynamics (e.g., foster care, adoption, and divorce). In addition to capturing relationships and roles associated with the patient (see <a href="Recommendation3">Recommendation 3</a>), including a mechanism in the EHR to manage access authority and changing circumstances supports pediatric care.

The status of a minor patient may also change over time. A minor patient may become emancipated either by attaining a certain age or entering a designated condition (such as pregnancy, experiencing abuse, or entering active military status). State law or court order determines when emancipation occurs. The parents or guardians of an emancipated child may cease to have access to a child's health record or the authority to consent to treatment on behalf of the child. State and local laws play a critical role in determining the status of a minor and, accordingly, the authority of the minor's guardians.

Appropriate access control ensures that the appropriate and current caregivers and guardians are given the right permissions to a minor's health record. [49]

This functionality provides a mechanism to enable access control, which ultimately allows access authority to be provided to appropriate care team members and is critical to ensuring both the safety and privacy of the patient. The implementation of this recommendation allows users to have the ability to change access to the health record based on changing healthcare providers, guardians, or circumstances. The functionality may also extend to different types of authority beyond the ability to view, download, and transmit information, such as medical decision-making authority.

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria	New or Revised
Standardized API for Patient and Population Services	New
Security Tags – Summary of Care – Send	Revised
Security Tags – Summary of Care – Receive	Revised
View, Download, and Transmit to Third Party	Revised

Standardized API for Patient and Population Services is replacing the existing certification criterion Application Access – Data Category Request as part of the 2015 Edition Cures Update.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Identify members of the care team (see <u>Recommendation 3</u>);
- Allow a system to document all care team members for a given patient (see <u>Recommendation 3</u>);
- Allow the modification of authority to access a child's health record for parents, guardians, and/or caregivers; and
- Allow parents, guardians, and/or caregivers to view, download, and transmit a child's health information. [9]

#### Health IT can also include functions that:

- Record the status of a minor (i.e., emancipated) as well as related information, such as the age of emancipation;
- Transition a pediatric patient to emancipated minor status either automatically or manually within the EHR and enable features for the patient to define access rights;
- Allow for time-constraints on health information that is shareable or access that expires
  when a minor turns the age state or federal law requires information be transitioned to
  the minor; [9], [50]
- Distinguish authority to access, exchange, or use patient data from medical decision making authority;
- Apply applicable local, state, and federal privacy and confidentiality rules when establishing access authority;
- Build in information from state laws to assist healthcare providers in applying access rules to different guardians and caregivers; and
- Apply specific access control techniques the healthcare provider prefers to utilize. [9],
   [50], [40]

#### **Considerations and Challenges**

**State and local laws.** As with Recommendation 4, state and local laws play a large role in this recommendation. Regulations around privacy and consent determine which caregivers or guardians have access to information and/or medical decision-making authority for a child. For additional information about consent laws, refer to Recommendation 4.

**Lack of standard nomenclature.** There is a limited nomenclature for the different rights for caregivers. Rights may span from access to information, ability to add information, and ability to make medical decisions. They may also vary from state to state depending on how different roles are named and defined.

## Applicable Children's EHR Format Requirements

- Req-2026: Transferrable Access Authority
- Req-2040: Age of Emancipation

Healthcare providers may need to discuss the different tiers or types of potential access with developers to understand what capabilities can be implemented and in what way.

Suggested Questions for Discussion with Your Health IT Developer:
How are different permissions for my patients' caregivers or guardians documented?
Can roles be edited or deleted if circumstances change or errors are found?
What information in the patient's record is available to be identified/selected for access control?
Can the EHR distinguish between permission to access the patient record and medical decision-making authority?
Is there a way to document any disagreements between caregivers or guardians and their desired decision-making priority?
How can this functionality be used to enable the transition of care from pediatrics to other specialties?

#### For Further Reading – Where Can I Get More Information?

Issues related to access control can be important for children in foster care or protective custody.

- Improving Information Sharing for Youth in Foster Care states that designated caregivers may require select health information on chronic diseases, immunizations, or medication, for example, to ensure appropriate care for youth in foster care. [51]
- Sharing Personal Health Record Data Elements in Protective Custody: Youth and Stakeholder Perspectives states that it is crucial to allow adolescents to control what data elements are shared with a trusted adult and to allow the adolescent to revoke that access. [52]
- Recommendation 4 discusses Consent2Share, a software application that allows a healthcare provider to manage roles and permissions associated with those roles.
- The American Academy of Pediatrics' Committee on Bioethics released a policy statement (2016) that discusses the ethical and legal roots of informed consent, which provide the framework for decision-making by a proxy. Decision-making by a minor patient is dependent on several factors, including cognitive ability, maturity of judgment, and moral authority. [53]
- Research Issues for Privacy and Security of Electronic Health Services explores
  access control techniques, noting, "Access control is a way of preventing or limiting
  access to a resource according to properties and requirements of the system." [49]
   There are three categories of access control techniques:

- Role-Based Access Control this technique restricts access to unauthorized users according to pre-assigned roles. For example, a healthcare provider may be able to enter in a patient's information but another healthcare provider in the health system may not have the same editing capabilities for that record because of role.
- Attribute-Based Access Control this technique allows users to access a
  system only if they have attributes (i.e., illness, age, gender) that are desired
  by the system. This technique could be used to limit access for cancer
  researchers if cancer is used as an attribute.
- 3. Identity-Based Access Control this technique relies on a user's identify information, such as name or email, to encrypt information. A key from a third-party is then needed to decrypt the information or message.

# RECOMMENDATION 8: ASSOCIATE MATERNAL HEALTH INFORMATION AND DEMOGRAPHICS WITH NEWBORN

#### **Description**

Point-of-care access to some maternal health and demographic information is critical for the care of a newborn patient. [16] Critical health information may include but is not limited to maternal infections, immunizations, blood type, maternal substance use that can affect babies (tobacco, alcohol, opiates), behavioral health disorders, and heritable genetic conditions. [9], [16] Associating relevant maternal information with a newborn supports optimal care at inpatient hospitals and upon transfer to an outpatient pediatric setting or another hospital. [9] Information important to newborn care can be found in more than one place in the maternal record, including in the maternal history, lab test results, care plan, and care transition documents, and such information is not always accessible to or connected to the newborn record. [46], [54]

This recommendation supports clinicians by allowing access, at the point of decision making, to maternal information needed for the care of the infant while ensuring healthcare providers do not need to hand copy information over from one chart to the infant's chart, decreasing risk of error and making the process more efficient. [16], [54]

While there are no current standards for either identifying the content or specifying the transfer of this information, healthcare providers may work with their health IT developers to implement this recommendation by importing key maternal information to the newborn record [16], [4], [46] or linking the maternal and newborn record. [4], [16], [55] Some standards may not require provenance information (the information's author, or the date and time the information was created) or allow for easy incorporation of information from a different patient. With the ongoing advancement of different types of standards (both content and transfer), there is growing capability to identify provenance and better incorporate and identify maternal information critical to the newborn's care.

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Care Plan	Revised
Transitions of Care	Revised
Demographics	
Family Health History	
Social, Psychological, and Behavioral Data	
Data Standard: United States Core Data for Interoperability (USCDI)	New

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Directly incorporate and record maternal information (which may be found in multiple places in the maternal record) into the pediatric record as discrete information:
- Link and de-link the maternal and pediatric record; and
- Include the provenance (author, institution) of maternal health information incorporated in the pediatric records. [4], [16], [56]

## Applicable Children's EHR Format Requirements

- Req-2011: Synchronize Immunization Histories with Registry
- Req-2027: Produce Completed Forms from EHR Data
- Req-2028: Use Established Immunization Messaging Standards

Health IT can also include functions that:

- Flag errors found or suspected in maternal information; and
- Incorporate updates or corrections made to maternal information. [16], [4], [56]

#### **Considerations and Challenges**

**Exchange Across Different Systems**. There may be different ways that information from a maternal record can be shared with or incorporated into the pediatric record when mother and newborn are treated at different hospitals or when an inpatient pediatric record is transferred to an ambulatory pediatric record. Developers and healthcare providers may need to brainstorm where information can be generated and how to associate maternal information from disparate EHR systems with the newborn record.

Identification of Maternal Data Elements and Standards. There are maternal data elements that may be useful to incorporate into the newborn record. [9] The elements that are critical to travel with the newborn record are not always clearly identified, and developers may not know which data should be prioritized. Healthcare providers may wish to work with their developers to determine which data elements are critical (versus nice to have) for association with the newborn record so that developers can implement the recommendation as effectively as possible.

Other Important Family Health Information. Health information that impacts a newborn may expand beyond the maternal record and be found in the paternal record or in the records of other family members associated with the newborn. There is more work that needs to be done in the information technology space to develop standards that support the documentation of family history. Healthcare providers can work with developers to suggest linkages that are important for care as well as how to define relationships between different family members. Standards for confidentiality of PHI will always need to be incorporated into planning for transfer of information from one person's chart to another.

Maternal Privacy. This recommendation does not specifically contemplate the privacy of maternal information captured in the pediatric record or, if maternal and newborn records are linked, privacy

considerations for the maternal record linked to the newborn record. It is likely that practices and hospitals already have in place policies and procedures that describe when and what information may be transferred from one person's confidential medical record to another person's confidential medical record, as well as how long that information should be retained in the recipient's record. Based on those policies and procedures, maternal consent (or refusal to consent) may be obtained and documented for specified information elements. Healthcare providers may wish to discuss with their developers how to execute acknowledgement of consent in the pediatric record as well as how to expunge information if maternal information is kept in the pediatric record on a time-limited basis.

Suggested Questions for Discussion with Your Health IT Developer:		
Associating Information		
How will the EHR associate information when the mother and newborn are treated at different hospitals?		
How will the EHR associate information when the mother and newborn are treated in the same hospital?		
How can maternal information be associated when the newborn is cared for in the ambulatory setting?		
How will sources/provenance of information be identified?		
How will maternal information be displayed in the newborn record?		
Can the healthcare provider select the maternal information that is associated with the newborn record?		
Family Members		
What options are there to incorporate information from the maternal record that relates to other family members (such as family history)?		
Can information be flagged as being from a surrogate mother versus a genetic mother?		
Privacy		
Can the maternal information incorporated into the pediatric record be tagged as sensitive data for maternal privacy when the child reaches a certain age or a specific milestone?		
Can a mother request that maternal information incorporated into the pediatric record be tagged as sensitive data and shielded from the child's view?		
Can a copy of maternal consent to share information be included in the pediatric record?		

#### For Further Reading – Where Can I Get More Information?

- In The Impact of Implementation of a Clinically Integrated Problem-Based Neonatal Electronic Health Record on Documentation Metrics, Provider Satisfaction, and Hospital Reimbursement: A Quality Improvement Project, the authors evaluate the creation of an integrated clinical platform that captures data entry from the obstetrical suite, delivery room, neonatal intensive care unit nursing and respiratory therapy staff.
   [57]
- The Cincinnati Maternal and Infant Data Hub (<a href="https://cincyinformatix.org/maternal-infant-data-hub">https://cincyinformatix.org/maternal-infant-data-hub</a>) is a regional perinatal data repository that securely integrates maternal, neonatal, and pediatric patient records. The Hub links records in a secure manner from different institutions, leveraging identifier fields or geospatial measures linked at either the individual or area level respectively. Although the Hub is used for research, it provides an example of how to link records (across different institutions. [58]
- A study reported in the Journal of Healthcare Engineering in 2017, A Granular
  Ontology Model for Maternal and Child Health Information System, developed and
  evaluated the usefulness of a granular data model for maternal child health that
  leverages existing standards, including FHIR, as well as clinical terminologies. The
  goal of the model was to improve recordkeeping and interoperability in the maternalchild health domain and to ensure the capture of information. [59]
- Integrating the Healthcare Enterprise (<a href="https://www.ihe.net/resources/">https://www.ihe.net/resources/</a>) maintains different technical resources, including specifications that define profiles for integrating perinatal care (2010), labor and delivery care (2013), and newborn admission notifications (2016) into EHR workflows.
- The Joint Commission implemented three Elements of Performance requirements to improve the identification of mothers upon admission to labor and delivery who are at risk for transmitting certain infectious diseases to their newborns. One requirement includes the documentation of maternal infection status in the newborn's medical record. [60]
- The Children's EHR Format Req-2001, Link Maternal and Birth Data to Child Health Record, suggests a number of commonly required data elements from the maternal record for inclusion in the pediatric record. [9]

P IHE Patient Care Coordination Technical Framework Supplement, Perinatal Workflow, https://ihe.net/Technical\_Framework/upload/IHE\_PCC\_Suppl\_PW\_Rev1-1\_TI\_2010-08-30.pdf, Labor and Delivery Profiles,

https://www.ihe.net/uploadedFiles/Documents/PCC/IHE\_PCC\_Suppl\_Labor\_and\_Delivery\_Profiles.pdf, and Newborn Admission Notification Information,

https://www.ihe.net/uploadedFiles/Documents/QRPH/IHE QRPH Suppl NANI.pdf.

# RECOMMENDATION 9: TRACK INCOMPLETE PREVENTATIVE CARE OPPORTUNITIES

#### **Description**

Clinical guidelines for the care and treatment of pediatric patients are well established and regularly updated to incorporate new evidence-based practice and research. [4], [16] Pediatric clinical guidelines such as Bright Futures Guidelines and the Bright Futures Periodicity Schedule provide age-specific preventive care recommendations for the frequency and content of well-child visits, including screenings, assessments, immunizations, and anticipatory guidance. Identifying preventive care that is overdue or expected soon is key to maintaining a pediatric patient's health. [9]

This recommendation addresses the need to alert healthcare providers when a child presenting at a visit has not received or is due for preventive care services. [9], [16] Prompts visible at the point of care support a healthcare provider's review of the preventive care schedule with the guardian. [9] This recommendation leverages an EHR's ability to detect clinical criteria and the absence of events such as well-child visits or age-appropriate screenings.

Aligning with this recommendation can include using quality reporting infrastructure to provide a list of patients who have missed preventive services to support patient outreach, prospective reporting to provide a list of patients who should be scheduled for preventive services, and implementation of integrated workflow notifications. [9]

This recommendation can improve the care of pediatric patients by allowing healthcare providers to generate lists or reports of patients who have missed visits or interventions pursuant to preventive care guidelines established by specialty societies. [9] It can also provide a quick overview of what elements of preventive care a patient who is in an office visit may be missing. Having the ability to easily and rapidly be up to date on which patients need follow up or a scheduled visit can facilitate needed check-ups and interventions. In addition, alerts or flags that indicate if a patient has missed a wellness visit or other intervention can enable closing care gaps while the patient is in the office for other reasons.

See <a href="https://brightfutures.aap.org/Pages/default.aspx">https://brightfutures.aap.org/Pages/default.aspx</a> and <a href="https://downloads.aap.org/AAP/PDF/periodicity\_schedule.pdf">https://downloads.aap.org/AAP/PDF/periodicity\_schedule.pdf</a>.

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, support this recommendation:

ONC Certification Criteria	New or Revised
Standardized API for Patient and Population Services	New
Clinical Quality Measures	Revised
Clinical Decision Support	

Standardized API for Patient and Population Services is replacing the existing certification criterion Application Access – Data Category Request as part of the 2015 Edition Cures Update.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

- Incorporate a schedule of wellness visits and childhood immunizations into the EHR;
- Flag or generate a list of patients who have missed preventive care; and
- Offer alerts during office visits for patients who have missed preventive care. [9]

Health IT can also include functions that:

 Align with quality measurement program requirements, including those established by payers including commercial, Medicaid, and CHIP. [61]

## Applicable Children's EHR Format Requirements

- Req-2024: Track Incomplete Preventive
   Care Opportunities
- Req-2047: Identify Incomplete Preventive
   Care Opportunities

#### **Considerations and Challenges**

**Selection of Guidelines**. Although the AAP Bright Futures Guidelines are a well-known and frequently used set of clinical guidelines, not all state Medicaid programs, practices, or health systems align with the Bright Futures recommendations. [62] Healthcare providers may want to have a clear conversation with their developers about the sets of guidelines their practice uses and by which criteria the guidelines differ.

Adequacy of Guidelines as Patients Age. Some sets of pediatric clinical guidelines may be less specific and actionable as the patient ages. More work may need to be done between the healthcare provider and the developer to determine the functionalities included in the EHR as pediatric patients grow older and recommendations grow less specific or actionable. [4]

#### **Screening Tools in Practice**

Birth to 5: Watch me Thrive! is a coordinated federal effort to encourage developmental and behavioral screening and support for children, families, and the healthcare providers who care for them. https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive

In A Compendium of Screening Measures for Young Children (2014), federal partners identified 11 screening tools that met the following quality criteria: (a) tool accuracy (sensitivity and specificity of 0.7 and above), (b) inclusion of family input, and (c) inclusion of the social and emotional domain of development. https://www.acf.hhs.gov/sites/default/files/ecd/screening\_compendium\_march2014.pdf

Screening Made Easy is a set of tools by Patient Tools to administer screenings. Screens can be configured into age-based, outcome-based, or visit-based screening protocols. https://www.patienttools.com/

AAP provides a set of resources, *Screening Time*, to help healthcare providers screen for maternal depression, developmental concerns, and social determinants of health. <a href="https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/Screening-Process-Resources.aspx">https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/Screening-Process-Resources.aspx</a>

The Oregon Pediatric Improvement Partnership released a tip sheet (2019) on improving EHR templates related to developmental screening. The sheet includes key factors to consider when building the EHR template. It also includes key areas where it is valuable to create EHR fields that yield searchable data to access through reports for tracking developmental screening results and follow-up assessments. https://www.oregon.gov/oha/HPA/dsi-tc/Documents/DevScreening-EHR-supports.pdf

Absence of Computable Guidelines. Currently, not all clinical guidelines are easily implemented into electronic health records. More work is needed to translate the clinical guidelines and periodicity schedules into computable standards that can be incorporated into health IT systems. Tools are beginning to be developed to make this translation simpler and more efficient but healthcare providers may initially encounter few computable guidelines. Healthcare providers may therefore have to work with their developers to identify and prioritize guidelines that can be implemented to support their practice.

	Suggested Questions for Discussion with Your Health IT Developer:	
Patient Missed Visits		
	Can a report be run on demand that creates a list of all patients who have missed a well child visit? Can the list be sorted by age, type of visit (e.g., 2 month, 12 month), or other factors?	
	Are there alerts if a patient misses a scheduled visit or is due for a specific intervention?	
	Can alerts be turned off or limited for patients who have missed more than one visit? Are there other ways to mitigate healthcare provider alert fatigue?	
Clinical Guidelines		
	If clinical guidelines from more than one organization or program are needed, how are they differentiated in the EHR?	
	Can different guidelines be matched to different subpopulations (e.g., children with special healthcare needs)?	

Suggested Questions for Discussion with Your Health IT Developer:	
	How and when will newly implemented guidelines be incorporated into the EHR?
	How can guidelines that need to be implemented into an EHR be prioritized and communicated? How can updates to those guidelines be executed?
	Can the FHIR-based APIs available to me reference external sources?
Social Determinants of Health	
	Can relevant social determinants of health be captured in an EHR?

#### For Further Reading – Where Can I Get More Information?

- The Computer Automated Developmental Surveillance and Screening project assessed whether a CDS system integrated with routine care could improve standardized developmental screening during 9-, 18-, and 30-month well-child visits and surveillance for developmental disabilities at all pediatric visits. [63]
- Effect of a Computer-Based Decision Support Intervention on Autism Spectrum Disorder Screening in Pediatric Primary Care Clinics discusses a study that determined the impacts of computer-automated screening and CDS on autism spectrum disorder screening rates. [64]
- Using CHIPRA Quality Demonstration Grants
   (<a href="https://www.ahrq.gov/policymakers/chipra/demoeval/promote-it/index.html">https://www.ahrq.gov/policymakers/chipra/demoeval/promote-it/index.html</a>), twelve states are promoting the use of health IT to improve children's health care. Healthcare providers can access information and evaluation reports from the demonstration projects. For example, in 2013, Maine published an evaluation of the First STEPS (Strengthening Together Early Prevention Services) Learning Initiative implementation to support its pediatric and family practices in improving preventive and screening processes. <a href="http://muskie.usm.maine.edu/Publications/PHHP/FirstSTEPS-PhaseII-Developmental-Austism-Lead-Screening.pdf">http://muskie.usm.maine.edu/Publications/PHHP/FirstSTEPS-PhaseII-Developmental-Austism-Lead-Screening.pdf</a>

# RECOMMENDATION 10: FLAG SPECIAL HEALTHCARE NEEDS

#### **Description**

Many healthcare providers care for children and youth with special healthcare needs. These patients are defined by HRSA as children and youth who are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, or that require health or health-related services of a type and amount beyond that required generally. [65] Practices may subjectively identify such patient populations; for example, a specialty practice may define special needs differently than a primary care practice.

Tools built into EHRs that allow for the flexible, customizable identification of patients with special needs, including medical complexity, can support the effective implementation of this recommendation. These tools can support accurate and timely reporting and allow an individual's or population's designation to be communicated in a clear and intuitive manner. [22]

Healthcare providers can easily flag individuals whose care may benefit from specific decision support, care management, or other focused attention, and can also have the flexibility to unflag patients as needed. Flags may be added to patients during a clinician workflow or automatically applied as a result of a CDS rule. Tools built into the EHR for flagging and identification purposes may also support the reporting of quality measures.

Using flags to identify individuals can support improved pediatric care in various ways, especially if the flags are flexible enough to serve different or multiple purposes. For example, a flag can be used for ongoing decision support and can be used to generate lists, identify who should be contacted for an office visit, and create health reminders. Flags can also be used to identify children who are at high-risk, potentially based on screening results or certain social determinants of health. [22]

As patients with medically complexity are among the highest risk because of the potential for adverse medical, developmental, psychosocial, and family outcomes, EHR support for this recommendation can promote proactive care as well as early identification of and intervention with such patients. [66]

#### **How Health IT Implements This Recommendation**

The following ONC certification criteria, including those new in the 2015 Edition Cures Update, and data standard support this recommendation:

ONC Certification Criteria and Data Standard	New or Revised
Standardized API for Patient and Population Services	New
Clinical Quality Measures	Revised
Clinical Decision Support	
Data Standard: United States Core Data for Interoperability (USCDI)	New

An existing certification criterion which also supports this recommendation, *Problem List,* is being removed as part of the 2015 Edition Cures Update.

Together with the technical resources identified in the Developer IR, these certification criteria enable the following functions in support of this recommendation:

## Applicable Children's EHR Format Requirements

 Req-2014: Flag Special Health Care Needs

- Flag patients with special healthcare needs or complex conditions;
- Unflag patients who no longer need to be specifically identified;
- Identify and display a population of patients by diagnosis and/or other criteria;
- Identify patients with special needs who have missed an intervention or interaction;
   and
- Suggest evidence-based care plans for patients with specific diagnoses. [9]

Health IT can also include functions that:

- Allow information to be shared with third parties (e.g., healthcare providers at different systems, care team members, schools);
- Develop/generate reports of associated diagnoses or based on treatment or other criteria; and
- Aggregate and view data across a cohort of patients (dashboard functionality). [4], [66]

#### **Considerations and Challenges**

**Incorporation of Screening Tools.** Some organizations and government agencies have created screening tools and other practice supports specific to the care of children with special healthcare needs and which may be used to inform an EHR implementation. For example, the Child & Adolescent Health Management Initiative offers the Children with Special Health Care Needs Screener based on the Maternal and Child Health Bureau's definition of special health needs. Healthcare providers may also leverage the Bright Futures clinical guidelines and identify those guidelines focused on health supervision and health promotion for children and youth with special healthcare needs.

Enabling the Use of Computable Guidelines with CDS Connect. Healthcare providers may work with their developers to identify relevant clinical guidelines that have been adapted by professional societies for implementation in EHRs. For those that have not been adapted and that should be, tools such as the CDS Connect authoring tool (see the section in the Appendix, Clinical Decision Support) may provide a way for healthcare providers and their developers to adapt guidelines into a technical format. Some of these tools have been created to make it easy for healthcare providers to adapt guidelines on their own. There is,

See https://www.cahmi.org/projects/children-with-special-health-care-needs-screener/.

s See https://brightfutures.aap.org/clinical-practice/Pages/default.aspx.

however, a risk to interoperability between different implementations of these kinds of adapted guidelines when they are not socialized or peer reviewed.

Lack of Clinical Coding for "Special Healthcare Needs". Healthcare providers may wish to consider that one challenge for incorporation or implementation is that there is no specific definition, or ICD-10 or SNOMED code, indicating a child has special healthcare needs. An area for future development in this space could be the creation of a relatively generic code that indicates children with special healthcare needs, and then the creation of subcodes for physical needs, social care needs, and mental health needs. Alternatively, value sets could be created that could be amended as needed.

Lack of Guidelines for Specific Needs. Other challenges are children who have conditions for which there are no evidence-based guidelines, or situations such as when a child's special healthcare need are impacted by family social risk factors or resources. Healthcare providers may wish to determine how they will define populations of patients that they wish to assess and track for special needs. Healthcare providers may also wish to discuss with their developers whether and how to establish a flagging system, and how the EHR system could be defined to provide maximum flexibility to identify and monitor patients. Ideally, healthcare providers could have the ability to create categories of specific needs through the functionality of the EHR without relying on additional work by the developer.

Suggested Questions for Discussion with Your Health IT Developer:	
	Can the health IT implement existing screening tools, such as the Children with Special Health Care Needs Screener <sup>t</sup> , in the EHR?
	How can a patient with a special healthcare need be designated so that a healthcare provider looking at the record knows right away that the patient has special needs?
	Can the health IT implement a screening tool in such a way that it triggers an alert if certain criteria are either missing, not met, or met?
	Can the health IT capture social determinants of health relevant for the patient?
	Can patients be unflagged?
	Can alerts or flags be designed by healthcare providers to signal specific needs or interventions?
	Can a flag be shared between EHR systems to ensure that a recipient system "understands" the patient has special healthcare needs?

#### For Further Reading – Where Can I Get More Information?

 AAP issued a Policy Statement in 2011, Health Information Technology and the Medical Home, which discuss in part recommended EHR functionalities for children with special health care needs. [67]

t See https://www.cahmi.org/projects/children-with-special-health-care-needs-screener/.

- HRSA's Maternal & Child Health Programs and Initiatives provides additional resources for identifying and managing care for children with special needs. HRSA provides an extensive list of resources and programs that provide tools or serve as models for clinical practices serving medically complex patients. https://mchb.hrsa.gov/maternal-child-health-initiatives/mchb-programs.
- The Improving Pediatric Safety and Quality with Healthcare Information Technology
  project evaluated CDS tools such as visit-based reminders, including reminders for
  checking symptoms for patients with persistent asthma, reminders for checking
  symptoms for patients with ADD/ADHD, and reminders for influenza vaccinations
  among patients with asthma. [22]
- Authors in Implementing an EHR-based Screening and Referral System to Address Social Determinants of Health in Primary Care evaluated the feasibility of implementing a systematic clinical strategy to screen new primary care patients for social determinants of health. [68]

# Appendix 1: Background Information and Resources

#### **FHIR**

#### What is HL7 FHIR?

HL7® Fast Healthcare Interoperability Resources® (FHIR®, pronounced "fire") is an application programming interface (API)-focused standard used to represent and exchange health information. The FHIR standard defines how health care information can be exchanged between different computer systems regardless of how the information is stored in those systems. FHIR allows health care information, including clinical and administrative data, to be available securely to those who have a need and a right to access it. While FHIR is not the only existing health IT standard, the healthcare community, and in particular, the ONC Health IT Certification Program, is moving toward FHIR-based standards.

#### How can FHIR support pediatric health care?

FHIR can support pediatric health care in a number of ways. For example, FHIR can help represent and exchange pediatric vital signs and other health information, such as BMI percentile, care team members, patient demographics, family health history, problems, and medications. FHIR is also an underlying standard that supports the secure exchange and use of information in novel health care applications. These applications (apps) can give healthcare providers and patients secure access to their health information from various health care systems, such as when a patient sees a number of healthcare providers for various health concerns. This information access can support better care coordination and improve the patient care experience. Apps also support visualization tools such as pediatric growth charts and can provide clinical decision support such as tools to assist with appropriate medication dosing.

#### For more information on FHIR:

#### **FHIR Resources**

ONC "What is FHIR" Fact Sheet

https://www.healthit.gov/topic/standards-technology/standards/fhir-fact-sheets

HL7 FHIR Overview (an overview of FHIR written for clinicians)

https://www.hl7.org/fhir/overview-clinical.html

4 Basics to Know about the Role of FHIR in Interoperability: What is the Fast Healthcare Interoperability Resource (FHIR), how does it work, and what does it mean for the future of health data interoperability? <a href="https://healthitanalytics.com/news/4-basics-to-know-about-the-role-of-fhir-in-interoperability">https://healthitanalytics.com/news/4-basics-to-know-about-the-role-of-fhir-in-interoperability</a>

Heat Wave: The U.S. is Poised to Catch FHIR in 2019

https://www.healthit.gov/buzz-blog/interoperability/heat-wave-the-u-s-is-poised-to-catch-fhir-in-2019

Substitutable Medical Apps, Reusable Technology (SMART® <a href="https://smarthealthit.org/">https://smarthealthit.org/</a>) Health IT is an open, standards-based technology platform that enables innovators to create apps that seamlessly and securely run across the health care system. SMART apps are developed using the Fast Healthcare Interoperability Resources (FHIR) standard. If an EHR system or data warehouse supports the SMART standard, healthcare providers can draw on this library of apps. SMART on FHIR apps can be found here: <a href="https://apps.smarthealthit.org/">https://apps.smarthealthit.org/</a>. The SMART app gallery also has a section on FHIR Tools: <a href="https://apps.smarthealthit.org/apps/category/fhir-tools">https://apps.smarthealthit.org/apps/category/fhir-tools</a>.

Suggested Questions for Discussion with Your Health IT Developer:	
	What health care needs are being served with FHIR or other standards? What functionalities are being planned?
	What health care standards is my organization implementing? Does that include FHIR?
	Can I provide feedback to my health IT developer on how certain functions are working or could be improved?
	If my organization is transitioning to FHIR, what are the implications to the care setting, such as downtimes and backwards compatibility?

## **APPLICATIONS (APPS)**

#### What are applications or "apps"?

An application (app) is a software program that performs a specific function directly for a user. Applications include games, email organizer tools, note-taking systems, or EHR software like clinical decision support (CDS) tools. [69]

#### How do apps access health care data?

Apps can access data through APIs. APIs are the mechanism that allows software programs to communicate with one another. A common example of an API is a web-based application or a mobile "app" on a device to purchase a flight or pay a bill. If healthcare providers are interested in installing an app (e.g., for CDS) that was developed by someone other than their health IT developer, the app will need to use an API to access and use data in the EHR. Likewise, the EHR will need to use an API to integrate the app's information. An API can be thought of as a pipeline to exchange data between systems with built-in security checks and other processes.

For more information, ONC's learning module, How APIs in Health Care can Support Access to Health Information (https://www.healthit.gov/topic/patient-access-to-medical-records/learning-module-apis-and-health-data-sharing) provides a basic overview of how APIs work.

#### How do apps improve pediatric care?

Apps and APIs may help healthcare providers improve or simplify care delivery. For example, an app specifically designed for pediatric care can automatically perform detailed data analysis during regular checkups and provide instant feedback to the parents on the child's health.<sup>u</sup>

Suggested Questions for Discussion with Your Health IT Developer:
What APIs are available for what data? Are there APIs for patient demographic data, patient admission/discharge/transfer data, or clinical data such as problems, medications, and allergies?
What apps are being used or developed in my health care organization? What health care needs do these apps provide or serve?
What pediatric health care needs does my organization or care setting have? Are there apps available or that can be built to help meet these needs?
What apps are available through my health IT developer? Do the apps available relate to the 10 recommendations presented in this IR?
What apps are available that I would like my health IT developer to incorporate into my EHR?
What is the data capacity for data calls using APIs?
What are the API privacy and security protocols being used or planned?
How will the use of apps affect clinical workflow?
Am I able to customize the app to meet my unique needs?

The American Academy of Pediatrics has a forthcoming policy statement and technical report on web services/web applications in pediatric care.

#### **Privacy and Security Considerations**

A third-party application may not be a covered entity or a business associate under HIPAA. If a third-party app is not subject to HIPAA, any protected health information received by that app will no longer subject to the protection of the HIPAA Rules.

For more information, see the Health and Human Services' Office of Civil Rights' FAQs (<a href="https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access-right-health-apps-apis/index.html">https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access-right-health-apps-apis/index.html</a>) and ONC's Key Privacy and Security Considerations for Healthcare Application Programming Interfaces (APIs) (<a href="https://www.healthit.gov/sites/default/files/privacy-security-api.pdf">https://www.healthit.gov/sites/default/files/privacy-security-api.pdf</a>).

### **CLINICAL DECISION SUPPORT (CDS)**

#### **What is Clinical Decision Support?**

Clinical decision support (CDS) describes a variety of tools that take available information and translate it into context-specific guidance. [70] CDS provides clinicians, staff, patients and other individuals with person-specific information that is intelligently filtered and/or presented at appropriate times.

#### Why Is CDS Important for Pediatric Care?

Pediatric patients are at higher risk for medical errors than adults with age-specific physiologic and developmental variances that may not be addressed by adult oriented workflows and rules in EHRs and health IT systems.

CDS can help address these risks. By computerizing alerts or displaying contextually relevant reference information, for example, it can:

- Increase quality of care and health outcomes
- Help avoid errors and adverse events
- Improve efficiency, cost-benefit, and healthcare provider and patient satisfaction. [16]

While considering the specific clinical workflow and needs of a practice, healthcare providers can work with their health IT developers to determine whether a particular CDS tool will work in a care setting. Healthcare providers may also consider whether certain clinical practice guidelines and recommendations could form the basis for the CDS tools in a practice.

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For example, Bright Futures, Guidelines for the Health Supervision of Infants, Children, and Adolescents (<a href="https://www.aap.org/en-us/Documents/periodicity\_schedule.pdf">https://www.aap.org/en-us/Documents/periodicity\_schedule.pdf</a>).

Suggested Questions for Discussion with Your Health IT Developer:		
	What are the clinical recommendations for pediatric care underlying a CDS tool?	
	Where in the clinical workflow can CDS tools have impact?	
	Are there priority health issues in my care setting where CDS tools can assist?	
	What are the tradeoffs to the current workflow of introducing a CDS tool? Will there be disruption to clinical workflows?	
	Are there existing examples of successful CDS tools used in pediatric care settings to adopt?	
	How will healthcare providers be trained on CDS tools and proper clinical protocol?	
	How can a healthcare provider evaluate the effectiveness of CDS tools on quality of care, health outcomes, and healthcare provider and patient satisfaction?	

#### **CDS** Resources

Below is a list of resources related to the use of CDS tools that may be applicable to any of the recommendations in this document and additional areas in which CDS could be implemented.

Resource	Description
CDS Hooks	An HL7 published specification for clinical decision support. CDS Hooks aims to help healthcare providers determine which applications are helpful at a certain point in their workflow. An event triggered by the healthcare provider's EHR invokes a third-part CDS system that can then provide information to the EHR. <a href="https://cds-hooks.hl7.org/">https://cds-hooks.hl7.org/</a>
Optimizing Strategies for Clinical Decision Support	Summary of a Meeting Series: ONC collaborated with the National Academy of Medicine (NAM) to engage key experts and develop a series of strategies and recommendations to optimize CDS in support of improved care. The project's goals were to identify actionable opportunities to accelerate progress in CDS creation, distribution, and use; inspire action on priority opportunities amongst diverse stakeholder groups; and drive progress toward usable, interoperable CDS. <a href="https://www.healthit.gov/sites/default/files/page/2018-04/Optimizing_Strategies_508.pdf">https://www.healthit.gov/sites/default/files/page/2018-04/Optimizing_Strategies_508.pdf</a>
ONC Safety Assurance Factors for EHR Resilience (SAFER) Guides	Recommendations to achieve safe and effective EHR implementation and use via proactive risk assessments to mitigate and minimize EHR-related safety hazards. Each SAFER Guide consists of between 10 to 25 recommended practices that can be assessed as "fully implemented," "partially implemented," or "not implemented." Implementing recommended practices helps further safe use of the EHR. <a href="https://www.healthit.gov/topic/safety/safer-guides">https://www.healthit.gov/topic/safety/safer-guides</a> Healthcare providers may want to consider in particular the SAFER Guide on Computerized Provider Order Entry with Decision Support. <a href="https://www.healthit.gov/sites/default/files/safer/guides/safer_cpoe.pdf">https://www.healthit.gov/sites/default/files/safer/guides/safer_cpoe.pdf</a>

Resource	Description
CDS Connect	Clinical and technical translation of guidelines into computable CDS, testing and monitoring, implementation protocols, and feedback loops. The project includes open source CDS artifacts that are available for healthcare providers to use and supports the CDS community to identify evidence-based care, translate and codify information into an interoperable health IT standard, and leverage tooling to promote a collaborative model of CDS development. https://cds.ahrq.gov/cdsconnect

Below is a select list of current or previously funded projects relating to CDS tools. These pilot implementations and evaluations can be informative on challenges, lessons learned, and general implementation:

Resource	Description
Improving Asthma Care in an Integrated Safety Net through a Commercially Available Electronic Medical Record (2011)	This project tested electronic asthma action plan applications to improve the quality and patient-centeredness of asthmatic ambulatory care for children and adults. The project report shares lessons learned in operationalizing evidence-based guidelines and maintaining clinical content for CDS tools. <a href="https://digital.ahrq.gov/ahrq-funded-projects/improving-asthma-care-integrated-safety-net-through-commercially-available">https://digital.ahrq.gov/ahrq-funded-projects/improving-asthma-care-integrated-safety-net-through-commercially-available</a>
Improving Post-Hospital Transitions and Ambulatory Care for Children with Asthma (2015)	This project developed an asthma-specific Reminder and Decision Support system to help hospital providers improve care transitions from the hospital setting to the ambulatory and home settings. <a href="https://digital.ahrq.gov/ahrq-funded-projects/improving-post-hospital-transitions-and-ambulatory-care-children-asthma">https://digital.ahrq.gov/ahrq-funded-projects/improving-post-hospital-transitions-and-ambulatory-care-children-asthma</a>
Improving Otitis Media Care with Electronic Health Record (EHR)-based Clinical Decision Support and Feedback (2011)	This project developed and evaluated a CDS tool for Otitis Media. Significant resources were used to create the tool, including substantial investment in clinical informatics. Project participants identified a need to understand and overcome barriers to physician adoption. <a href="https://digital.ahrq.gov/ahrq-funded-projects/improving-otitis-media-care-electronic-health-record-ehr-based-clinical">https://digital.ahrq.gov/ahrq-funded-projects/improving-otitis-media-care-electronic-health-record-ehr-based-clinical</a>
Development of a Clinical Decision Support Tool for Facilitating Naturalistic Decision-Making and Improving Blood Culture Utilization (2020)	This project developed an EHR-embedded CDS tool using a sociotechnical systems approach and user-centered design. https://digital.ahrq.gov/ahrq-funded-projects/development-clinical-decision-support-tool-facilitating-naturalistic-decision
Using Electronic Health Records to Support Decision-Making in Pediatric Obesity Care (2020)	This project evaluated different tools within EHRs to assist pediatric primary care clinicians with providing higher quality childhood obesity care to help families slow weight gain in children with obesity. <a href="https://digital.ahrq.gov/ahrq-funded-projects/using-electronic-health-records-support-decision-making-pediatric-obesity-care">https://digital.ahrq.gov/ahrq-funded-projects/using-electronic-health-records-support-decision-making-pediatric-obesity-care</a>

Resource	Description
Health Information Technology to Support Clinical Decision Making in Obesity Care (2014)	This project evaluated clinician decision support and tailored patient education to the implementation of the current guidelines at school based health clinics. https://digital.ahrq.gov/ahrq-funded-projects/health-information-technology-support-clinical-decision-making-obesity-care
Improving Anxiety Detection in Pediatrics Using Health Information Technology (2018)	This project piloted an anxiety module within an existing CDS system to automate concurrent administration of validated screening instruments for anxiety and attention deficit hyperactivity disorder among pediatric patients. <a href="https://digital.ahrq.gov/ahrq-funded-projects/improving-anxiety-detection-pediatrics-using-health-information-technology">https://digital.ahrq.gov/ahrq-funded-projects/improving-anxiety-detection-pediatrics-using-health-information-technology</a>
Clinical Decision Support Optimizing Necrotizing Enterocolitis Prevention Implementation in Neonatal Intensive Care Unit (2020)	This ongoing project aims to improve the application of evidence-based practices for prevention and early recognition of necrotizing enterocolitis (NEC) among premature infants by integrating CDS into neonatal intensive care unit workflows. The CDS will deliver evidence-based guidelines for early recognition and prevention of necrotizing enterocolitis in an intervention called "NEC-Zero." <a href="https://digital.ahrq.gov/ahrq-funded-projects/clinical-decision-support-optimizing-necrotizing-enterocolitis-prevention">https://digital.ahrq.gov/ahrq-funded-projects/clinical-decision-support-optimizing-necrotizing-enterocolitis-prevention</a>
GuideLines Into DEcision Support (GLIDES) (2020)	This project will develop, implement, and evaluate demonstrations that advance understanding of how best to incorporate CDS into the delivery of healthcare. <a href="https://medicine.yale.edu/cmi/glides/">https://medicine.yale.edu/cmi/glides/</a>

#### **PRIVACY**

#### Why is privacy an issue in the pediatric care setting?

There are special considerations concerning privacy in pediatric health care settings. While laws on the rights of minors to consent to health care services vary by state, health information privacy may be of particular concern for adolescent patients.

Maintaining confidentiality is critical to addressing sensitive and potentially stigmatizing health issues facing adolescents such as mental health disorders, violence, substance abuse, and sexual activity. [30], [71] When minors reach the age of emancipation or are emancipated earlier for a specific reason, there are issues concerning transfer of authority to access patient data and medical decision-making authority.

For various reasons, therefore, parents or guardians may be allowed to access parts or all of the minor patient's data to protect the patient's care and well-being.

#### What health IT tools and approaches help address pediatric privacy concerns?

#### Security Tagging and Data Segmentation

Security tagging enables computer systems to recognize the existence of sensitive elements in data, ensuring that only the appropriate individuals and entities can access it. [3] Segmentation is a way of identifying data for which access and sharing should be controlled differently than other less-sensitive data. Some EHRs may be able to segment portions of the electronic health care record to limit the access, use,

and exchange of health care information to certain authorized users. [72] One health care standard that supports tagging is the HL7 Data Segmentation for Privacy (DS4P), which describes the technical means to apply security tags to a health record and data may be tagged at the document-level, the section-level, or individual data element-level. [73] In the 2015 Edition Cures Update, two previously adopted certification criteria, "data segmentation for privacy-send" and "data segmentation for privacy-receive" have been replaced with two new certification criteria that will support security tagging at the document section and entry levels of C-CDA 2.1 formatted documents.

Tagging of documents is not a fully automated segmentation of the record but rather a first, technological step or tool to support healthcare providers in replacing burdensome manual processes for tagging sensitive information. Specific policies and constraints can then determine data segmentation for tagged sensitive information.

#### Consent

While in pilot stages, the health care industry is working on emerging standards to support electronic consent management:

- The HL7 Fast Healthcare Interoperability Resources standard includes a Resource to document a patient's consent. [74]
- ONC's website provides information on capturing and maintaining consent decisions (select Patient Consent for Electronic Health Information Exchange resources): https://www.healthit.gov/topic/health-information-technology
- The Electronic Consent Management Landscape Assessment, Challenges, and Technology report includes suggestions for overcoming barriers associated with implementing electronic consent management, which may be considered for further research and discussion. [75]
- Consent2Share is an open source software application sponsored by the U.S.
   Substance Abuse and Mental Health Administration (SAMHSA) that allows patients to
   determine, through an online consent process, which health information they would like
   to share and not share with their primary and specialty healthcare providers.
   https://bhits.github.io/consent2share/

#### Billing and Health Care Claims Processing Considerations

Health information can also include billing information, such as health insurance explanations of benefits, and may also be a concern when protecting pediatric patient confidentiality. For example, an explanation of benefits for a minor adolescent patient who is a dependent on a family health insurance plan may include specific or inferential information about tests for sexually transmitted diseases. Healthcare providers and health insurance payers can establish policies and procedures so that health care billing and insurance claims processes do not impede the ability of healthcare providers to deliver health care on a confidential basis to minors covered as dependents on a family's health insurance plan. [76]

#### **General Privacy Resources**

The following, is general resources are related to the use of privacy and confidentiality tools and policy statements from medical societies:

- AAP's Standards for Health Information Technology to Ensure Adolescent Privacy
  policy statement reviews the challenges to privacy for adolescents posed by
  commercial health information technology systems and recommends basic principles
  for ideal electronic health record systems. [40]
- AAP's Policy Statement: Electronic Communication of the Health Record and Information with Pediatric Patients and Their Guardians includes recommendations to address the challenges and pitfalls of using EHR and non-EHR electronic communication with patients and guardians regarding the child's or adolescent's health record. [27]
- AAP offers other resources that can assist healthcare providers in understanding the importance of confidentiality, how to overcome the insurance and billing issues, and how to deliver care to adolescents and young adults. [77]
- ONC's Health Information Privacy Law and Policy page includes privacy law resources: https://www.healthit.gov/topic/health-information-privacy-law-and-policy
- A Health Information Technology Advisory Committee (HITAC) task force provided recommendations on the 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program proposed rule. As part of this transmittal, a discussion of data segmentation for privacy and a list of general resources are provided starting on page 59. [78]
- Authors in one study discuss the benefits of permitting patients to segment certain
  fields of sensitive information from the main body of the EHR in their recent article
  Privacy Risks of Interoperable Electronic Health Records: Segmentation of Sensitive
  Information Will Help, published in the Journal of Law, Medicine & Ethics. [79]

Suggested Questions for Discussion with Your Health IT Developer:		
What are the federal and state laws in place concerning minor consent, authority for medical decision making, and data exchange in my care setting?		
Do multiple state or jurisdiction laws apply to my care setting concerning consent and information sharing (such as areas where patients may cross borders frequently)?		
What is the current standard of practice for getting patient consent?		
Does my organization offer patients electronic means of accessing patient health information? How is consent for access of health information obtained?		
Are electronic data segmentation and consent management tools being used or planned in my care setting?		
What approaches can be taken to minimize privacy risks as the use of health IT tools to share health information increases?		

Suggested Questions for Discussion with Your Health IT Developer:	
	If apps are being used, what are the privacy and confidentiality risks of using apps in providing healthcare?
	How is consent management handled with the health IT tools used in my practice? Can patients change their consent over time and how quickly is that effectuated in health IT tools?
	Are there billing and healthcare claims processing concerns to be addressed with the use of health IT tools?

## **Privacy Resources Discussed Further with Specific Recommendations:**

The following recommendations feature specific resources relevant to the functionalities discussed here:

- Recommendation 4: Segmented access to information
- Recommendation 7: Transferrable access authority

# **Acronym Definitions**

Acronym Definitions	
Term	Definition
AAP	American Academy of Pediatrics
AHRQ	Agency for Healthcare Research and Quality
API	Application Programming Interface
ВМІ	Body Mass Index
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
CDSi	Clinical Decision Support for Immunizations
CMS	Center for Medicare & Medicaid Services
CPOE	Computerized Provider Order Entry
DS4P	Data Segmentation for Privacy
EHR	Electronic Health Record
FHIR®	Fast Healthcare Interoperability Resource
HIE	Health Information Exchanges
HL7®	Health Level Seven
HRSA	Health Resources & Services Administration
IIS	Immunization Information Systems
IR	Informational Resource
IT	Information Technology
NCPDP	National Council for Prescription Drug Programs
ONC	Office of the National Coordinator for Health Information Technology

Acronym Definitions	
SAFER	Safety Assurance Factors for EHR Resilience
SAMHSA	Substance Abuse and Mental Health Services Administration
SMART®	Substitutable Medical Applications, Reusable Technologies
SNOMED	Systematic Nomenclature of Medical Terminology
STEPStools	Safety Through Enhanced e-Prescribing Tools
USCDI	United States Core Data for Interoperability
VDT	View, Download, and Transmit to Third Party
WHO	World Health Organization

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