



Office of the National Coordinator
for Health Information Technology

ONC Health IT for the Care Continuum
Pediatric Health Information Technology:
**Neonatal Abstinence
Syndrome Informational
Resource**

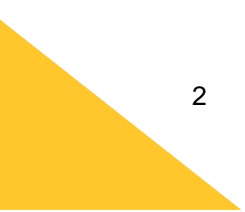
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Foreword

The development of this resource was guided by recommendations, sources, and relevant findings from the development of two pediatric health information technology (IT) resources that were previously released by the Office of the National Coordinator for Health Information Technology (ONC). [1] Further guidance was obtained from additional stakeholders and was used to identify priorities and refine content applicable to the care of infants with neonatal abstinence syndrome (NAS). This resource was developed in accordance with select provisions of the SUPPORT Act, such as Sections 1003(aa)(2)(D)(i) and 1005(a).

INTRODUCTION AND PURPOSE

The Office of the National Coordinator for Health Information Technology (ONC) is making available this Neonatal Abstinence Syndrome (NAS) Informational Resource (IR) to support the implementation of health IT products used by clinicians that provide healthcare for infants with NAS. This resource is intended to help healthcare providers work with their health IT developers to implement 12 priorities, seven of which have been amended from recommendations in the prior Pediatric Health IT Provider and Developer IRs released by ONC.

In this resource, for the purposes of streamlining, the title “healthcare provider” captures any clinician or clinical site dedicated to providing healthcare for infants diagnosed with NAS (or in some cases, at high risk of developing NAS). As users of electronic health records (EHRs) and health IT, healthcare provider input and direction to developers implementing recommended practices in clinical settings are critical. Incorporating healthcare provider insights into health IT development efforts can help to maximize the quality of children’s healthcare and enhance coordination of services.

This NAS IR is one of several efforts led by ONC and the U.S. Department of Health and Human Services (HHS) to address the health IT needs for pediatric care. The priorities and complementary health IT information related to NAS care included in this resource were derived from analysis of available evidence and stakeholder input. These priorities include related technical details based on the Children’s Electronic Health Record Format, the ONC Health IT Certification Program, Health Level Seven’s (HL7’s) set of international standards, and other standards resources.

To develop this document, ONC engaged in a collaborative approach to incorporate input on clinical priorities from a variety of stakeholders involved in supporting NAS care. Many priorities outlined in this document were informed by the American Academy of Pediatrics (AAP) clinical guidance [2] and considerations when selecting an EHR for pediatric patients [3]. In addition, the content builds 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); recommendations of expert organizations, such as the American College of Obstetricians and Gynecologists (ACOG) and the Association of State and Territorial Health Officials (ASTHO); and input from clinical and technical experts in the field. ONC also conducted technical analysis to evaluate how developers could use relevant resources to support health IT needs for NAS care.





CONSIDERATIONS FOR USE OF THIS RESOURCE

Addressing prenatal exposure to potentially harmful substances is a high priority for HHS. The Protecting Our Infants Act (POIA) of 2015 called for HHS to review planning and coordination of activities related to prenatal opioid exposure and NAS. [4] Select provisions of the SUPPORT Act also address improving care for infants with NAS. [5] HHS continues to work across agencies on efforts to promote and enhance opportunities to achieve these objectives. For example – in 2018, HHS held a one-day national convening on NAS/ Neonatal Opioid Withdrawal Syndrome (NOWS) in Philadelphia that included a strong focus on health IT strategies. [6]

This NAS IR is part of a broader ONC effort to promote the availability of certified health IT for medical specialty care providers and care settings. [7] ONC's approach to supporting the advancement of interoperable health IT across the care continuum [8] has been applied here to the care of infants with NAS. The goal is to improve care for this population and to demonstrate how the process followed (delineated in Figure 1 below) could be reused to develop similar resources for a variety of conditions and populations. In fact, many of the issues addressed in this IR could apply more broadly than to just the care of infants with NAS.

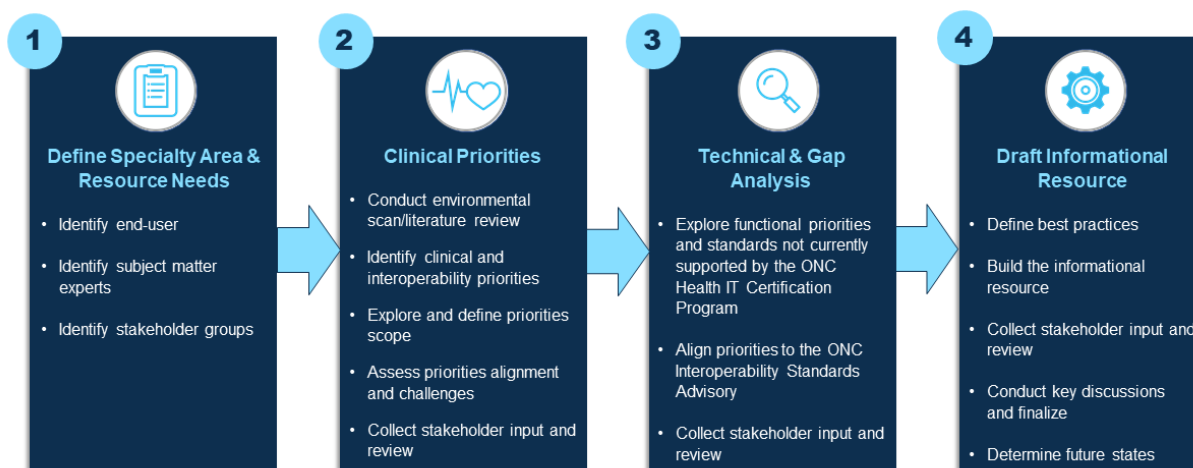


Figure 1

To make the best use of this resource, the following considerations should be noted:

Key NAS-Related Terms and Definitions [9, 2]

- **Neonatal abstinence syndrome (NAS)** – General term for the group of signs and symptoms of withdrawal that may occur in a newborn exposed in utero to opioids or other non-opioid drug substances (e.g., benzodiazepines, selective serotonin reuptake inhibitors). In this IR, this term is generally inclusive of infants diagnosed with NAS and at risk of developing NAS. The syndrome is managed with nonpharmacologic interventions but may require pharmacotherapy.

- **Neonatal Opioid Withdrawal Syndrome (NOWS)** – Specific term for the constellation of withdrawal signs and symptoms that may occur in a newborn exposed primarily to opioids in utero. Opioid exposure in utero may be due to a birthing parent’s illicit use of opioids (e.g., heroin), prescription drug misuse, or prescribed use of opioids— such as pharmacotherapy for opioid use disorder (OUD) during pregnancy. The term NOWS, rather than NAS, captures more accurately the specific population of infants experiencing withdrawal primarily from opioid exposure; although, infants with NOWS may be exposed to other substances in utero. The syndrome is managed with nonpharmacologic interventions but may require pharmacotherapy.
- **Opioid** – Refers to compounds broadly related to opium, although not all opioids will be structurally similar or derived from derivatives of opium. These include medications such as methadone, buprenorphine, and oxycodone. Note, opiates are compounds that are directly derived from opium, including its three natural derivatives: morphine, codeine, and thebaine.
- **Opioid Use Disorder** – Is defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association [APA], 2013). The diagnosis of OUD can be applied to someone who uses opioid drugs and has at least two of the 11 symptoms occurring within a 12-month period. Key aspects of OUD include loss of control, continued use despite adverse consequences, tolerance, and withdrawal.

In this IR, the term NAS is generally used rather than NOWS to address the population of infants affected by opioids and non-opioid substances in utero. While NAS is a broader classification, the health IT priorities identified here apply to infants identified as having NAS or NOWS.

Language

Given the relationship between NAS and substance exposure during pregnancy, some of the topics addressed in this document may be considered unique to the female sex as determined by biology. However, to the extent possible, this document uses gender-inclusive language recognizing that there are many individuals who give birth that do not gender identify as female. NAS and its associated impacts may affect families and individuals regardless of their gender identity or expression.

Information on Key Technical Issues

This document focuses on the clinical priorities and technical standards that healthcare providers and informaticists consider critical for health IT to support the safe and effective healthcare of all children, with specific considerations for infants with NAS.

- The IR explores how healthcare providers can effectively incorporate clinical best practices in their care of NAS patients, as well as understand and collaborate with health IT professionals to adopt standards, implementation, and technical resources, and tools to support efforts across pediatric settings.

- It identifies other technical resources and tools to support the successful implementation in health IT of pediatric clinical priorities in practice to help address gaps with the existing certification criteria and interoperability standards that are broadly supportive across various settings.
- Through the inclusion of various examples, the IR provides context for how the clinical priorities may be met with appropriate technical implementation.

Content Relevant to Developers

Selected technical content that may assist healthcare providers working with health IT developers is incorporated, as applicable, throughout this resource. Developers interested in more technical details about pediatric health IT may wish to consult the previously developed [Pediatric Healthcare Developer IR](#). In select cases, notable relevant advancements in health IT may be spotlighted. For example, in 2020, an HL7 EHR Workgroup project was initiated to establish the HL7 Pediatric Care Health IT Functional Profile Informative Standard to support the recommendations for Voluntary Certification of Health IT in pediatric care settings. [10]

- **Children’s EHR Format:** This IR builds on previous federal and stakeholder activities, including the Children’s Electronic Health Record Format supported by AHRQ and CMS. The AAP supported AHRQ’s development of the Children’s EHR Format to help bridge the gap between functions present in most EHRs and functions that would provide optimal support for the care of children. The Children’s EHR Format expands on the hierarchy created by HL7 for the EHR System Functional Model and incorporates the HL7 Child Health Functional Profile.
- **ONC Health IT Certification Program:** This IR documents certification criteria that are issued via regulation part of the which assures purchasers and other users that a system meets the technological capability, functionality, and security requirements adopted by HHS. [11]

HOW TO USE THIS MATERIAL

This document provides resources and considerations for 12 clinical health IT priorities for the care of infants with NAS. For healthcare providers who wish to go directly to items for discussion with developers, Part 1 provides an abbreviated description of each priority. Part 2 presents the central content focused on each priority.

The structure of each priority contains the following information:

- **Description** - a brief description of the priority.
- **How Health IT Supports This Priority** - an overview of the functionality that supports the implementation of the priority in practice. [12] [13]
- **Considerations and Challenges** - common barriers to implementation of the priority 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**



- **Where Can I Get More Information?**

GENERAL APPROACH AND LIMITATIONS

The functionalities identified in this document reflect commonly accepted features of current technical standards. The standards supporting priorities may not be at full maturity and their reference in this IR does not intend to limit progress, innovation, or flexibility to improve technical capabilities and guidelines. To optimize care for patients with NAS, providers and health IT developers are encouraged to work together to integrate functionality into the workflow, design specific to providers' sites of practice, and update systems to keep pace with best practices in EHR design. Both providers and developers should rely on the NAS IR only as a starting point. This NAS IR does not offer specific workflows or comprehensive solutions for providers; they are first steps. The priorities 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 priorities 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 potentially inform how health IT can support these priorities in telehealth delivery. For example, the United States Core Data for Interoperability (USCDI) data standard could support telehealth visits by making key information available before a visit for a child receiving care outside an integrated network system. Future work could explore such examples for the telehealth use case. Of particular note, the occurrence of the COVID-19 pandemic had a substantial impact on use of telehealth for prenatal and postpartum care in many states, leading to new potential opportunities and challenges in addressing opioid use disorder and NAS outcomes. [14]

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





Part 1: Summary Guide to the Priorities

PRIORITY 1: IMPLEMENTATION OF A NAS SCORING AND ASSESSMENT TOOL

Implementing this priority benefits NAS care by:

- Supporting the standardized assessment and management of infants at risk for or diagnosed with NAS.
- Facilitating the capture of NAS scoring and assessment data to understand individual and population trends.

PRIORITY 2: USE BIOMETRIC-SPECIFIC NORMS FOR GROWTH CURVES AND SUPPORT GROWTH CHARTS FOR CHILDREN

Implementing this priority benefits NAS care by:

- Facilitating age and sex-specific weight, height/length, and head circumference measurement.
- Allowing assessment of normal or abnormal growth patterns to evaluate nutritional and general health status.

PRIORITY 3: COMPUTE WEIGHT-BASED DRUG DOSAGE

Implementing this priority benefits NAS care by:

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

PRIORITY 4: AGE- AND WEIGHT-SPECIFIC SINGLE-DOSE RANGE CHECKING

Implementing this priority benefits NAS 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.





PRIORITY 5: DOCUMENT ALL GUARDIANS AND CAREGIVERS

Implementing this priority benefits NAS care by:

- Allowing accurate understanding of the social context influencing an infant’s health and wellbeing.
- Better managing who needs access to the infant’s record and who has authority to make decisions for the infant.

PRIORITY 6: TRANSFERRABLE ACCESS AUTHORITY

Implementing this priority benefits NAS care by:

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

PRIORITY 7: FLAG SPECIAL HEALTH CARE NEEDS

Implementing this priority benefits NAS care by:

- Allowing the easy flagging of infants whose care may benefit from specific decision support, care management, or other focused attention.
- Facilitating identification of high-risk patients based on screenings or other tools or factors.
- Promoting proactive care for unique patient populations.

PRIORITY 8: SUPPORT STANDARD DATA DOCUMENTATION IN DISCHARGE SUMMARY

Implementing this priority benefits NAS care by:

- Providing healthcare providers with easier access to important prenatal and newborn period information when they see infants with NAS for follow-up care in an outpatient clinic or other clinical setting.
- Promoting the inclusion of a comprehensive plan of care at the time of discharge that can act as an initial basis for ongoing tracking of needs and goals.

PRIORITY 9: DOCUMENT SOCIAL DETERMINANTS OF HEALTH

Implementing this priority benefits NAS care by:

- Providing more structured data on social determinants of health (SDoH) for infants with NAS, which may affect clinical care and facilitate connecting families with appropriate social supports and educational resources through community partnerships.



- Furthering potential for new research on the impact of SDoH on infants with NAS.

PRIORITY 10: ASSOCIATE MATERNAL HEALTH INFORMATION AND DEMOGRAPHICS WITH NEWBORN

Implementing this priority benefits NAS care by:

- Allowing access to maternal information at the point of decision-making necessary for the care of an infant.
- Ensuring healthcare providers do not need to copy information from the maternal chart to the infant's chart, thereby decreasing the risk of documentation errors and increasing efficiency.

PRIORITY 11: DOCUMENT LACTATION SUPPORT AND FEEDING DISCUSSIONS

Implementing this priority benefits NAS care by:

- Providing the care team with opportunities to track breastfeeding education and initiation, exclusivity, and duration.
- Encouraging the use of standardized feeding assessment instruments.
- Supporting consistent, structured documentation in accordance with a well-written breastfeeding policy for substance-exposed newborns.
- Enhancing care team communication and coordination across the continuum of care regarding the infant feeding plan by using a consistent format.

PRIORITY 12: DOCUMENT INDIVIDUALIZED NON-PHARMACOLOGIC INTERVENTIONS AND RESPONSE

Implementing this priority benefits NAS care by:

- Supporting the consistent use, tracking, and application of non-pharmacologic interventions to review and assess which interventions should be maximized for each infant with NAS.
- Optimizing the approach to use of specific non-pharmacologic interventions over time through better tracking of outcomes associated with specific interventions shown to be effective under various circumstances.



Part 2: Priority Descriptions

Note: There may be numerous certification criteria, technical standards, and other technical resources that can support implementation of the priorities, 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 priorities.

For more information on the certification criteria, visit [ONC](#); for other technical resources related to Priorities 2, 3, 4, 5, 6, 7, & 10, visit the [Developer IR](#). See also the ONC’s 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](#). [The Pediatric Technical Worksheets Appendix](#) from the 21st Century Cures Act Proposed Rule discusses in detail how select certification criteria support each priority.

PRIORITY 1: IMPLEMENTATION OF A NAS SCORING AND ASSESSMENT TOOL

Description

This clinical priority supports the implementation and documentation of quantitative NAS scoring and assessment tools intended for use after infants are identified as at-risk for NAS. The AAP recommends that providers evaluate all infants at risk for NAS with a standardized approach using a tool to assess the presence and severity of withdrawal and treatment response; all providers should be trained in the accurate use of the chosen tool. [2, 15] Tools such as the Finnegan Neonatal Abstinence Scoring Tool (including modified versions) or the Eat, Sleep, Console tool are already used in clinical care to quantify common clinical signs and symptoms of neonatal withdrawal and to guide providers as to when non-pharmacologic and pharmacologic interventions should be initiated, escalated, and weaned away.

Evidence demonstrates that consistent and accurate use of NAS scoring and assessment tools, coupled with a standard treatment protocol, can reduce variation in medical care, facilitate better decision-making, and improve clinical outcomes. [15]

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria
§170.315(g)(10) Standardized API for Patient and Population Services
§170.315(a)(9) Clinical Decision Support (CDS)

This certification criterion and Children’s EHR Format Requirements enable the following functions in support of this priority:



- Use assessment and scoring instruments.
- Capture the administration and completion status of assessment and scoring instruments.

Health IT can also include functions that:

- Support structured data capture to track patient-specific or population trends, or aggregate data for quality assessment.
- Integrate Clinical Decision Support (CDS) with the scoring and assessment tool to guide clinical decision-making regarding approaches to care.

Applicable Children's EHR Format Requirements

[Req 124: Support for Identification of Potential Problems and Trends](#)

[Req 2043: Scales and Scoring](#)

[Req 2004: Screening tool status](#)

Examples in Practice

In 2020, researchers at Washington State University published an article describing a pilot study involving application of an electronic bedside primer and reference assessment tool for medical providers assessing infants with NAS. [16] The group was able to establish connectivity of the tool with their electronic medical records and plans to study its ability to streamline care and impact clinical outcomes.

Considerations and Challenges

Tool Selection: Varied NAS scoring and assessment tools are available. Existing clinical practice guidelines do not endorse a specific scoring and assessment tool given insufficient evidence regarding the superiority of one tool over another. [2] Healthcare providers may wish to work with developers to identify the NAS scoring and assessment tool of their choice. Copyright or other intellectual property laws may apply to use of certain tools, so institutions should also be aware of the associated requirements and potential fees associated with adopting existing tools within health IT systems.

Preterm Infants: Most NAS scoring and assessment tools were developed for term or late-preterm infants¹ and may not accurately capture signs and symptoms of withdrawal in all preterm infants. [15] Healthcare providers may wish to address the use of NAS scoring and assessment tools for preterm infants at risk for NAS.

¹ Term is defined as any infant delivered after 37 or more completed weeks of gestation. Preterm is defined as an infant delivered before 37 weeks of gestation, and late preterm is defined as an infant delivered at 34 to 36 completed weeks of gestation.



Suggested Questions for Discussion with Your Health IT Developer:	
<input type="checkbox"/>	Can the health IT implement existing NAS scoring and assessment tools in the EHR? If yes, what tools? (e.g., Finnegan Neonatal Abstinence Scoring Tool)
<input type="checkbox"/>	Can the health IT implement the NAS scoring and assessment tool in such a way that it triggers an alert if certain criteria are either missing, not met, or met?
<input type="checkbox"/>	Can alerts or flags be designed by providers to signal specific scores, responses, needs, or interventions?
<input type="checkbox"/>	Can the health IT query specific information captured in the scoring and assessment tool? (e.g., peak scores, responses, specific withdrawal signs/symptoms)
<input type="checkbox"/>	Will the health IT allow healthcare providers to track trends in NAS scores or responses (e.g., yes/no)? <ul style="list-style-type: none"> • For individual infants? • For aggregate populations?
<input type="checkbox"/>	Will the health IT allow providers to visually display trends in NAS score or responses (e.g., yes/no)? <ul style="list-style-type: none"> • For individual infants? • For aggregate populations?

Where Can I Get More Information?

- The HL7 FHIR Structured Data Capture standard describes how to present and process forms / questionnaires to an end user – in this case a clinician evaluating a NAS infant. This standard was initiated with the ONC Standards and Infrastructure Framework.
- The HL7 EHRM-FM (Electronic Health Record System Functional Model) Release 2 Functional Profile: Child Health Functional Profile Release 1; Developmental Screening and Reporting Services Derived Profile, Release 1 – US Realm complements the HL7 Child Health Functional Profile Release 1. This standard describes a set of functions and criteria for pediatric developmental screening, which may be applicable to NAS screening.
- In Neonatal Abstinence Syndrome: assessment and management [17] and A scoring system for the evaluation and treatment of the neonatal abstinence syndrome: A new clinical research tool, [17] the authors describe the Finnegan Neonatal Abstinence Scoring Tool (FNAST). The FNAST is still used in clinical settings and is often referred to in the literature as the Neonatal Abstinence Scoring System (NASS) or the Finnegan Neonatal Abstinence Scoring System (FNASS). While individuals often reference “the modified Finnegan”, many modifications of the Finnegan Neonatal Abstinence Scoring Tool exist. For more information on the history of the tool, naming terminology, and modified versions, we refer readers to Assessment of the newborn prenatally exposed to drugs: the history. [18]



- In Neonatal Abstinence Syndrome after methadone or buprenorphine exposure, [19] the authors describe the Maternal Opioid Treatment Human Experimental Research Trial (MOTHER) Neonatal Abstinence Measure, a modified version of the Finnegan Neonatal Abstinence Scoring Tool.
- In A novel approach to assessing infants with neonatal abstinence syndrome Eat, Sleep, Console, [20] the authors describe the Eat, Sleep, Console approach an effective assessment and treatment method for the management of infants with NAS.

Of note, additional scoring and assessment tools exist, and the inclusion of references to specific tools in the “Where Can I get More Information” section does not imply endorsement over other tools.

PRIORITY 2: USE BIOMETRIC-SPECIFIC NORMS FOR GROWTH CURVES AND SUPPORT GROWTH CHARTS FOR CHILDREN

Description

This priority 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/length, weight, head circumference, and body mass index (BMI) percentiles over time on standardized Centers for Disease Control and Prevention/World Health Organizations (CDC/WHO) growth curves as appropriate. [21, 22] Age and sex-specific weight, height/length, head circumference measurement, and BMI percentile calculation are important for assessing normal or abnormal growth patterns to evaluate nutritional and general health status. [23]

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 priority allows proactive visualization of a child’s growth pattern and the ability to provide alerts for body measurements that fall outside a growth standard. [21] This priority also allows for displayed values to reference correct data sets.

For infants with NAS, it is important that weight is documented in grams (or in kilograms to 3 decimal places). [21] Whereas nearly all infants lose weight after birth, infants with NAS are at high risk for excessive weight loss due to poor or uncoordinated oral feeding, rapid gut transit time, and excess calorie needs and expenditure associated with physical withdrawal symptoms (e.g. jitteriness, tremors). [24] These infants may need more frequent feeding, tube feeds, or augmented calories to grow in the first few weeks of life. Growth monitoring (i.e., rate of weight loss and post-birth weight gain) is critical to care of infants with NAS both in and out of the hospital setting. Clear graphical presentation of weight changes in the first few weeks of life allows healthcare providers to identify growth concerns more easily, intervene as appropriate, and reinforce caregiver education.

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.



ONC Certification Criteria and Data Standard
§170.315(a)(9) Clinical Decision Support (CDS)
§170.315(a)(5) Demographics
§170.315(g)(10) Standardized API for Patient and Population Services
Data Standard: United States Core Data for Interoperability (USCDI)

Together with the [technical resources identified in the Developer IR](#), these certification criteria enable the following functions in support of this priority:

- 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. [25, 21]

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

Health IT can also include functions that:

- Incorporate CDS at the point of care when growth measurements are being recorded and when providers are using height/length and weight data to guide clinical decision-making for weight-based dosing.
- Add alerts that could indicate deviations from established norms. 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 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, providers could recommend ways to display the author or citation in a manner that is useful. [26, 21, 13]





Considerations and Challenges

Availability of Normative Datasets and Standardized Formats: Priority 2 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. [23] Providers could work with their health IT developers to base the functionality on data in the public domain where possible. For example, providers could request that developers implement functionality based on the growth charts and public data sets recommended by the CDC and WHO. [22, 27]

Lack of standardized formats for growth charts may add time and effort to the development and implementation process. [25] Health IT developers may also need providers' assistance to determine which data and calculations are most relevant to the 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. [22] Providers are encouraged to work with their developers to verify that the underlying data informing this priority's functionality comes from a reliable source and is cited in the system for provider reference. The 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 priority. [22]

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:

Suggested Questions for Discussion with Your Health IT Developer:	
Underlying Data	
<input type="checkbox"/>	Will the health IT account for adjusted gestational age for premature infants and specialized growth charts?
<input type="checkbox"/>	On what data sources will this functionality rely and are they in the public domain?
<input type="checkbox"/>	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?
Data Visualization	
<input type="checkbox"/>	Will the health IT allow providers to visually display longitudinal growth information with automatic calculation of growth patterns (e.g., percentage weight loss after birth)? If so, what will these displays look like, and can they be manipulated at the point-of care?



Suggested Questions for Discussion with Your Health IT Developer:	
<input type="checkbox"/>	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	
<input type="checkbox"/>	What alerts could be available to inform providers of significant changes in the weight of an infant or if an infant is below or above a certain percentile?
<input type="checkbox"/>	Can providers customize alerts if they wish?
Patient Access	
<input type="checkbox"/>	Will an infant's authorized representatives be able to access their growth information? If so, how?

Where Can I Get More Information?

- The CDC's website serves as a central resource for 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 priority. <https://www.cdc.gov/growthcharts/index.htm>
- The 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. <https://www.cdc.gov/nccdphp/dnpao/growthcharts/index.htm>

Tools:
The CDC recommends that health care providers use the WHO growth standards to assess growth for pediatric patients aged 0 to 2 years of age https://www.cdc.gov/growthcharts/who_charts.htm .
The Fenton Preterm Growth Chart provides preterm growth chart applications supporting the WHO growth standard to reflect actual age instead of completed weeks. https://ucalgary.ca/resource/preterm-growth-chart/preterm-growth-chart
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. https://cran.r-project.org/web/packages/anthro/index.html
The Olsen 2010 Growth Calculator for Preterm Infants, which leverages growth curves from Olsen, et al., [28] 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. https://peditools.org/olsen2010/

We refer readers to Recommendation 1 in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.





PRIORITY 3: COMPUTE WEIGHT-BASED DRUG DOSAGE

Description

This priority supports displaying a calculated medication dose and displaying how the calculated dose was determined to support safe medication prescribing for infants with NAS by enabling independent, redundant checking. [21] Pediatric patients are at higher risk of medical errors than adults, in part due to complex drug dose calculations based on size. Infants with NAS may be at a particularly high risk of medication errors due to variation across healthcare institutions in the medication types, concentrations (mg/ml), and dosing protocols used to treat NAS. Accurate and recently recorded weight is a key input to dose calculation for infants when the medication dose varies based on this factor. [29] Displaying a calculated medication dose and displaying how the calculated dose was determined is critical to reducing the risk of weight-based dosing errors in common drugs used for NAS therapy, which are often compounded and come in various mg/ml concentrations.

Weight-based dosing also has been shown to reduce errors and potential patient harm in continuous infusions and nutrition orders as well as regular medications. [Ref] Medication ordering tools with prepopulated unit/weight (i.e., mg/kg) dosing recommendations can support standardization, reduced prescribing errors, and increased safety to pediatric patients. [30]

Dose calculation for pharmacologic treatment of NAS can be particularly challenging and lead to errors because there may be varying concentrations (mg/ml) of the drug(s) available in the pharmacy. To ensure proper dosing, the provider must order the correct drug concentration and appropriate mg/kg dose of the drug, and the pharmacy must use the correct drug concentration when dispensing the drug. In addition, the final volume of the drug dispensed must be accurately measurable and safely dosed. Finally, the individual administering the drug must be able to easily confirm that the dose ordered matches the dose to be administered. This priority also includes rounding to an administrable dose, meaning a volume of drug that can be accurately measured and administered. [21]

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children's EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(b)(3) Electronic Prescribing
Data Standard: USCDI

Together with the [technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- 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;
- 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. [31]

Applicable Children's EHR Format Requirements
Req 2012: Medication Management, Compute Weight-Based Drug Dosage
Req 2035: Medication Management, Rounding for Administrable Doses

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;
- Transmit the patient weight to the pharmacy with e-prescribing so that pharmacies can perform the dose-range checks to provide independent redundancy;
- 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, and total dose and total daily dose; and
- Provide medication order tools with prepopulated dosing recommendations. [21]

Considerations and Challenges

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 users to “second check” their medication selection, [11] 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. [30] Tools may be included to inform 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. [32] 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](#).

Patients Not Within Age-Specific Norms. Alerts to a clinician may be of value when, for example, the patient's weight or height/length is not within age-specific norms. [32] Alerts could serve as an additional check or pause during ordering or prescribing for pediatric patients to alert providers that the patient may require special considerations when it comes to medication dosing.





Examples 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 issues.”

Ferris, T., et al., Grant Final Report, Improving Pediatric Quality and Safety with Health Care Information Technology, Grant ID: 5R01HS15002 (2008),
<https://digital.ahrq.gov/sites/default/files/docs/publication/r01hs015002-ferris-final-report-2008.pdf>

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.”

Ginzburg, R., et al., Effect of a Weight-Based Prescribing Method Within an Electronic Health Record on Prescribing Errors, Am J Health-Sys Pharm (November 2009) 66:22; 2037-2041,
<https://pubmed.ncbi.nlm.nih.gov/19890088/>

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





Where Can I Get More Information?

- Researchers studying use of Clinical Decision Support to Improve Dosing Weight Use in Infants with Neonatal Abstinence Syndrome found that CDS was a helpful tool for guiding prescribing behavior but noted a need to minimize workarounds that may limit its impact. <https://pubmed.ncbi.nlm.nih.gov/31572886/>

We refer readers to Recommendation 2 in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.

PRIORITY 4: AGE- AND WEIGHT-SPECIFIC SINGLE-DOSE RANGE CHECKING

Description

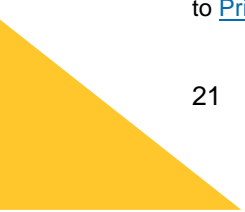
This clinical priority supports medication single-dose range checking by leveraging existing pediatric or neonatal-specific drug database references and tools and displaying normal ranges for reference and weight-based dose calculations. Additionally, this priority supports detection and alerts for drug doses which fall outside of the minimum-maximum range based on infant age, weight, and maximum recommended dose for a single medication administration. [21] When infants with NAS are administered opioids as pharmacologic therapy for withdrawal symptoms, these doses can be prepared with varying concentrations (mg/ml) in hospital pharmacies—so ensuring proper calculation and dosage is paramount to the health and safety of the infant. [33]

Pediatric patients are at an increased risk of medication errors, especially overdosing. ²

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. [30] 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. [21] It is crucial to have accurate patient measurements documented in the EHR. [34] The implementation of this priority allows the system to alert the user 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.

² For a discussion of factors that contribute to a higher risk of medical errors among pediatric patients, please refer to [Priority 3](#).





How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(a)(9) Clinical Decision Support (CDS)
§170.315(g)(10) Standardized API for Patient and Population Services
Data Standard: USCDI

Together with the [technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- The ability to 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 or neonatal-specific medication databases with 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. [21, 35, 36, 31]

Applicable Children’s EHR Format Requirements
Req 2037: Age- and Weight-Specific Single Dose Range Checking





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);
- Transmit the patient age and weight to the pharmacy with e-prescribing so that pharmacies can perform the dose-range checks to provide independent redundancy;
- 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. [31]

Considerations and Challenges

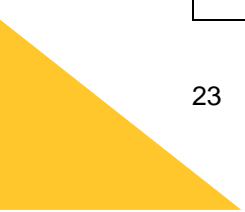
Minimum dose range alert: Minimum dose range alerts have been shown to have limited value to clinicians. [37] This may be an important point of discussion with your developer as to what is useful in your practice.

Other CPOE and CDS Tools

Using care to avoid factors contributing to errors, CPOE and CDS tools can further support patient safety, [30] including:

- Incorporate CDS tools that encourage users to “second check” their drug selection; [34]
- Prompts to enter or confirm up-to-date patient clinical parameters (height, weight, etc.); [30]
- Standardization of medication dose range concentrations at the system/EHR level to prevent calculation errors; [32] and
- Design of CPOE and CDS tools to factor in workflow, human factors design principles, and usability standards (see also the section in the Appendix, [Clinical Decision Support](#)).

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





Where Can I Get More Information?

We refer readers to Recommendation 6 in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.

PRIORITY 5: DOCUMENT ALL GUARDIANS AND CAREGIVERS

Description

This priority supports the documentation of all guardians and caregivers for infants with NAS. Approximately one-half of U.S foster care placements of infants are associated with parental substance use. [38]ⁱ Due to the unique and potentially complex caregiver and guardianship scenarios for infants with NAS, maintaining an accurate and structured record of an infant’s care team has been identified as a critical component of their care. Standard documentation of all guardians and caregivers can improve care coordination and the safety of infants during inpatient care and after discharge, as well as support the development of child welfare “Plans of Safe Care”³ for families impacted by substance use. [39]

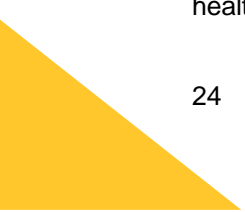
A care team includes all of the people, teams, and organizations who participate in the coordination and delivery of care for a patient. [40] In addition to clinical team members, the care team may include caregivers and guardians such as biological parents, foster parents, adoptive parents, surrogates, 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. [29] [41]

The composition of a care team is dynamic and could change over time. [42] 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. [41]

Use of a structured format to capture information ensures that guardian and caregiver information is not comingled with patient data. [41] 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 an infant’s electronic health information or have authority to make some or all medical decisions. For example, clear identification of a guardian with contact details is critical if an infant is to be placed in the custody of someone other than the biological parent. Priority 6 (Transferrable Access Authority) 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 clinician, patient, relative, friend, guardian, or organization. [32]. 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

³ A child welfare Plan of Safe Care is a plan designed to ensure the safety and well-being of an infant with prenatal substance exposure following release from the care of a healthcare provider by addressing the health and treatment needs of the infant and affected family or caregiver.





structured nature of care team members established by this priority supports the privacy and security features discussed in Priority 6 - Transferrable Access Authority. [41]

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standards
§170.315(g)(10) Standardized API for Patient and Population Services
§170.315(b)(9) Care Plan
§170.315(b)(1) Transitions of Care
§170.315(a)(5) Demographics
§170.315(b)(7) Security Tags – Summary of Care – Send
§170.315(b)(8) Security Tags – Summary of Care – Receive
Data Standard: USCDI

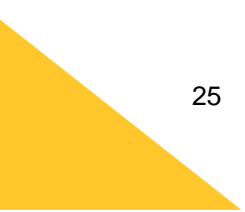
Together with the [technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- 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. [21]

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;
- 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. [21]

Applicable Children’s EHR Format Requirements
Req 2006: Ability to Access Family History, Including All Guardians and Caregivers
Req 2032: Authorized Non-Clinician Viewers of EHR Data





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. [42, 41] 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.” [32, 42]

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 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, providers may need to determine and share a preferred format for documenting caregiver start/end dates so they can be applied to the implementation. [32]

Financial responsibility data. A parent or guardian may not be financially responsible for the child depending on the care team structure and other factors. [43] 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:	
<input type="checkbox"/>	What information can I document about a caregiver?
<input type="checkbox"/>	What roles can I assign to the different care team members for a single patient record?
<input type="checkbox"/>	How are non-clinician viewers of the EHR designated in the record?
<input type="checkbox"/>	Is there any limit on the number of names that can be added to the guardians and caregivers?
<input type="checkbox"/>	Am I able to view the decision-making authority of care team members?
<input type="checkbox"/>	How can I archive caregivers who are no longer involved with the child?
<input type="checkbox"/>	Can historical care team members be reactivated?

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. [44]
<https://www.sciencedirect.com/science/article/pii/S1532046418301357?viewFullText=true>



- Plans of Safe Care for Infants With Prenatal Substance Exposure and Their Families describes state laws and policies regarding the development and implementation of plans of safe care that are required by the Child Abuse Prevention and Treatment Act to ensure the safety and well-being of infants who are identified as being affected by prenatal substance use. The issues addressed include notification/reporting requirements; assessment of the infant and family; development of the plan of safe care; services for the infant, parents, or other caregivers; and monitoring plans of safe care. [39]

We refer readers to **Recommendation 3** in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.

PRIORITY 6: TRANSFERRABLE ACCESS AUTHORITY

Description

This clinical priority supports the ability to change health record access authority for an infant with NAS. For infants with NAS, a caregiver or guardian's ability to change health record access authority is essential to ensure a smooth transition in cases where the custody of the infant may shift – for example, from a biological parent to a foster parent or other guardian. Since the patient cannot make the transfer of access authority decision, it is critical that health systems identify and clearly communicate with care team member(s) that may access the health record and have healthcare decision making authority. Implementing this priority can benefit infants with NAS by ensuring that appropriate and current caregivers and/or guardians have the correct permissions to access the infant's health record and that access permissions appropriately adjust with changes in the care team.

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, divorce). In addition to capturing relationships and roles associated with the patient (see Priority 5), including a mechanism in the EHR to manage access authority and changing circumstances supports pediatric care.

Appropriate access control ensures that the appropriate and current caregivers and guardians are given the right permissions to an infant's health record. [45]

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 priority allows users to have the ability to change access to the health record based on changing care 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 Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children's EHR Format Requirements, and additional functionalities.



ONC Certification Criteria
§170.315(g)(10) Standardized API for Patient and Population Services
§170.315(e)(1) View, Download, and Transmit to Third Party
2015 Edition Cures Update Health IT Certification Criteria includes: §170.315(b)(7) Security Tags – Summary of Care – Send §170.315(b)(8) Security Tags – Summary of Care – Receive

Together with the [technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- Allow a system to document all care team members for a given patient (see Priority 5);
- Allow the modification of authority to access an infant's health record for parents, guardians, and/or caregivers; and
- Allow parents, guardians, and/or caregivers to view, download, and transmit an infant's health information. [21]

Applicable Children's EHR Format Requirements
Req 2026: Transferrable Access Authority

Health IT can also include functions that:

- 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 providers in applying access rules to different guardians and caregivers; and
- Apply specific access control techniques the practice prefers to utilize. [21, 46, 47]

Considerations and Challenges

Substance Abuse Confidentiality Regulations. Given that records for infants with NAS may contain information on substance use disorder diagnoses associated with their birthing parents, attention may need to be given to the provenance of that information and if it is subject to restrictions on the redisclosure of information from patient encounters under a Part 2 program. [9]

State and local laws. [48] As with Priority 5, state and local laws play a large role in this priority. Regulations around privacy and consent determine which caregivers or guardians need access to information and whether someone has medical decision-making authority for a child. For additional information about consent laws, please refer to [Priority 5](#).

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

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

Where can I get More Information?

- As mentioned in the Pediatric Developer IR, the HL7 V3 D4SP supports this priority. HL7 FHIR is developing a new version of the D4SP standard that provides guidance for applying security labels. This standard should be evaluated when implementing data segmentation. The Integrating Healthcare Enterprise IT Infrastructure Technical Framework Volume 4 National Extensions (Section 3.1 Data Segmentation For Privacy) provides more information. Issues related to access control can be important for children in foster care or protective custody.
- The resource, Improving Information Sharing for Youth in Foster Care, states that designated care givers may require select health information on chronic diseases, immunizations, or medications, for example, to ensure appropriate care for youth in foster care. [49] <https://pediatrics.aappublications.org/content/144/2/e20190580.long>
- The resource 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." [45] <https://www.sciencedirect.com/science/article/pii/S0167739X16302667?viewFullText=true>

We refer readers to Recommendation 7 in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.





PRIORITY 7: FLAG SPECIAL HEALTHCARE NEEDS

Description

This clinical priority supports integration of EHR tools that appropriately serve children with special healthcare needs.⁴ [50] Infants with NAS may be considered children with special healthcare needs as they have an increased risk of neurodevelopmental alterations [2] and often have health and social service needs beyond that required generally by most infants. Flagging these infants as having special healthcare needs allows healthcare providers to identify infants that may benefit from specialized screening and assessment, decision support, care management, health surveillance, and other focused attention or intervention.

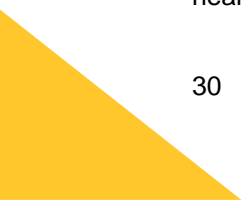
Tools built into EHRs that allow for the flexible, customizable identification of these infants can support the effective implementation of this priority. These tools can also support accurate and timely reporting, along with the designation of an infant with special healthcare needs to be communicated in a clear and intuitive manner. [51]

Healthcare providers can easily flag infants at risk for or diagnosed with NAS and can also have the flexibility to unflag these infants as needed. [48] Flags may be added to an infant's record during a clinician workflow or automatically applied as a result of a CDS rule. [48, 11] Tools built into the EHR for flagging and identification purposes may also support the reporting of quality measures and public health reporting and surveillance. [47]

Using flags can support improved NAS 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 (e.g., to identify infants requiring NAS screening and assessment). A flag can be used to generate lists, identify who should be contacted for an office visit or receive a referral, and create health reminders (e.g., Hepatitis C exposure follow-up). Flags may also be used to identify infants with NAS who are at higher risk for adverse outcomes, potentially based on screening results or certain social determinants of health. [51]

EHR support for this priority promotes proactive care as well as facilitates early identification, intervention, and care management for infants at risk for or with NAS. The capacity to record and monitor unique needs over time supports a healthcare provider's ability to provide personalized care for this patient population. [20, 52]

⁴ Children and youth with special healthcare needs 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





How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(g)(10) Standardized API for Patient and Population Services
§170.315(c)(1) Clinical Quality Measures [also: §170.315(c)(2)-(4)]
§170.315(a)(9) Clinical Decision Support (CDS)
Data Standard: USCDI

Together with [the technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- Flag infants with special healthcare needs or complex conditions;
- Unflag infants who no longer need to be specifically identified;
- Identify and display a population by diagnosis (e.g., NAS) and/or other criteria;
- Identify infants with special needs who have missed an intervention or interaction; and
- Suggest evidence-based care plans for infants with specific health or social service needs.⁵

Applicable Children’s EHR Format Requirements
Req 2014: Flag Special Health Care Needs

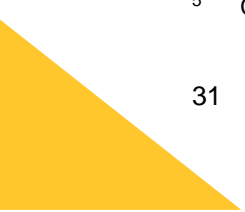
Health IT can also include functions that:

- Allow information to be shared with third parties (e.g., providers at different systems, care team members, child welfare, public health reporting and surveillance registries, schools);
- Develop/generate reports of associated diagnoses or treatments; and
- Aggregate and view data across a cohort of patients (dashboard functionality). [25]

Considerations and Challenges

Defining the NAS Population: Infants included in the NAS population may vary across healthcare settings. In some healthcare institutions, any infant exposed to substances (such as opioids) in-utero are included in the NAS population. Others may only include infants with clinical signs of withdrawal or requiring pharmacologic treatment in the NAS population. [53] Providers may wish to collaborate with other stakeholders to define the NAS population to be flagged as children with special healthcare needs so that the population included in the designation is clear across institutions.

⁵ Children’s EHR Format Req-2014.





Enabling the Use of Computable Guidelines with CDS Connect: Providers may work with their developers to identify relevant NAS guidelines that have been adapted by professional societies for implementation in EHRs. For those guidelines 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 providers and their developers to adapt guidelines into a technical format. [54] There is, however, a risk to interoperability between different implementations of adapted guidelines when they are not socialized or peer reviewed.

Lack of Clinical Coding for “Special Healthcare Needs”: 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. [47] A diagnosis of NAS implies special needs. It may be sufficient to flag a patient with the diagnosis, or it may be necessary to specify certain needs. Any solution should be flexible to support both.

Lack of Guidelines for Specific Needs: Other challenges are children who have needs for which there are no evidence-based guidelines or situations such as when a child’s special healthcare needs are impacted by family social risk factors or resources. Providers may 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 the provider to identify and monitor patients. Ideally, providers could have the ability to create categories of specific needs (e.g., NAS-related) through the functionality of the EHR, without relying on additional work by the developer.

Suggested Questions for Discussion with Your Health IT Developer:	
<input type="checkbox"/>	How can a patient with a special healthcare need be designated so that a provider looking at the record knows right away that the patient has special needs?
<input type="checkbox"/>	Can patients be unflagged?
<input type="checkbox"/>	Can alerts or flags be designed by providers to signal specific needs or interventions?
<input type="checkbox"/>	Can a flag be shared between EHR systems to ensure that a recipient system “understands” the patient has special healthcare needs?

Where Can I Get More Information?

- In Development and Validation of a Model to Predict Neonatal Abstinence Syndrome, [55] the authors describe study results for creation and evaluation of predictive models to stratify infants at risk of NAS based on 30 demographic and antenatal exposure variables collected before birth. The models successfully risk stratified infants at risk for developing NAS, which might be tied to a flag for special follow-up.

We refer readers to **Recommendation 10** in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.





PRIORITY 8: SUPPORT STANDARD DATA DOCUMENTATION IN DISCHARGE SUMMARY

Description

This clinical priority supports the standard documentation of information in a discharge summary for infants with NAS, who often have a more complex medical course than infants without NAS. Neonates with in utero opioid exposure are at risk for post-discharge adverse outcomes, including hospital readmission and increased emergency department use. [56] A discharge summary targeted to NAS could include: drugs to which the infant was exposed prenatally; signs of drug withdrawal in the infant; information about whether the infant was treated with drug therapy for NAS symptoms (including which drugs, for how long, and plans for continued treatment); any delivery complications; feeding status, concerns, and future plans; weight gain trajectory; and residual symptoms that the infant displayed at discharge that a healthcare provider needs to follow.

Additional information in the discharge summary may encompass follow-up recommendations for infants exposed to HIV or Hepatitis C or referrals to home visiting services, a primary care physician, and other services (e.g., early intervention, child welfare) that could mitigate adverse outcomes and support continued care coordination. [57] Standard data documentation in the discharge summary can improve the care of infants with NAS because healthcare providers will have easier access to important prenatal and newborn period information when they see the infants in an outpatient clinic or other clinical setting. In addition, inclusion of a comprehensive plan of care in the discharge summary can act as a basis for ongoing tracking of goals and plans for the infant’s care and services.

How Health IT Supports This Priority ⁶

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(b)(1) Transitions of Care
§170.315(e)(1) View, Download, and Transmit to Third Party
§170.315(g)(10) Standardized API for Patient and Population Services
Data Standard: USCDI

⁶ Providers are advised that there may be numerous steps to implement this priority 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 providers to share information and specifics about their practice to effectively implement health IT pursuant to this priority.





These certification criteria enable the following functions in support of this priority:

- Structured documentation of discharge summary data; and
- Ability to export structured discharge summary data in a timely manner to support continuity of care. Health IT can also include functions that:
- Required versus optional structured data capture for selected NAS-specific elements in the discharge summary.
- Alert healthcare providers of critical information missing in the infant record that will be necessary for complete discharge documentation.
- Facilitate customized automated extraction of discharge summary data from relevant fields within the infant’s record. Support
- Coordinate initiation and tracking of referrals specified in the discharge summary.

Applicable Children’s EHR Format Requirements
Req 267: Produce a Summary Record of Care
Req 481: Capture and Communicate Referrals
Req 686: Medication Administration Details
Req 2002: Record all vital signs and growth parameters precisely

Examples in Practice
Substantial variation exists in care practices for infants with NAS. [53] Efforts to implement plans of safe care for substance-exposed newborns in Massachusetts involve a focus on identifying common components across hospitals, including setting up an appointment with the patient’s primary care pediatrician in the community prior to discharge and having the discharge summary sent to the pediatrician; the community primary care pediatrician then becomes the “point person” for the infant’s ongoing care. [59] Standard EHR documentation of the infant’s NAS-specific history, inpatient care, referrals, and plan of care in the infant’s discharge summary can help make such transitions more efficient and effective.

Considerations and Challenges

Identification of Structured Elements. No standard set of structured elements or format currently exists for the discharge summary of infants with NAS. As a starting point, healthcare providers and other stakeholders may be able to identify essential elements to be included in all NAS discharge summaries based on best practices. Further work will be needed to develop consensus on the minimum set of items and how they should be structured.

Exchange Across Systems. It is essential to ensure that discharge documentation for infants with NAS can be effectively exchanged across health IT systems to support continuity of care for post-discharge encounters in various settings, particularly as the infant may require multiple types of referrals.





Suggested Questions for Discussion with Your Health IT Developer:	
Functionality	
<input type="checkbox"/>	<p>What minimum set of NAS-specific data elements will be included in standard discharge reports? Examples include but are not limited to:</p> <ul style="list-style-type: none"> • Prenatal drug exposures • Toxicology results • NAS diagnosis (with emphasis on clear documentation of the diagnosis in the EHR problem list when relevant) • Summary of withdrawal symptoms and assessment scores prior to discharge • Pharmacotherapy intervention (medication dosing/taper) • Birth parent's hepatitis C and HIV status • Referrals • Scheduled follow-up appointments • Social work/child welfare information (e.g., caregiver to whom the infant is being discharged, child protective services involvement) • Breastfeeding status and feeding/nutrition plan • Birth weight and discharge weight • Care Plan/follow-up actions
<input type="checkbox"/>	How will permissions be established for modifying required entry of NAS-specific discharge summary elements?
<input type="checkbox"/>	Are providers able to customize the discharge summary format for infants with NAS?
Data Access and Follow-up Care	
<input type="checkbox"/>	What APIs are available for discharge summary data?
<input type="checkbox"/>	If there is maternal data in the infant discharge summary, how can this be effectively managed?
<input type="checkbox"/>	Will relevant information from the infant's discharge summary be accessible and usable for the infant's caretaker(s)?
<input type="checkbox"/>	Can alerts be triggered for information missing from the discharge summary?
Alerts/ CDS	
<input type="checkbox"/>	What alerts could be available to inform providers of significant changes in the weight of an infant or if an infant is below or above a certain percentile?
<input type="checkbox"/>	Can providers customize alerts if they wish?
Patient Access	
<input type="checkbox"/>	Will an infant's authorized representatives be able to access their growth information? If so, how?



Where Can I Get More Information?

- Health IT standards support documenting the discharge summary in general. Certified EHRs must support:
 - HL7 Consolidated Clinical Document Architecture (CDA) Release 2 IG: C-CDA Templates for Clinical Notes R2.1 Companion Guide Release 2 - US Realm.
 - HL7 Implementation Guide for CDA Release 2: Consolidated CDA Templates for Clinical Notes (US Realm), Draft Standard for Trial Use Release 2.1
 - [HL7 FHIR US Core Implementation Guide](#)
- In [An Evaluation of the Content of Pediatric Discharge Summaries](#), the authors highlight areas of opportunity to improve pediatric discharge summaries, specifically noting that discharge diagnosis, medications, and follow-up appointments have the lowest rates of completion and accuracy. [60]
- The Monroe Carell Jr. Children’s Hospital at Vanderbilt established consensus around discharge of opioid-exposed newborns that identified the following items: [56]
 - scheduled follow-up appointment with the primary care physician;
 - referral to home-visiting services;
 - referral to early intervention services;
 - for infants diagnosed with NAS, referral to a pediatric development clinic; and
 - if exposed to hepatitis C virus, a pediatric gastroenterology or infectious disease referral.

Other referrals and a plan of safe care (including coordinating with child welfare, as appropriate), may also be considered. [2]

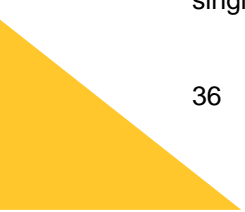
- In the Children’s Minnesota NAS Reference Guide, the authors include discharge considerations, planning, and a readiness checklist for infants with NAS. [61]

PRIORITY 9: DOCUMENT SOCIAL DETERMINANTS OF HEALTH

Description

This clinical priority allows healthcare providers to document social determinants of health (SDoH) data in the patient’s electronic health record, with respect to standard SDoH screening tools. Optimal care of patients relies in part on providers’ ability to identify, understand, and document individuals’ SDoH, defined as the “conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of-life-risks and outcomes.” [62] The AAP and its Bright Futures initiative recommend surveillance for social risk factors related to SDoH during all patient encounters. [63] [64] Social risk factors, which are specific negative or adverse social determinants, can have detrimental effects on infants (e.g., developmental delays), particularly those born with special healthcare needs— including infants with NAS. Research has shown that elevated NAS rates are linked to areas with high long-term unemployment rates and rural counties with poor socioeconomic conditions and limited health resources. [64]

SDoH screening is associated with improved health outcomes and may enable care plan improvements and referrals to community and social services by identifying social risk factors and needs. [65] There is no single preferred screening tool for SDoH, but several organizations have made tools and resources





available for use by providers. These screening tools assess SDoH for patients and their families and may be administered by providers, care coordinators, community health workers, health coaches, patient navigators, or other non-clinical staff – depending on the institution. Some tools have been specifically designed with a pediatric focus, including child-specific or caregiver questions. [66]

NAS is influenced by social factors, particularly those associated with prenatal drug exposure, including access to adequate housing, food, community support systems, primary care, and behavioral healthcare providers. SDoH data may be useful for promoting health equity, improving the clinical care of infants with NAS, and connecting families with appropriate social supports and educational resources through community partnerships. [67, 68] Developing a workflow for implementing screening and addressing positive screens is essential. Better SDoH data may also facilitate future research on the impact of SDoH on infants with NAS.

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standards
§170.315(a)(15) Social, Psychological, And Behavioral Data
Interoperability Standards Advisory Content: Social Determinants of Health
Data Standard: USCDI

Applicable Children’s EHR Format Requirements
Req 917: Maternal Substance Abuse and Social History
Req 2033: Placement setting in out-of-home care
Req 1200: Family and patient history of intimate partner violence
Req 2004: Screening tool status
Req 2043: Scales and Scoring

These certification criteria enable the following functions in support of this priority:

- Collect SDoH data using industry standards without adding burden to clinician workflow.
- Display and/or report SDoH information as part of the clinical health record.
- Enable data-sharing to or integration with social service organizations, community partners, and/or referral platforms to act on SDoH data in a meaningful way.
- Identify opportunities to incorporate population-level information on SDoH (e.g., based on patient zip code) to supplement responses from SDoH screening.
- Incorporate the use of SDoH data within clinical decision support tools.

Considerations and Challenges

Workflow and SDoH documentation. The feasibility of successful SDoH documentation hinges on the ability of providers to adjust their workflows to include SDoH screenings. Effective use of SDoH data will also generally require an established process for addressing unmet social needs, such as through referrals to community health workers. Providers may also need to iterate workflows based on their staffing





resources or the nature of a screening question. For example, some patients (or their proxies) may feel more comfortable self-reporting SDoH information about sensitive topics such as intimate partner violence, homelessness, and child abuse using a portal or kiosk. [69] Health IT functionality must consider how to best capture data when such sensitivities and preferences exist. [69]

Use of SDoH Data. Although SDoH screening and targeting of social risk factors and needs is associated with improved health outcomes, outstanding questions remain on how best to use this information to inform patient care and population management. The sensitive nature of the information obtained through SDoH screening and the use of SDoH data for certain applications (e.g., risk stratification or population segmentation) may raise concerns for patients regarding ethical use. [70, 71] Healthcare organizations may wish to consider whether to adopt ethical standards around the use of SDoH data.

Coding Standards. While health IT developers report the use of ICD-10, LOINC, and SNOMED codes in the documentation of SDoH factors in the patient record, there are challenges related to overlap and ambiguity of these codes. [69] To benefit from structured SDoH documentation, the relevant scoring/screening tools and underlying terminologies must be standardized. The HL7 Gravity Project, initiated in 2018, is a direct response to the gaps and calls to action around the national standards for representing SDoH data in electronic health records. [72]

Suggested Questions for Discussion with Your Health IT Developer:	
Screening Tools	
<input type="checkbox"/>	What SDoH screening tools does the Health IT support?
<input type="checkbox"/>	How does the Health IT map SDoH screening tool concepts or results to ICD-10, LOINC, and SNOMED codes?
<input type="checkbox"/>	Will the Health IT allow healthcare providers to assign the task of screening to specified staff (i.e., medical assistant, non-clinical)?
	Where will the Health IT store SDoH screening data, and is it accessible to all healthcare providers?
	Will the Health IT allow healthcare providers to restrict access to screening results?
	How can healthcare providers use the Health IT to query, aggregate, or display SDOH data for a population of patients?
Follow-Up	
<input type="checkbox"/>	If a patient has multiple social needs, will the Health IT allow healthcare providers to indicate prioritization for addressing each item?
<input type="checkbox"/>	If a patient (or authorized representative) declines assistance with addressing a social need, will the Health IT allow healthcare providers to document this information using a structured format?
<input type="checkbox"/>	How does the Health IT support closing the referral loop for social need referrals?
<input type="checkbox"/>	Will the Health IT allow healthcare providers to link or auto-populate screening tool results as part of care plan documentation?





Where Can I Get More Information?

- The **Gravity Project** is a community-led HL7 Fast Healthcare Interoperability Resources (FHIR) Accelerator that works to enable documentation and integration of social risk factors in clinical care with the development of data elements and standards to gather, exchange, and utilize SDoH data. <https://www.hl7.org/gravity/> [72]
- In Screening for Social Determinants of Health: Children's Hospitals Respond, the authors provide a list of common SDOH screening tools and referral platforms healthcare providers are using. [73]
- A Morbidity and Mortality Weekly Report on State Strategies to Address Opioid Use Disorder Among Pregnant and Postpartum Women and Infants Prenatally Exposed to Substances, Including Infants with NAS noted social considerations (including gaps in provision of social services) that were accounted for by some state teams. <https://www.cdc.gov/mmwr/volumes/68/wr/mm6836a1.htm>
- In **An Integrative Review of Social Determinants of Health Assessment and Screening Tools Used in Pediatrics**, the authors assessed 13 SDoH screening tools using the SDoH Framework outlined by Healthy People 2020 and conclude that there is a lack of high quality, comprehensive, and multidimensional SDoH screening tools for implementation in pediatric settings. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5865646/>
- In Variation in Electronic Health Record Documentation of Social Determinants of Health Across a National Network of Community Health Centers, the authors describe SDOH screening and documentation patterns and barriers, which vary widely across community health centers, and note that the availability of health IT tools for SDOH screening does not ensure widespread adoption of screening documentation. [https://www.ajpmonline.org/article/S0749-3797\(19\)30322-8/fulltext](https://www.ajpmonline.org/article/S0749-3797(19)30322-8/fulltext)
- Researchers at Boston Medical Center worked on Implementing an EHR-based Screening and Referral System to Address Social Determinants of Health in Primary Care. https://journals.lww.com/lww-medicalcare/Abstract/2019/06001/Implementing_an_EHR_based_Screening_and_Referral.9.aspx

Tools:
AAP's Screening Technical Assistance & Resource (STAR) Center provides information and tools on screening, referral, and follow-up for social determinants of health. [74]
National Academy of Medicine Social and Behavioral Measures: A set of measures spanning 12 domains that include race, ethnicity, education, financial resource strain, stress, depression, physical activity, tobacco use, alcohol use, social connection or isolation, intimate partner violence, and geocodable residential address. [75]
Center for Medicare and Medicaid Innovation's (CMMI) Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) tool: A 10-Item Screening tool to help providers identify patients' needs in 5 core domains that community services can help with: Housing instability, Food insecurity, Transportation problems, Utility help needs, interpersonal safety; there are also 8 supplemental



domains including Financial strain, Employment, Family and community support, Education, Physical activity, Substance use, Mental health, and Disabilities. [76]

The Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) is an effort focused on collection of data related to SDOH, including an assessment tool. [78]

PRIORITY 10: ASSOCIATE MATERNAL (BIRTHING PARENT) HEALTH INFORMATION AND DEMOGRAPHICS WITH NEWBORN

Description

This clinical priority supports healthcare providers by allowing access, at the point of decision-making, to information about the birthing parent needed for care of the infant at-risk for or with NAS. This priority also ensures that healthcare providers do not need to copy information from the birthing parent's chart to the infant's chart, thereby decreasing the risk of documentation errors and increasing documentation efficiency. [32, 77]

Point-of-care access to the birthing parent's health information and demographic information is critical to NAS treatment. [6] The clinical presentation of NAS varies with many factors, including the drug(s) used, the use of other central nervous system (CNS)-acting drugs (e.g., antidepressants, benzodiazepines), polysubstance use, and the duration, frequency, dose, and timing of the most recent use of the drug(s) before delivery. Information in the birthing parent's chart that infant healthcare providers may find useful include: 1) substance use history, including the drug(s) used, frequency of use, usual route of use, and other CNS-acting drug exposures during pregnancy; 2) substance use disorder medication treatment history, including use, duration, and dose(s) of medication treatment; 2) toxicology results for screenings performed throughout the pregnancy and upon delivery; 3) other co-morbidities that could affect immediate neonatal care (e.g., infections, acute and chronic medical conditions, and heritable genetic conditions); [78] and 4) sociodemographic factors that may impact infant welfare.

Healthcare providers caring for infants at risk for or with NAS often need to search for this critical information as it often found in more than one place in the birthing parent's record, including in the history, lab test results, care plan, and care transition documents. Such information is not always accessible to or connected to the infant record, [77] and as result healthcare providers may not have a complete picture of the extent of fetal drug exposure. Associating relevant birthing parent information with an infant supports optimal inpatient care and continuity of care upon discharge to the ambulatory setting or transfer to another hospital. [21]ⁱⁱ

Currently, there are no standards for either identifying the content or specifying the transfer of this information. Providers may work with their health IT developers to implement this priority by identifying and importing key information about the birthing parent, relevant to NAS care, to the infant record [32, 77] or linking the records of the birthing parent and infant. [79] 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. [47]ⁱⁱⁱ 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 information about the birthing parent critical to the infant's care.



How Health IT Supports This Priority ⁷

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities. ⁸

ONC Certification Criteria and Data Standard
§170.315(g)(10) Standardized API for Patient and Population Services
§170.315(b)(9) Care Plan
§170.315(b)(1) Transitions of Care
§170.315(a)(5) Demographics
§170.315(a)(12) Family Health History
§170.315(a)(15) Social, Psychological, And Behavioral Data
Data Standard: USCDI

Together with the [technical resources identified in the Pediatric Developer IR](#), these certification criteria enable the following functions in support of this priority:

- Directly incorporate and record the birthing parent’s information (which may be found in multiple places in their record) into the pediatric record as discrete information;
- Link and de-link the records of the birthing parent and infant; and
- Include the provenance (author, institution) of birthing parent health information incorporated in the pediatric records. [80]

Applicable Children’s EHR Format Requirements :
Req 2001: Link Maternal and Birth Data to Child Health Record
Req 2021: Associate Mother’s Demographics with Newborn
Req 917: Maternal Substance Abuse and Social History

Health IT can also include functions that:

- Flag errors found or suspected in birth information; and
- Incorporate updates or corrections made to birthing parent’s information. [25] [29] [81]

⁷ Providers are advised that there may be numerous steps to implement this priority 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 providers to share information and specifics about their practice to effectively implement health IT pursuant to this priority.

⁸ For more information on the certification criteria, visit ONC; for other technical resources that support this priority, visit the [Developer IR](#). 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. <https://www.govinfo.gov/content/pkg/FR-2020-05-01/pdf/2020-07419.pdf>





Considerations and Challenges

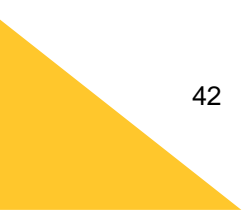
Structured Documentation of the Birthing Parent’s Substance Use: Technical standards do exist to support the structured documentation of substance use history. However, evidence suggests that providers outside of behavioral health treatment settings commonly use unstructured data fields to document substance use history. [81] Healthcare providers may wish to work with developers to ensure that substance use structured data fields are accessible in a manner that providers can easily access and use to support comprehensive documentation of the birthing parent’s substance use history for association with the newborn record.

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

Other Important Family Health Information: Health information that impacts a newborn may expand beyond the birthing parent’s record and be found in the non-birthing parent’s 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. Providers can work with developers to suggest linkages that are important for care and infant welfare 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.

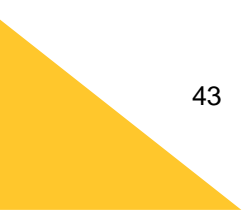
Identification of Data Elements and Standards: For all infants, there are data elements from the birthing parent’s record that may be useful to incorporate into the newborn record. [21] The elements that are critical to travel with the newborn record are not always clearly identified, and developers may not know which data should be prioritized. 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 to optimize NAS care and outcomes, so that developers can implement the priority as effectively as possible.

Privacy: Privacy requirements, considerations, and concerns are higher with regards to substance use history and treatment. [9] This priority does not specifically contemplate the privacy of the birthing parent’s information captured in the infant’s record or, if the birthing parent and newborn records are linked, privacy considerations for linked records of the birthing parent and newborn. 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, the birthing parent’s consent (or refusal to consent) may be obtained and documented for specified information elements. 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 the birthing parent’s information is kept in the pediatric record on a time-limited basis.





Suggested Questions for Discussion with Your Health IT Developer:	
Associate	
<input type="checkbox"/>	How will the EHR associate information when the birthing parent and newborn are treated in varied settings? (same/different hospitals and same/different ambulatory settings)
<input type="checkbox"/>	<p>What elements of the birthing parent's substance use history can healthcare providers document in structured data fields for association with the newborn record? Examples include, but are not limited to:</p> <ul style="list-style-type: none"> • Substance(s) • Usual route of administration (e.g., oral, injection, inhalation) • Frequency of use • Age at first use • Timing and amount of last use • Number of prior treatment episodes • Referrals for treatment • Current treatment (e.g., none, inactive, active, planned)
<input type="checkbox"/>	How will sources/provenance of information be identified?
<input type="checkbox"/>	How will the birthing parent's information be displayed in the newborn record?
<input type="checkbox"/>	Can the provider select the birthing parent's information that is associated with the newborn record?
Family Members	
<input type="checkbox"/>	What options are there to incorporate information from the birthing parent's record that relates to other family members?
<input type="checkbox"/>	Can information be flagged as being from a non-birthing parent versus a birthing parent?
Privacy	
<input type="checkbox"/>	Can the birthing parent's information incorporated into the pediatric record be tagged as sensitive data for privacy?
<input type="checkbox"/>	Can the birthing parent request that information incorporated into the pediatric record be tagged as sensitive data and shielded from the child's view?
<input type="checkbox"/>	Can a copy of the birthing parent's consent to share information be included in the pediatric record?





Where Can I Get More Information?

- MAT-LINK— MATernaL and Infant NetworK to Understand Outcomes Associated with Treatment for Opioid Use Disorder during Pregnancy is project developing a data platform to collect linked data for infants and pregnant persons treated for OUD during pregnancy. [82]

We refer readers to **Recommendation 8** in the Pediatric [Provider IR](#) and [Developer IR](#) for additional information to support this clinical priority.

PRIORITY 11: DOCUMENT LACTATION SUPPORT AND FEEDING DISCUSSIONS

Description

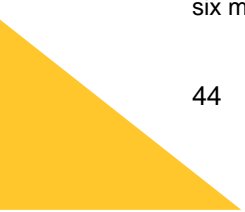
This clinical priority supports the structured documentation of feeding and lactation discussions to promote and support breast/chest feeding for infants with NAS. It includes structured data capture of elements related to lactation practices and feeding preferred and administered to the infant during and after inpatient stay. It also includes supporting structured data capture from an established feeding assessment instrument (e.g., LATCH). [83]

Breast/chest feeding is recommended for infants with NAS unless absolute contraindications exist such as HIV infection or active, untreated substance use. [84] Additionally, individuals receiving opioid-agonist therapy for opioid use disorder during and after pregnancy are encouraged to breast/chest feed. [85, 9] For infants with NAS, breast/chest feeding is an important non-pharmacologic intervention. [86] Evidence indicates that breast/chest feeding helps calm and comfort infants exposed to opioids in utero. [87] Breast/chest feeding is also associated with reduced severity of NAS, decreased need for and duration of pharmacologic treatment, and shorter length of hospital stay. [2] The AAP recommends that all hospitals have a written protocol for breast/chest feeding infants with substance exposure and that lactation support should be available in inpatient and outpatient settings. [2]

Infants with NAS are at increased risk for feeding difficulties [88] and breast/chest feeding parents of infants with NAS often experience challenges or barriers to breast/chest feeding such as inconsistent support, inadequate education, or infant separation. [89, 90] Rates of breast/chest feeding initiation, exclusivity,⁹ and duration remain low for breast/chest feeding parents of infants with NAS compared to other populations. [2, 91] Effective feeding and lactation discussions can help providers identify feeding difficulties, minimize barriers, and provide support, education, resources, and strategies to promote breast/chest feeding initiation, exclusivity, and continuation for infants with NAS.

Feeding and lactation discussions often include but are not limited to the following components: (1) medical history, including discussion of infant pharmacologic treatment for NAS, parental pregnancy and postpartum history, and parental plans for substance use disorder treatment; (2) breast/chest feeding

⁹ Exclusivity means that means that no other liquid or solid food is fed to the infant, except for medications. Per USDA and AAP guidelines, exclusive breastfeeding (human milk feeding) is recommended for all infants for the first six months of life, with continued breastfeeding with solid food introduction through the first year of life.





history, including intent, prior experience, risk factors, supports, and barriers; (3) infant feeding (e.g., substance, route, intake, output, timing, problems/concerns); (4) direct observation and assessment of breast/chest feeding using a standard assessment instrument; (5) education and anticipatory guidance; and (6) a feeding care plan including interventions, resources, supplies, and referrals, as appropriate.

Applicable Children’s EHR Format Requirements:
Req 119: Documentation for Patient Education Materials
Req 2043: Scales and Scoring

How Health IT Supports This Priority ¹⁰

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children’s EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(a)(13) Patient-Specific Education Resources
§170.315(b)(9) Care Plan
Data Standard: USCDI

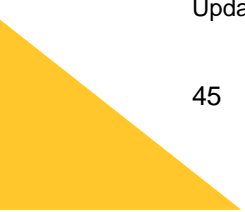
These certification criteria enable the following functions in support of this priority:

- Structured documentation of lactation and feeding discussions; and a
- Structured format for documenting patient-specific infant feeding care plans.

Health IT can also include functions that:

- Support structured data capture enabling quality data collection to identify gaps in care, inform quality improvement efforts, or support breast/chest feeding public health initiatives.
- Align with breast/chest feeding quality measurement (e.g., Joint Commission Perinatal Care Measures) and practice standards (e.g., US Baby-Friendly Hospital Initiative).
- Add alerts/CDS with feeding assessment instruments to inform decision-making, appropriate follow-up, and referrals for care.

¹⁰ For more information on the certification criteria, visit ONC; for other technical resources that support this priority, visit the Pediatric [Developer IR](#). 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. <https://www.govinfo.gov/content/pkg/FR-2020-05-01/pdf/2020-07419.pdf>





Considerations and Challenges

- Exchange Across Different Encounters and Systems.** Feeding and lactation discussions and documentation may occur during an infant or birthing parent’s clinical encounters, across varied inpatient and ambulatory settings. Bidirectional flow of information [92] or associating or linking birthing parent and infant records may support continuity of care across encounters and settings. There may be different ways that information from a birthing parent or infant record can be shared with or incorporated into the respective birthing parent or infant record. Developers and providers may need to brainstorm where information can be generated and how to associate or link information from the infant and birthing parent’s records. Clinical Priority 10 contains discussion on using Health IT to associate the birthing parent’s health information with the infant.
- Identification of Structured Elements.** The content of lactation or feeding discussions may vary. It may not be necessary nor practicable for all data to be captured in a structured manner, and developers may not know which elements to prioritize. Providers may wish to work with their developers to identify which elements are critical or best practice versus nice to have, so that developers can implement the priority as effectively as possible.
- Lack of Clinical Coding.** Specific clinical codes may not be available to support all lactation and feeding elements of interest. This may lead to inconsistent use in terms and challenges when this information is exchanged electronically. Healthcare providers may need to select standard terms and definitions to use for some elements and ensure that individuals across healthcare settings understand these standard terms. Providers may also wish to work with developers, breast/chest feeding organizations, and other stakeholders to identify standard terms and definitions for clinical elements for future inclusion in standard terminologies.

Suggested Questions for Discussion with Your Health IT Developer:	
Documentation	
<input type="checkbox"/>	<p>What feeding and lactation information can healthcare providers document in a structured format? Examples include but are not limited to:</p> <ul style="list-style-type: none"> • Intent to breast/chest feed • Breast/chest fed at time of birth • Contraindications to breast/chest feeding • Risk factors for feeding difficulties • Completion of a lactation consult • Infant food substance(s) (e.g., parent’s milk, donor human milk, human milk substitute) • Route (s) of feeding (e.g., direct breast, bottle, cup, finger, supplemental nursing system)





Suggested Questions for Discussion with Your Health IT Developer:	
	<ul style="list-style-type: none"> • Reason for other substance or route if other than parent's milk and direct breast • Supplementation, including substance and reason • Exclusively breast/chest fed or formula fed from birth • Lactation supplies • Detailed education and anticipatory guidance components • Infant separation and reason, if applicable • Feeding care plan • Referrals
Assessment Tools	
<input type="checkbox"/>	What feeding assessment instruments does the health IT support? (e.g., LATCH)
<input type="checkbox"/>	Will the Health IT allow healthcare providers to link or auto-populate screening tool results as part of care plan documentation?

Where Can I Find More Information?

- **In LATCH:** a breastfeeding charting system and documentation tool, the authors describe the LATCH tool, which assesses five components of breast/chest feeding: Latch, Audible swallowing, Type of nipple, Comfort level of the parent, and the amount of Help the parent needs to hold the infant to the breast/chest. [83].^{iv}
- In Breastfeeding Measurement in the Outpatient Electronic Health Record: Current Practices and Future Possibilities, County of San Diego Health Works program, April 2016, the authors discuss challenges and current practices for the inclusion of breast/chest feeding measures in outpatient EHRs. [92]
- In Best Practices Guide for Implementation of Newborn Exclusive Breast Milk Feeding in Electronic Health Records: A guide to meaningful capture of Breast Milk Feeding Data for quality measure and designation programs in the United States, the authors describe best practices for supporting exclusive breast milk feeding data documentation, measurement, and reporting in the EHR. [93]
- The Joint Commission Perinatal Core Measure PC-05 Exclusive Breastmilk Feeding assesses the rate of newborns exclusively fed breast milk during the newborn's entire hospitalization; specifications are available at:
<https://ecqi.healthit.gov/ecqm/eh/2021/cms009v9>





PRIORITY 12: DOCUMENT INDIVIDUALIZED NON-PHARMACOLOGIC INTERVENTIONS AND RESPONSE

Description

This clinical priority supports the standardized documentation of non-pharmacologic interventions, including documenting the response to administered non-pharmacologic interventions, such as whether they are effective, ineffective, or associated with an increase or decrease in NAS assessment scores.

Non-pharmacologic interventions are the first-line treatment for infants with NAS and are critical to the clinical management of NAS regardless of an infant's need for pharmacologic interventions. [94, 95] Common non-pharmacologic interventions include: 1) Environment and stimuli control (e.g., room lighting, positioning, rhythmic devices), 2) Feeding methods and practices (e.g., breast/chest feeding, supplementation, caloric fortification), and 3) Social interaction and human touch (e.g., rooming-in, caregiver presence, skin to skin contact, massage). [52] Optimizing non-pharmacologic interventions has been reported to reduce length of hospital stay and need for pharmacologic therapy for infant with NAS. [52]

Non-pharmacologic interventions are tailored to an infant's individual needs based on their signs and symptoms of withdrawal. However, there is limited evidence regarding the efficacy of specific non-pharmacologic interventions, and the approach or use of specific non-pharmacologic interventions may vary across healthcare providers. [2] Standard documentation of use and response to non-pharmacologic interventions supports consistent tracking and facilitates assessment of which interventions should be maximized for each infant with NAS.

How Health IT Supports This Priority

Health IT could potentially support this priority through additional development of existing ONC certification criteria, Children's EHR Format Requirements, and additional functionalities.

ONC Certification Criteria and Data Standard
§170.315(b)(9) Care Plan
Data Standard: USCDI

This certification criterion enables the following functions in support of this priority:

- Document the use of non-pharmacologic interventions in a standardized and structured format.
- Document a patient's response to non-pharmacologic interventions, such as whether they are effective or ineffective.
- Health IT can also include functions that:
- Record parental involvement in the administration of non-pharmacologic interventions to allow healthcare providers to document parent participation and engagement in infant's care.





- Provide a summary to the infant’s care team regarding effective and ineffective non-pharmacologic interventions in the infant’s NAS management.
- Track or trend non-pharmacologic intervention administration and response at an aggregate level to support consistent use and application and expand knowledge regarding the efficacy of specific non-pharmacologic interventions.

Applicable Children’s EHR Format Requirements:
Req-698: Manage Non-Medication Patient Care Orders
Req-569: Support for Non-Medication Ordering

Considerations and Challenges

- **Variation in non-pharmacologic interventions:** The use of specific non-pharmacologic interventions may vary across healthcare providers. Healthcare providers will need to determine which interventions to prioritize for standardized documentation.
- **Lack of clinical coding.** Specific clinical codes may not be available to support all non-pharmacologic interventions. This may lead to inconsistent use in terms and challenges when this information is exchanged electronically. Healthcare providers may need to select standard terms and definitions for non-pharmacologic interventions and ensure that individuals across healthcare settings understand these standard terms. Providers may also wish to work with other stakeholders to identify terms and definitions for future inclusion in standard terminologies.
- **Single vs. bundled non-pharmacologic interventions and response:** Healthcare providers often administer multiple interventions in combination (bundled) rather than independently (single). Healthcare providers may wish to work with developers to address how response will be documented for bundled non-pharmacologic interventions.

Suggested Questions for Discussion with Your Health IT Developer:	
Documentation	
<input type="checkbox"/>	<p>Will the health IT allow healthcare providers to record the administration of each non-pharmacologic intervention? Examples may include but are not limited to:</p> <ul style="list-style-type: none"> • Care clustering (e.g., clinical care assessments during awake times) • Feeding • Holding by parent/caregiver/cuddler • Low stimulation environment (e.g., dim lighting, quiet room, visitor limitation) • Non-nutritive suck (e.g., pacifier or finger) • Parental/Caregiver presence • Positioning Swaddling/Flexed





Suggested Questions for Discussion with Your Health IT Developer:	
	<ul style="list-style-type: none"> • Rhythmic movement gentle rocking/swaying/jiggling • Rooming-in/room-in (infant and birthing parent share a room and remain together 24 hours a day unless separation is indicated for medical reasons or safety concern) • Skin-to-skin contact
<input type="checkbox"/>	Will the health IT allow healthcare providers to record a patient’s response to a non-pharmacologic intervention? What are the response options?
<input type="checkbox"/>	Will the health IT allow healthcare providers to record parental involvement in non-pharmacologic intervention administration?
<input type="checkbox"/>	Will the health IT allow healthcare providers to track/trend non-pharmacologic intervention administration and responses?

Where Can I Get More Information?

- Health IT standards support this priority in general with the FHIR Plan Definition, Care Plan and Nutrition Order resources.
- In Non-Pharmacological care for opioid withdrawal in newborns, a Cochrane meta-analysis noted the lack of an established definition of non-pharmacologic care practices in this population and insufficient evidence to inform specific clinical practices, highlighting a need for more studies. [96]





Appendix A: Background Information and Resources

NAS TOOLKITS

Tools:
<p>The Association of State and Territorial Health Officials (ASTHO)'s Opioid Response Kit provides information on the comprehensive treatment approaches for substance-exposed newborns. https://www.astho.org/Programs/Prevention/Injury-and-Violence-Prevention/Prescription-Drug-Misuse-and-Abuse/PRDOH-Neonatal-Abstinence-Syndrome-Toolkit-English/</p> <p>ASTHO's Community Health and Prevention Team provides guidance on innovative approaches to treating neonatal abstinence syndrome, including focusing on educating and empowering mothers and other caregivers to be more involved in managing their infants' withdrawal symptoms. https://www.astho.org/StatePublicHealth/Innovative-Approaches-to-Treating-Neonatal-Abstinence-Syndrome/7-31-18/</p>
<p>The National Center on Substance Abuse and Child Welfare's Opioid Safety Toolkit builds awareness for the need for emerging models for treating babies born with NAS (as compared to the current standard of care). The implementation of new treatment approaches hinge on the ability for facilities to provide trainings and technical assistance to clinical staff and provide data to support measurement of outcomes. https://www.chcf.org/wp-content/uploads/2019/02/EmergingTreatmentOptionsNAS.pdf</p>
<p>The American Academy of Pediatrics has engaged a national effort to empower and educate providers about NAS, #NavigatingNAS Campaign, which will provide resources and education materials for clinical practice and families. https://services.aap.org/en/news-room/campaigns-and-toolkits/neonatal-abstinence-syndrome/</p>

FHIR

What is HL7 FHIR?

FHIR 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 through health IT 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



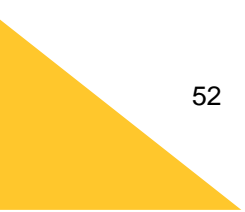


team members, patient demographics, family health history, problems, and medications. FHIR is also the underlying standard that supports the secure exchange and use of information in novel health care applications. These applications (apps) can give providers and patients secure access to their health information from various health care systems, such as when a patient sees a number of 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:
<p>ONC “What is FHIR” Fact Sheet https://www.healthit.gov/topic/standards-technology/standards/fhir-fact-sheets</p>
<p>HL7 FHIR Overview (an overview of FHIR written for clinicians) https://www.hl7.org/fhir/overview-clinical.html</p>
<p>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? https://healthitanalytics.com/news/4-basics-to-know-about-the-role-of-fhir-in-interoperability</p>
<p>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</p>

Substitutable Medical Apps, Reusable Technology (SMART® <https://smarthealthit.org/>) 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 developed using the Fast Healthcare Interoperability Resources (FHIR) standard. If your EHR system or data warehouse supports the SMART standard, you can draw on this library of apps. SMART on FHIR apps (<https://apps.smarthealthit.org/>). The SMART app gallery also has a section on FHIR Tools (<http://apps.smarthealthit.org/apps/category/fhir-tools>).

Suggested Questions for Discussion with Your Health IT Developer:	
<input type="checkbox"/>	What health care needs are being served with FHIR or other standards? What functionalities are being planned?
<input type="checkbox"/>	What health care standards is my organization implementing? Does that include FHIR?
<input type="checkbox"/>	Can I provide feedback to my health IT developer on how certain functions are working or could be improved?
<input type="checkbox"/>	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. [97]

How do apps access health care data?

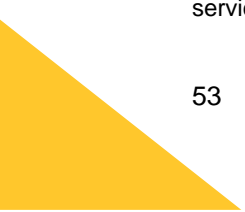
Apps can access data through APIs. APIs are the mechanism that allows software programs to communicate with one another. If you have ever used a web-based application or a mobile “app” on a device to purchase a flight or pay a bill, you’ve probably used an API. If you install an app (e.g., for CDS) that was developed by someone other than your health IT developer, the app will need to use an API to access and use data in your EHR. Likewise, your 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#api-module>) provides a basic overview of how APIs work.

How do apps improve pediatric care?

Apps and APIs may help health care professionals improve or simplify care delivery. For example, a clinician could use an app specifically designed for pediatric care to automatically perform detailed data analysis during regular checkups and provide instant feedback to the parents on the child’s health.¹¹

¹¹ The American Academy of Pediatrics has a forthcoming policy statement and technical report on web services/web applications in pediatric care.





Considerations for Discussions with Health IT Developers

Discuss with your health IT developer whether apps can be incorporated into your EHR or other health IT systems.

Suggested Questions for Discussion with Your Health IT Developer:	
<input type="checkbox"/>	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?
<input type="checkbox"/>	What apps are being used or developed in my health care organization? What health care needs do these apps provide or serve?
<input type="checkbox"/>	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?
<input type="checkbox"/>	What apps are available through my health IT developer? Do the apps available relate to the 12 priorities presented in this IR?
<input type="checkbox"/>	What apps are available that I would like my health IT developer to incorporate into my EHR?
<input type="checkbox"/>	What is the data capacity for data calls using APIs?
<input type="checkbox"/>	What are the API privacy and security protocols being used or planned?
<input type="checkbox"/>	How will the use of apps affect clinical workflow?
<input type="checkbox"/>	Am I able to customize the app to meet my unique needs?

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 be subject to the protection of the HIPAA Rules.

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

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. [98] 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 provider and patient satisfaction. [32]

Considerations for Discussions with Your Health IT Developer

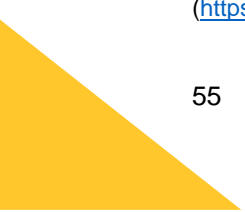
With your clinical expertise as well as your knowledge of your practice's clinical workflow, you can work with your health IT developer to determine whether a particular CDS tool will work in your care setting. Consider whether certain clinical practice guidelines and recommendations could form the basis for CDS tools in your practice.¹²

Some issues you can consider when working with your health IT developer around CDS include:	
<input type="checkbox"/>	What are the clinical recommendations for pediatric care underlying a CDS tool?
<input type="checkbox"/>	Where in the clinical workflow can CDS tools have impact?
<input type="checkbox"/>	Are there priority health issues in your care setting where CDS tools can assist?
<input type="checkbox"/>	What are the tradeoffs to the current workflow of introducing a CDS tool? Will there be disruption to clinical workflows?
<input type="checkbox"/>	Are there existing examples of successful CDS tools used in pediatric care settings you can adopt?
<input type="checkbox"/>	How will providers be trained on CDS tools and proper clinical protocol?
<input type="checkbox"/>	How can you evaluate the effectiveness of CDS tools on quality of care, health outcomes, and provider and patient satisfaction?

CDS Resources

Below, you will find a list of general resources related to the use of CDS tools that may be applicable to any of the priorities in this IR and additional areas in which CDS could be implemented.

¹² For example, Bright Futures, Guidelines for the Health Supervision of Infants, Children, and Adolescents (https://www.aap.org/en-us/Documents/periodicity_schedule.pdf).





Resource	Description
<p>Human Factors Guide to Enhance EHR Usability of critical user interactions when supporting pediatric care (NISTIR 7865)</p>	<p>Pages 20-21 contain recommendations for improving the effectiveness of alerts, reminders, and warnings for pediatric settings, including recommendations that:</p> <ul style="list-style-type: none"> • Support flexibility in unit-based settings for alarms, warnings, and alerts based upon weight and age; • Ensure that adult-based thresholds do not replace pediatric-specific thresholds following a system-wide crash; • Prohibit “hard stops” for changes to medication orders; • Cap a dose at the standard adult dose but allow an override if justification is provided; • Display normal ranges for medication doses and lab values based upon weight and age information; and • Display parameters together that are continuously monitored to facilitate rapid interventions. <p>https://nvlpubs.nist.gov/nistpubs/ir/2012/NIST.IR.7865.pdf</p>
<p>CDS Hooks</p>	<p>An HL7 published specification for clinical decision support. CDS Hooks aims to help providers determine which applications are helpful at a certain point in their workflow. An event triggered by the provider’s EHR invokes a third-part CDS system that can then provide information to the EHR. https://cds-hooks.hl7.org/</p>
<p>Optimizing Strategies for Clinical Decision Support</p>	<p>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. https://www.healthit.gov/sites/default/files/page/2018-04/Optimizing_Strategies_508.pdf</p>
<p>ONC Safety Assurance Factors for EHR Resilience (SAFER) Guides</p>	<p>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. https://www.healthit.gov/topic/safety/safer-guides</p> <p>Providers may want to consider in particular the SAFER Guide on Computerized Provider Order Entry with Decision Support. https://www.healthit.gov/sites/default/files/safer/guides/safer_cpoe.pdf</p>



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 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

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. [99, 100] 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.





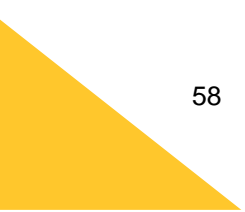
What health IT tools and approaches help address pediatric privacy concerns?

Privacy and Security Certification Criteria in the 2015 Edition

Criteria	Description
<u>§170.315(d)(1)</u>	<u>Authentication, access control, authorization</u>
<u>§170.315(d)(2)</u>	<u>Auditable events and tamper-resistance</u>
<u>§170.315(d)(3)</u>	<u>Audit report(s)</u>
<u>§170.315(d)(4)</u>	<u>Amendments</u>
<u>§170.315(d)(5)</u>	<u>Automatic access time-out</u>
<u>§170.315(d)(6)</u>	<u>Emergency access</u>
<u>§170.315(d)(7)</u>	<u>End-user device encryption</u>
<u>§170.315(d)(8)</u>	<u>Integrity</u>
<u>§170.315(d)(9)</u>	<u>Trusted connection</u>
<u>§170.315(d)(10)</u>	<u>Auditing actions on health information</u>
<u>§170.315(d)(11)</u>	<u>Accounting of disclosures</u>
<u>§170.315(d)(12)</u>	<u>Encrypt authentication credentials</u>
<u>§170.315(d)(13)</u>	<u>Multi-factor authentication</u>

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. [7] 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. [101] 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. [72] Tagging of documents is not a fully automated segmentation of the record but rather a first, technological step or tool to support providers to replace burdensome manual processes for tagging sensitive information. Specific policies and constraints can then determine data segmentation for tagged sensitive information.





Consent

While considered by many to be immature and 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. [102]
- ONC's Health Information Technology page under Patient Consent for Electronic Health Information Exchange provides information on capturing and maintaining consent decisions. <https://www.healthit.gov/topic/health-information-technology>
- ONC's 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. https://www.healthit.gov/sites/default/files/privacy-security/ecm_finalreport_forrelease62415.pdf
- 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 health care 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. 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 providers to deliver health care on a confidential basis to minors covered as dependents on a family's health insurance plan. [103]

General Privacy Resources

Below, you will find a list of general resources 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. <https://pediatrics.aappublications.org/content/130/5/987>
- 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. <https://pediatrics.aappublications.org/content/144/1/e20191359>





AAP offers other resources that can assist 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. <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/adolescent-sexual-health/Pages/Confidential-Health-Care-Services.aspx>

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. https://www.healthit.gov/sites/default/files/page/2019-07/2019-06-03_All%20FINAL%20HITAC%20NPRM%20Recs_508-signed.pdf

Considerations for Discussion with Health IT Developers	
<input type="checkbox"/>	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)?
<input type="checkbox"/>	What is the current standard of practice for getting patient consent?
<input type="checkbox"/>	Does my organization offer patients electronic means of accessing patient health information? How is consent for access of health information obtained?
<input type="checkbox"/>	Are electronic data segmentation and consent management tools being used or planned in my care setting?
<input type="checkbox"/>	What approaches can be taken to minimize privacy risks as the use of health IT tools to share health information increases?
<input type="checkbox"/>	If apps are being used, what are the privacy and confidentiality risks of using apps in providing health care?
<input type="checkbox"/>	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?
<input type="checkbox"/>	Are there billing and health care claims processing concerns to be addressed with the use of health IT tools?

Privacy Resources Discussed Further with Specific Priorities:

We also refer you to the following priority which features specific resources relevant to the functionalities discussed here:

[Priority 6: Transferrable access authority](#)





Appendix B: General Resources

In addition to the resources and information contained in this NAS IR, 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 infants with NAS:

Resource	Description
<p>Human Factors Guide to Enhance EHR Usability of critical user interactions when supporting pediatric care (NISTIR 7865)</p>	<p>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. https://www.nist.gov/publications/nistir-7865-human-factors-guide-enhance-ehr-usability-critical-user-interactions-when</p>
<p>Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, 4th Edition</p>	<p>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 priorities outlined in this informational resource. https://brightfutures.aap.org/Pages/default.aspx</p>
<p>ONC Health IT Certification</p>	<p>The Office of the National Coordinator for Health Information Technology (ONC) Health IT Certification Program (Program) is a voluntary certification program established by the Office of the National Coordinator for Health IT to provide for the certification of health IT. Requirements for certification are established by standards, implementation specifications and certification criteria adopted by the Secretary. The Program supports the availability of certified health IT for its encouraged and required use under other federal, state, and private programs. The Program is run as a third-party product conformity assessment scheme for health information technology (health IT) based on the principles of the International Standards Organization (ISO) and International Electrotechnical Commission (IEC) framework. https://www.healthit.gov/topic/certification-ehrs/certification-health-it</p>
<p>Certified Health IT Product List (CHPL) (ONC)</p>	<p>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. https://chpl.healthit.gov/#/search</p>





Resource	Description
<p>Children’s EHR Format (AHRQ)</p>	<p>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 [104] (2014) and incorporates the HL7 Child Health Functional Profiles [12] (2008) to help bridge the gap between functions present in most EHRs, and functions that would provide optimal support for the care of children. https://ushik.ahrq.gov/mdr/portals/cehrf?system=cehrf</p>
<p>Core Functionality in Pediatric Electronic Health Records (AHRQ)</p>	<p>AHRQ developed this technical brief (2015) on the state of practice and the current literature around core functionalities for EHRs supporting the care of children. The brief describes current practice and provides a framework for future research. https://www.ncbi.nlm.nih.gov/books/NBK293626/</p>
<p>EHR Contracts Untangled: Selecting Wisely, Negotiating Terms, and Understanding the Fine Print (ONC)</p>	<p>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 plan for the purchase of an EHR system and negotiate key terms with their health IT developers. https://www.healthit.gov/sites/default/files/EHR_Contracts_Untangled.pdf</p>
<p>EHR Selection, Purchasing & Implementation Resource Sets (HITEQ)</p>	<p>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). http://hiteqcenter.org/Resources/EHR-Selection-Implementation</p>
<p>Electronic Health Records for Pediatricians: A Shopper’s Guide (AAP)</p>	<p>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. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Informatics/Pages/ehrs-for-pediatric-care.aspx</p>
<p>Health IT Playbook (ONC)</p>	<p>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. https://www.healthit.gov/playbook/</p>
<p>Pediatric Aspects of Inpatient Health Information Technology Systems (AAP)</p>	<p>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</p>



Resource	Description
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. https://www.healthit.gov/isa/
Social Determinants of Health (ONC)	Many of the pediatric health IT priorities in this document involve aspects of social determinants of health. In certain priorities, 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. https://www.healthit.gov/topic/health-it-health-care-settings/social-determinants-health






Appendix C: Acronym Definitions

AAP	American Academy of Pediatrics
AHRQ	Agency for Healthcare Research and Quality
API	Application Programming Interface
BMI	Body Mass Index
CDA	Clinical Document Architecture
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
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
ONC	Office of the National Coordinator for Health Information Technology
SAFER	Safety Assurance Factors for EHR Resilience
SAMHSA	Substance Abuse and Mental Health Services Administration





ONC ONC Health IT for the Care Continuum Pediatric Health Information Technology:
Neonatal Abstinence Syndrome Informational Resource

SMART® Substitutable Medical Applications, Reusable Technologies

SNOMED Systematic Nomenclature of Medical Terminology

STEPStools Safety Through Enhanced e-Prescribing Tools

WHO World Health Organization



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