

Draft Technical Brief

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Core Functionality in Pediatric Electronic Health Records

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy, or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome comments on this Technical Brief. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the technical brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The Task Order Officer and the Evidence-based Practice Center work to balance, manage, or mitigate any conflicts of interest.

The list of Key Informants who participated in developing this report follows: [REDACTED]

Peer Reviewers

Prior to publication of the final evidence report, the EPC sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report does not necessarily represent the views of individual reviewers.

Peer Reviewers must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

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Structured Abstract

Background. Clinicians, informaticians, policy makers, and professional organizations such as the American Academy of Pediatrics have described the need for electronic health record (EHR) systems and information technology tools that better support pediatric health care through the availability of pediatric functionalities. The Model Pediatric EHR created over 700 requirements pertaining to pediatric functionality. While the report was exhaustive, the large number of requirements as well as the lack of prioritization may have had a paralyzing effect on vendors, who, confronted with Meaningful Use requirements, did not leverage the format to improve their products.

Purpose. A Technical Brief is a report of an emerging intervention for which there are limited published data and too few completed research studies to support definitive conclusions. The goals of the Technical Brief are to provide an objective description of the state of the science, identify a potential framework for assessing the applications and implications of the intervention, summarize ongoing research, and present research gaps. We developed a technical brief on the state of practice and the current literature around core functionalities for pediatric electronic health records to describe current practice and to provide a framework for future research.

Methods. We had conversations with Key Informants representing clinicians, policy experts, and researchers. We searched online sources for information about currently available programs and resources. We conducted a literature search to identify currently available research on the effectiveness of individual functionalities.

Findings. There is expert consensus in the literature that EHRs used in the care of children require specific functionalities to support the work of child health care providers and assure the delivery of quality care to pediatric patients. These functionalities relate to a child's evolving physiology and maturity and associated conditions. Key areas include vaccination, development, physiologic medication dosing, pediatric disease management, pediatric norms, and the relationship between pediatric patients and their caregivers, including adolescent privacy. Empirical evidence for health outcomes associated with the introduction of a pediatric EHR or for implementation of systems such as clinical decision support is largely limited to pre-post studies on a subset of important functionalities. Key Informants indicated that if these functionalities are implemented well, the EHR will also better support the care of all patients.

Summary and Implications. While many of the key functionalities identified in this brief are not purely pediatric, their key role in the care of children in contrast to their minimal role for adults could mean they can get overlooked in an EHR designed primarily for adult care. Incentives for developing pediatric functionalities for EHRs are currently driven by 1) meaningful use requirements and the patient-centered medical home; 2) a desire to support and maintain patient safety; and 3) the increasing presence of pediatric-specific clinical quality measures. Introducing a new pediatric functionality to an EHR should, therefore be done thoughtfully and ideally is done in consideration of utility, testability, and usability principles. Understanding the importance of computability and specificity of guidelines as well as motivations for development pediatric-specific functionalities provides further insight into how dissemination and development will be driven in the future.

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Background

Clinicians, informaticians, policy makers, and professional organizations such as the American Academy of Pediatrics (AAP) have described the need for electronic health record (EHR) systems and information technology tools that better support pediatric health care through the availability of pediatric functionalities.¹⁻³ In particular, they suggest that EHRs used in the care of children may increase patient safety through standardization of care and reducing error and variability in documentation and communication of patient data.⁴⁻⁹ However, adoption has lagged, and lack of pediatric functionality is often cited as a reason for the lower rates of adoption in pediatrics.^{10,11} Furthermore, while EHRs may improve safety, implementation of generic EHR systems that do not meet pediatric functionality and work flow demands could be potentially dangerous.¹²⁻¹⁵

Empirical data describing the benefits of pediatric EHRs are scarce, and few studies have been conducted in the pediatric setting to assess the potential benefits of pediatric functionalities, though a few studies have described improvements in immunization rates,^{8,16,17} attention-deficit/hyperactivity disorder care,¹⁸ preventive care counseling for children and adolescents,^{19,20} and hepatitis C status follow-up in infants.²¹ Ultimately, available research on outcomes has yielded inconsistent results, potentially due to great variety and variability of systems reviewed.²²⁻⁴⁴

While the Health Information Technology for Economic and Clinical Health (HITECH) Act has promoted adoption of EHRs by providers and hospitals, development and implementation of functionality to promote quality of pediatric care specifically has been inconsistent, even among supporters of EHR implementation.⁴⁵ Organizations including the Agency for Healthcare Research and Quality (AHRQ),⁴⁶ Health Level 7 (HL7) International,⁴⁷ and the AAP³ have attempted to achieve consistency by describing data formats and desired functionalities for use across pediatrics EHRs. Developed by AHRQ and CMS, the Children's EHR Format is particularly focused on the needs of children enrolled in Medicaid or the Children's Health Insurance Program (CHIP).⁴⁶

The question arises, however, in the face of several recommended core sets of functionalities for pediatric EHRs, which are truly essential. A 2007 AAP report noted immunization management, growth tracking, medication dosing, patient identification, data norms, terminology, and privacy as important concerns/requirements for EHR in pediatric populations.⁴⁸ Recent recommendations from the Society for Adolescent Health and Medicine also urge that EHR designs take into account "the special needs of adolescents for access to health information and the vigorous protection of confidentiality" and note that EHR developers should ensure that systems meet regulatory requirements and privacy needs.²² These various recommendations may be based on a range of empirical or other evidence.

Despite lack of consistent recommendations, "Meaningful Use" incentives associated with the HITECH Act have resulted in increased implementation and use of EHRs by pediatricians.⁴⁹ It is unclear whether pediatricians are adopting pediatric-specific tools, however. For example, suggested minimum requirements for a "pediatric-supportive" EHR include well-child visit tracking, support for anthropometric analysis such as growth charts, immunization tracking and forecasting, and support for weight-based drug dosing.^{48,50} Only 31 percent of pediatricians use

an EHR with basic functionality, and only 14 percent use a fully functional¹ EHR.⁵¹ Only 8 percent of pediatricians are using a fully functional EHR with pediatric functionality.⁵²

The Model Pediatric EHR created over 700 requirements pertaining to pediatric functionality. While the report was exhaustive, the large number of requirements may have had a paralyzing effect on vendors, who, confronted with Meaningful Use requirements, did not leverage the format to improve their products. Reports from CHIPRA D grantees indicate that vendors used a survey-based prioritization approach to identify items of high value to pediatrician and to add these items to their EHR design.⁵² Similarly, the HL7 requirements include over 100 unique pediatric items.

Scope

Issues and Challenges in the Evidence Base

A significant challenge in this brief is the breadth of pediatric practice, including subgroups and special populations requiring specific elements of care that may merit specific EHR functionalities, all of which may diffuse agreement on key pediatric EHR features. Pediatric patients may range from a few hundred grams to hundreds of pounds in weight and their developmental status changes from completely dependent and helpless to independent, mature individuals. While adult patients remain fairly static over time, the work of a pediatric provider includes monitoring of change and to assure that change occurs at the right pace and right time.⁵³

Another challenge is that requirements and EHRs for inpatient and outpatient settings may differ based on the work performed and be represented differently in the literature. Similarly, individual reports may address specific elements of EHRs such as order entry or electronic prescribing. Stakeholder groups such as the AAP have published numerous position papers and recommendations, which will provide important themes and crosscutting approaches. As expected given the relatively recent increase in adoption of pediatric EHRs and the significant costs of implementing them, few controlled trials of their effects exist, and the field is developing rapidly. Data are not available uniformly across categories of care or functionalities. We will focus on the functionalities, needs, and desiderata uniquely relevant to pediatric care that extend beyond those functionalities available for adult care. Some functionality required for pediatric care is also critical for aspects of adult care, and we will include those critical features (e.g., immunization tracking, which is a key aspect of children's care as well as that of pregnant women).

Technical Brief Objectives

A Technical Brief is a rapid report of an emerging intervention for which there are limited published data and too few completed research studies to support definitive conclusions. The goals of the Technical Brief are to provide an objective description of the state of the science,

¹ During 2007-2009, NAMCS defined a fully functional EHR system as having all 14 functionalities in basic systems plus the following additional features: 1) medical history and follow-up notes; 2) drug interaction or contraindication warnings; 3) prescriptions sent to pharmacy electronically; 4) computerized orders for lab tests; 5) test orders sent electronically; 6) providing reminders for guideline-based interventions; 7) highlighting out-of-range lab values; 8) computerized orders for radiology tests.

American Hospital Association administered survey on EHR adoption defines comprehensive EHR to include the basic EHR core functionalities plus 14 additional functionalities implemented across all units (see Nakamura et al., 2013 and Jha et al., 2009).

identify a potential framework for assessing the applications and implications of the intervention, summarize ongoing research, and present research gaps. A technical brief is not intended to be a comprehensive systematic review but should provide the reader with an overview of available research, practice and to some degree, perspective, around a given clinical intervention.

This report describes the state of the literature on pediatric EHR functionality and their effects on outcomes of pediatric EHR implementation. We sought comparative studies that assessed the potential benefits of pediatric EHR use. We searched published reports and grey literature sources to ascertain the evidence for pediatric-specific EHR functionalities. In addition, we engaged stakeholders to augment the findings from the literature, and inform the summary of contextual issues, barriers, and potential challenges.

Report Organization

We have organized the report by Guiding Question and have summarized the available literature and Key Informant perspectives. Guiding Questions 1, 2 and 4 reflect information found in published and unpublished literature, including opinion pieces and general materials. They also include the perspectives of our Key Informants. Guiding Question 3 is limited to a high-level evidence map of empirical studies. Thus, Guiding Questions 1 and 2 lay out the issues that were found to be of highest relevance, while Guiding Question 3 identifies the available empirical literature on those issues. Guiding Question 4 then addresses challenges and opportunities related to implementation and dissemination.

Guiding Questions

GQ1. Description of pediatric-specific functionalities for EHRs

GQ1A: Are there functionalities that have been identified in the literature and feature more prominently than others as potentially important to achieve for improving children's health?

GQ2. Description of the context in which EHRs are implemented

GQ2A: What is the potential value of pediatric-specific functionalities in the context of care transition, specifically from newborn care to pediatric primary care, from pediatric primary care to pediatric specialist care, and from pediatric primary care to adolescent care?

GQ2B: Are certain pediatric-specific functionalities beneficial for a pediatrician to conduct her work including sick and well-child visits? If so, does this vary by health care setting (e.g. primary care office, specialty care office, school health, and alternative care settings) or by type of visit (e.g., preventive vs. acute care)?

GQ2C: What are the challenges to implementing specific functionalities? Are some harder than others to implement by a) vendors; and/or b) pediatric providers?

GQ3. Description of the existing evidence

GQ3A: Is there any evidence that using an EHR adapted for the specific needs of pediatric providers compared with using a "regular" EHR or not using an EHR at all produces a) better quality, including safety and cost outcomes for patients; and/or b) improved workflow or job satisfaction for providers?

GQ3B: Which pediatric-specific functionalities influence a) patient outcomes (including safety; quality; cost; equity; standardization of care; and/or efficiency); b) the ability of a pediatric provider to conduct work within the EHR; c) improvement of workflow and provider

satisfaction; and/or d) involvement of patients and families (including their education and shared decision making)?

GQ4. Dissemination and future developments

GQ4A: How does testability and usability of core functionalities promote or impede dissemination and future development of pediatric EHRs?

Methods

We used discussions with Key Informants, a search of the gray literature, and a search of the published literature to collect relevant data and descriptions.

Data Collection

Discussions with Key Informants

We engaged Key Informants to offer insight into pediatric-specific functionalities for electronic health records, and suggest issues of greatest importance to clinicians, patients, researchers, and payers. We searched the Web sites of relevant professional organizations and research and policy groups to identify stakeholders whose work or interests indicate a high likelihood of interest and expertise in the topic.

In consultation with the investigative team and the Agency for Healthcare Research and Quality (AHRQ), we assembled a list of individuals representing a clinical, policy, research, or vendor perspective. Seven of ten invited individuals agreed to participate. Following approval by AHRQ of the completed Disclosure of Interest forms for proposed Key Informants, we conducted discussions with Key Informants, representing clinicians in practice as well as in policy roles in addition to accomplished researchers.

We conducted three group discussions by telephone with Key Informants. We invited the Key Informants to share their experiences and make suggestions to address the proposed Guiding Questions. Before the call, we provided the participants with a copy of the protocol and Guiding Questions. We recorded and transcribed the call discussion and generated a summary that we distributed to call participants.

We used the input from the Key Informants to establish functionalities considered to be of highest importance and weighed those against what we found most commonly in the literature. Ultimately, the data presented represent a Venn diagram of Key Informant input, functionalities identified in the literature and those described both by Key Informants and in the literature.

The Key Informants represented vendors, practicing pediatrician, quality improvement, public health, academic research. More details on the Key Informants and the discussions are in Appendix B and Appendix C.

Published Literature Search

We used a combination of controlled vocabulary terms and keywords to search the published literature for studies that specifically evaluated electronic health records in the pediatric health care setting. We used terms for electronic health records, computerized physician order entry (CPOE) and clinical decision support (CDS), as well as broad terms and descriptors for pediatrics. We searched the literature base from 1999 on. We reviewed the reference lists of retrieved publications for other potentially relevant publications missed by the search strategies. We present the literature search details in Appendix A. We screened the included literature for publications that addressed one or more Guiding Questions; we further evaluated the publications for evaluation studies that met prespecified criteria (Table 1) for Guiding Questions 3 (Evidence Map).

To identify newly published relevant literature, we will update the literature search during peer review and the posting period for public comments. We will incorporate the results from the literature update into the Technical Brief.

We developed forms (Appendix D) for screening and data collection from the published literature. We recorded the study design and study populations from relevant sources. We document reasons for exclusion of records that were promoted for full text review (Appendix H).

Table 1. Inclusion and exclusion criteria for evaluation studies

Category	Criteria
Study population	Pediatric, outpatient
Publication languages	English only
Admissible evidence	<p><u>Study design</u></p> <p>Randomized controlled trials, including wait-list control, cohorts with comparison, pre-post cohort without comparison, stepped wedge designs, and case-control.</p> <p><u>Outcomes</u></p> <ul style="list-style-type: none"> • Healthcare quality including safety and cost • Improved workflow • Job satisfaction for providers • Patient outcomes including safety, quality, cost, equity, standardization, efficiency • Patient and family involvement including education and shared decision making <p><u>Other criteria</u></p> <p>Original research studies that provide sufficient detail regarding methods and results to enable use and adjustment of the data and results.</p>

Gray Literature Search

We augmented the searches we conducted in bibliographic databases by searching for gray literature. Examples of sources of gray literature include the Internet, government Web sites, clinical trial databases, trade publications, and meeting abstracts. We crosschecked the findings from the gray literature searches against the literature retrieval for publications that we may have missed in the literature searches.

We searched relevant professional association and organization Web sites, as well as state and federal government Web sites descriptions or links to existing models. We present a summary of gray literature sources in Appendix E. We retrieved records from ClinicalTrials.gov to identify ongoing research (Appendix G).

In addition to the evaluation information from the indexed literature, we catalogued relevant pediatric-specific EHR resources, programs, and projects that we identified from gray literature sources. Finally, to glean insight into the issues and concerns of users of pediatric EHRs, we collected the comments submitted by pediatric providers who reviewed their own EHR systems on the AAP website and summarized those by functionality (User Perspective).

Data Organization and Presentation

We summarize information extracted from the published and gray literature in the results and discussion of this report. We identified themes from expert input and describe the findings from the literature, Key Informant discussions, and gray literature for each theme for Guiding Question 1. In Guiding Question 2, we address contextual issues including transition of care, health care setting, and implementation considerations from the literature base and the Key Informant input. For Guiding Question 3, we summarized existing systematic reviews and original research published since the end date of the systematic reviews. We present summary tables and text to characterize the existing evidence for pediatric-specific EHRs (Guiding

Question 3). We highlight the roles of testability and usability in the successful dissemination and future development of pediatric-specific EHRs in Guiding Question 4.

Based initially on key information input and with confirmation from the literature, we organize the report around eight categories for the pediatric functionalities: 1) vaccines; 2) development; 3) privacy; 4) managing pediatric populations; 5) medications and CPOE; 6) documentation and billing; 7) pediatric specific norms and growth charts; and 8) family dynamics;.

Peer Review

A draft of this Technical Brief will be posted to the AHRQ Web site for 4 weeks for public comments. During this time, the Scientific Resource Center distributes the draft report to individuals who agreed to serve as peer reviewers. The Scientific Resource Center collects the feedback from peer reviewers and forwards the compiled comments to report authors. We will review the comments and made appropriate changes to the final report.

We will document the report revisions and provide a summary of responses to the individual comments received from public and peer reviewers in a disposition of comments table. The disposition of comments table will be available on the AHRQ Web site after publication of the final Technical Brief Report.

Findings

In this section, we summarize information from the published and gray literature sources to address Guiding Questions 1–4. Much of the discussion with Key Informants was consistent with the salient topics that emerged from the body of literature, focusing primarily upon vaccination, growth and development, family dynamics and privacy challenges, medication ordering, and pediatric growth and development norms.

We summarize Key Informant discussion, the literature, and user feedback from the American Academy of Pediatrics (AAP) pediatric EHR review site to describe pediatric specific functionalities and current approaches for improving pediatric health care and delivery (Guiding Question 1). In Guiding Question 2, we provide a discussion of transition, care setting, and other contextual issues important to the implementation and adoption of pediatric-specific functionalities described in Guiding Question 1. The results presented in Guiding Question 3 are the combined summary of existing evidence from the published literature. We present implications and areas for future research in Guiding Question 4.

GQ1: Description of pediatric-specific functionalities for EHRs

GQ1A. Are there functionalities that have been identified in the literature and feature more prominently as potentially important to achieve for improving children’s health?

Pediatric-specific EHR functionality

The Key Informants on this project were clear and consistent that EHRs need to be optimized for the care of children, and that this is not yet happening. Key Informants noted that many functionalities overlap with adult care, but agreed that given the nuances associated with longitudinal and coordinated care for the pediatric population, some functionalities will be more critical than in adults to ensuring high quality and safe care. For example, while care coordination for adults is extremely important, effective coordination for children is prone to compromise if there are delays in information exchange or inaccuracies in patient identification or family relationships. Patient identification is a similarly critical issue given changes such as the ongoing evolution of family structure, the impact of family dynamics, changes in identifiers (e.g., unnamed child in newborn nursery), and issues that arise in foster care. These issues of identity have downstream effects on understanding family history, the impact of the family setting on the child’s wellness, privacy and information sharing, and payment for services.

Underlying many Key Informant comments was the importance of a flexible, longitudinal record that integrates critical information about the child, the family and family history as it affect health, capabilities tailored to the needs of the clinician treating the child, and agile information display that shows the right information at the right time, despite the high volume nature of pediatrics. Moreover, Key Informants emphasized that effective systems must be adapted seamlessly to the user workflow and be customizable to adapt easily to changes in practice.

The functionalities identified and described in this section are those that the Key Informants noted as both most important and specific to the pediatric environment and that featured

prominently in the published literature. That said, it should be noted that few of the functionalities have been studied empirically for their independent contribution to outcomes. The empirical data, where it exists, appears in the responses to Guiding Questions 3.

Vaccines

Summary of Recommended Functionalities and Issues Identified by Key Informants

Vaccine-related functionality is consistently identified as a core need for EHRs used in the care of children. Key Informants viewed this functionality as a necessity, and felt that it was well established as a need for pediatric EHRs due to its prominence both in public and personal health. They noted that while vaccine provision is important also in other age groups (e.g. influenza vaccine for the general population, shingles for the elderly), in no other age groups are as many vaccines recommended on as complex a schedule. Nor are there other age groups in which vaccine receipt is as tied to public health protection, including herd immunity, and to milestones, such as school entry.

As noted by the Key Informants, the EHR has the potential to provide a means of documenting vaccine receipt, forecasting, and reminding clinicians when vaccines are due and managing populations at particular risk of poor outcomes without vaccination. Decision support within the EHR can include identification of combinations of vaccines that can provide the greatest protection with the fewest inoculations. The vaccination record is required at multiple times in a child's life, including school and camp entry, all the way to adulthood. Therefore, Key Informants noted that the vaccination component of an EHR needs to be easily updated and displayed in a way that can be shared with families and the educational system.

Summary of Recommended Functionalities and Issues Identified in the Literature

Efficient recording of vaccine data

Examples of mechanisms to improve vaccine documentation efficiency include standard and 2D barcode technology and use of point of care documentation (using for example mobile devices) and may have varying levels of technological complexity. One approach, for example, to easily and accurately tracking vaccine lots, has been to incorporate bar code technology into the system.⁵⁵

Clinical decision support

Decision support that focuses on immunization forecasting, the ability to identify individuals eligible for vaccination and appropriate vaccinations, is commonly discussed, both in the published literature and among our Key Informants, and it is generally acknowledged to be a core element of a pediatric EHR.⁵⁶ While targeting a "captured audience" - patients presenting to an outpatient clinic - did not significantly improve immunization rates⁸

In several empirical studies, further described in Guiding Question 3, clinical decision support (CDS) has been associated with significant increases in appropriate vaccinations. For example, one study reported an increase in flu vaccine rates from 7.8 percent to 25.5 percent after implementation of decision support in an EHR,⁵⁷ and another reported an increase not only

in immunization rates, but also in the ordering of several other screening tests, suggesting a potential spillover effect.⁵⁸

Immunization status

There are two fundamental types of medical error that occur in the context of vaccination: missed opportunities to vaccinate (failure of omission) and incorrect vaccination (failure of commission). Clinical decision support in the context of vaccines in the EHR is designed to minimize or avoid both of these by assessing a child's immunization status as recorded in the EHR, and ideally, incorporating data from immunization registries when available.⁵⁹ In order to achieve these basic goals, a system must be able to distinguish not only which patient is up to date on vaccinations and which patient is not, but also in the interest of reporting quality measures which patient is late or overdue on their immunizations. It is important to note, however, that vaccine requirements may not be consistent across jurisdictions and being eligible for an immunization may not necessarily indicate that the current time is the best time to immunize. Therefore, a number of experts have recommended some flexibility in the forecasting functionality to allow compliance with local, state, or federal guidelines in cases where the guidelines do not reach agreement or in situations where delaying immunization in an eligible child will result in better immune responses.

Flexibility of formats to promote data sharing

Flexibility in vaccine information formatting is a core need in order to efficiently share records as needed with a school, parent, physician, or registry.⁵⁴ Pediatric EHRs need to interact with state-level immunization registries to support the public health activities of the state, and as such, must have functionality to exchange data with those electronic systems. Some immunization registries, in turn, feed information back into the EHRs and provide forecasting and reminders to ensure up to date status of the pediatric patients.⁵⁴ At a minimum, an EHR must permit the clinician to enter data on vaccinations that occurred at other institutions in order to maintain a complete record. Printouts of the immunization record would ideally incorporate data from all sources.⁵⁶ One recommendation has been that a flow sheet incorporated into the system provide additional information on recent or anticipated immunizations,¹¹ thus providing additional tracking.

User Perspective

Comments on functionality related to vaccinations were common on the AAP EHR review website, accounting for about 20 percent of comments. Although many providers were pleased to have access to a vaccination feature in their EHR, emphasis was placed on the following elements to assure full functionality and to support clinical practice:

- Ease of accessing, viewing, and using the vaccination features (most frequent comment);
- Ease of populating the Vaccines Administration Record;
- Ability to provide a printout of the vaccination record to the patient;
- Need to interface with state registries resulted in comments from some providers who had to change EHR systems to achieve information exchange;
- Decision support systems (also referred to as “forecasting system”) that are able to help scheduling due or overdue vaccines;

- Immunization functionality to recognize and manage combination vaccines – vaccines that deliver more than one component in a single inoculation (Example – MMR – Measles, Mumps, Rubella vaccine).
- Ability to enter the combination vaccine and have the system recognize that the vaccine provides adequate immunization to multiple illnesses.

Development

Summary of Recommended Functionalities and Issues Identified by Key Informants

Well-child care accounts for nearly half of healthcare visits made by children in the United States.⁶⁰ The visit is designed to incorporate a variety of services for health maintenance and disease prevention. Per the Key Informants, one of the most critical pieces to providing effective pediatric care is to track change over time through a longitudinal record. This is especially true for vaccine administration and growth and development, two key elements of a well-child visit.

Furthermore, the ability to track developmental milestones with support of the EHR was a topic of discussion that arose on multiple calls. The most widely used pediatric preventive care guidelines are the *Bright Futures Guidelines for the Health Supervision of Infants, Children, and Adolescents*⁶¹ and these are consistently referred to both in the literature about EHRs (below) and in discussions with Key Informants. These guidelines describe a comprehensive system of care and contain content for the 31 primary care visits recommended by the AAP for children from birth to 21 years of age.⁶²

Key Informants noted a lack of synchrony between currently available EHRs and Bright Futures, and noted that guidelines developed by professional organizations to guide clinical care are rarely directly programmable despite a decade of efforts by the AAP's Partnership for Policy Implementation, whose goal is to standardize and disambiguate guidelines and provide algorithms where possible (<http://www2.aap.org/informatics/PPI.html>). A translation process has to occur to move general clinical guidelines, intended to provide evidence-based recommendations for provision of care across a variety of practices, into specific algorithms that can be implemented into the available technology. In doing so, reference data can be difficult for the EHR vendor to obtain, resulting in the proliferation of one-off sets of reference data for fundamental issues like growth charts.

Summary of Recommended Functionalities and Issues Identified in the Literature

Currently, no existing EHRs are completely “Bright Futures compatible”, however several products that focus on the pediatric population have implemented portions. An idealized EHR that incorporates the *Bright Futures Guidelines*⁶² would utilize pre-visit questionnaires to obtain data about a new patient or the interval history of an existing patient. The questionnaires would also be used to obtain any concerns the patient or parent would like to discuss during the visit, perform selective screening risk assessment, and guide the choice of anticipatory guidance topics. The results of the questionnaire would serve as the starting point of the visit.⁶³

In addition, two additional features are necessary to support compliance with *Bright Futures*. The first of these is appropriate documentation for physical examination findings. A normal exam in a one-year old will be sufficiently different from an adolescent and requires different data elements for discreet data entry. The second is to supply patients and families with

documentation from the well-child visit, including height and weight, summary of anticipatory guidance, immunization forms, school or sports physical forms, and informational handouts. The AAP Task Force on Medical Informatics also recommends that EHRs should have the ability to supply patients and families with documentation and ideally would provide easily customize reports to match mandated school and camp physical forms.⁵⁴

This fact recently was described in a published⁶³ attempt to create an electronic version of the *Bright Futures* guidelines. The authors categorized the guidelines into actionable recommendation statements that are both decidable and executable. Decidable statements require that every condition is described clearly enough so that practitioners would agree on the clinical circumstances for which the recommendation should be applied. Executable statements describe recommended actions that are stated clearly and unambiguously.

After excluding recommendations concerning physical exam findings and immunizations, the investigators then consolidated the guidelines that were repeated across multiple visits. In doing this, they reduced the number of recommendations from 2161 to 245. Of these 245 it was determined that only 52 (21%) were actionable. These recommendations were divided into four categories; screening interventions (n=22), injury prevention (n=17), nutrition (n=6) and lifestyle guidance (n=7). To implement *Bright Future* guidelines electronically would require discrete recommendations, age-based topics, and completely standardized wording.⁶³

User Perspective

The development functionality appeared in about 6 percent of AAP EHR reviews. The main concern was the need for availability of developmental tools, although some reviewers indicated that an EHR should make standardized developmental screenings, tests, and questionnaires (like ASQ) available. Others preferred to have the ability to create and use subsets of customized milestones surveillance. Still others suggested that emphasis be placed on:

- The ease of documenting long lists of developmental milestones;
- The choice of developmental questions that need to be administered during patient's visit;
- The need to auto-populate developmental milestones into visit notes to ease documentation burden for patients with normal development.

Family Dynamics

Summary of Recommended Functionalities and Issues Identified by Key Informants

Discussion with our Key Informants recognized supporting dynamic family structures as a key functionality of a pediatric electronic health record. They noted that by successfully tying family structures together, an electronic health record can help identify and populate shared family history, social environment, and even billing structures. As family structures become more complex and sometimes dynamic, this feature is increasingly important to the physician to understand the influences on a child's health in order to provide the most appropriate care. Without the functionality for family within a product, workflow can become unduly complicated. For example, clinicians need to duplicate information for each child, or account for privacy and confidentiality for children who reach a certain age in the context of other family members in the clinical setting.

Summary of Recommended Functionalities and Issues Identified in the Literature

Despite a strong emphasis given by our Key Informants, very few published studies have addressed this issue. We identified only one study that described how maternal-child linkage supported detection of children at risk of perinatally acquired Hepatitis C.^{21,64} The AAP Council on Clinical Information Technology recognizes the importance the EHR to support dynamic family structures for privacy, consent, and billing purposes.⁴⁸ This reveals a disconnect between the silence of the literature and the emphasis identified by our Key Informants.

User Perspective

We identified few comments on functionality related to family dynamics on the AAP EHR review website. One reviewer commented on the lack of linking families or siblings as units within an EHR, underscoring Key Informant discussion about problems of ascertaining identity in systems. Reviewers also noted the need to identify more than one adult or caregiver as the guarantor associated with a child. Another reviewer commented on the need to make parental connections transparent.

Privacy

Summary of Recommended Functionalities and Issues Identified by Key Informants

One of the most difficult issues that pediatric providers currently face is the need to adhere to appropriate privacy limits as they pertain to health records of adolescents. Key Informants expressed concern that adolescents are being excluded from health information exchanges in some locations simply because available EHRs do not support the ability to segregate information that needs to remain in the sole purview of the adolescent patient and his or her clinician. In addition, Key Informants noted that the complex issues surrounding adolescent rights related to facets including reproductive health, choices in care, and drug use, make incorporation of privacy standards in record systems challenging. Privacy requirements may vary by age, and permission levels within the record may vary based on clinical role or family relationship, thus complicating universal standards or guidelines.

Summary of Recommended Functionalities and Issues Identified in the Literature

Laws in all 50 states and the District of Columbia allow adolescents to request and receive care for certain services without parental consent or notification.⁶⁵ If adolescents perceive that their care will not be handled confidentially, they are likely to forgo seeking health care, especially for reproductive health, mental health, or substance abuse concerns.^{22,66} Ensuring a safe location where an adolescent can receive services is critical to being able to address the sensitive and potentially stigmatizing issues for adolescents. While current laws mandate and most providers recognize the need to ensure adequate privacy for adolescents and young adults, few electronic health record systems support this functionality.^{11,67}

Currently, the responsibility for delivering confidential patient care is shared among clinicians, hospital and clinic administrators, patients, families, and EHR vendors.²² A breach of confidentiality can happen at any point in the process, from scheduling of the appointment to

billing for services provided (Table 2).^{22,66,68} Although the complexities in providing confidential care can make implementing privacy control daunting, the use of default privacy controls in an electronic health record could help mitigate a potential breach. A core functionality identified in both the literature and by Key Informants for a robust pediatric EHR is a robust privacy infrastructure with default controls that allow appropriate access to and transmission of needed health information based on an individual’s role and relationship with the patient.

Table 2. Potential breaches of confidentiality during a medical visit

Step
Scheduling an appointment
Confirmation of appointment
Reviewing and reconciling medication or problem lists with a parent present
Receiving and filling new medication prescriptions
Releasing sensitive laboratory results
Automated posting of a bill or after visit summary
Request for summary of care or copies of medical records ¹¹

Notes: Adapted from Table 1 in Anoshiravani et al., 2012 Year and Gracy et al., 2012.^{11,68}

Implementing the 2009 Health Information Technology for Economic and Clinical Health (HITECH) act “meaningful use” functionality while protecting a patient’s privacy can present a potential conflict for both providers and EHR designers. Meaningful use regulations require medication reconciliation, providing after-visit summaries, and generating lists of patients by condition. These activities may result in a confidentiality breach for adolescent patients, especially if results of such functionalities are automatically distributed to parents or insurance companies, resulting in inadvertent disclosure of protected confidential health information.²² The EHR must be able to support meaningful use functionalities while maintaining adolescent confidentiality.

Enable default privacy settings for adolescent patients

Ideally, an EHR defaults to initial privacy settings that are relatively strict, comply with state laws, and facilitate privacy at every step in the health care process.⁶⁶⁻⁶⁸ Different individuals with various relationships to the patient may need and have a right to different levels of access, so confidential data elements should have a scope of confidentiality indicating those who should and should not be able to access that particular information.⁶⁹ This scope should be robust to protect against both external (parents requesting information) and internal access to the information, such as restricting access to a family member who works at the institution where the care was provided. Information should be provided on a need to know basis.

Designate individual EHR items as private

A single patient encounter may generate both sensitive and non-sensitive data. An optimal EHR designates sensitive information private to unauthorized individuals while allowing access to non-sensitive. While most elements of the visit should remain confidential, some routine laboratory results and immunizations could be shared with a parent without risking dissemination of confidential health information. However, there are certain elements of the encounter that should remain confidential, such as psychological assessments, risk factor screening, reproductive health medications, and laboratory results.^{65,68}

While strict default privacy settings should protect against most breaches of confidentiality, they may fail to isolate certain portions of the medical record, especially free text items like narrative history and some problem lists. Conversely, default privacy settings may also isolate some patient information unnecessarily, such as when an oral contraceptive pill is being used to treat acne or when a drug like acyclovir, often used to treat a herpes simplex virus infection, is used to treat varicella.⁶⁸ The clinician in conjunction with the patient should have the ability to override the default confidentiality designation of an individual item, as appropriate. Gray et al. also note the important functionality of allowing parents to designate certain items as confidential from their child, such as a family history of Huntington's disease, HIV, or psychiatric illness.²²

Studies have noted the use of clear on-screen labeling of confidential data elements to help facilitate the differential designation of sensitive items within a single patient's record.⁶⁸ While EHR designers will undoubtedly develop their own implementations of this functionality, Anoshiravani et al., (2012) suggested the use of a specific background color or opaque shading of confidential elements to clearly delineate the confidential status of data item.

Transmit privacy settings with information

Designating a specific portion of a patient's record as confidential is worthless if that designation does not persist as the patient's information is propagated and used by those who need it. It is important that EHRs designed to access confidential information include a consistent set of vocabulary and labels that can be transmitted along with the patient's information and this information must persist through dissemination across a health information exchange.^{22,68} While this issue clearly exists with transmission of health information to another institution, protection must also be persistent with dissemination within the originating institution, for example when a problem or medication list is copied from one note to another. Data transmission privacy must also be considered when information is shared in a non-secure method, such as with a text, email, or patient portal message.

Special consideration to proxy access

The implementation of an online patient portal deserves special consideration. It would be inappropriate for an adolescent to sacrifice privacy for electronic access to her record.⁶⁸ Differential access to information should be provided in a way that is transparent to the adolescent patient.²² Proxy access is also complicated by the fact that even though an online account has been created for an adolescent, extra measures must be taken to be sure the individual logging in is actually the patient and not a guardian or a peer.

Allow differential access to protected health information

While default general privacy settings will be sufficient for most conditions, some special conditions may demand either more or less stringent confidentiality. The AAP Council on Clinical Information Technology recognizes the importance of flexibility in the electronic health record to account for a wide array of dynamic family structures.⁴⁸ Complex issues of confidentiality and consent for treatment arise in cases of stepparents, foster care providers, adoptive parents, and guardians. In many cases, such an individual is a primary caregiver for a child and may accompany her to primary care visits where routine treatments such as immunizations or basic screening are provided. This person may be granted permission to consent for routine or limited care based on a custodial parent's wishes. In some cases, a parent

who no longer has custody of a child may retain access to the child's medical record and even the right to provide consent. This dynamic is additionally complicated in situations of child abuse, especially in the early stages of an investigation. The safety of the child must be the top priority.⁷⁰ An EHR must allow dynamic documentation of who is allowed to consent and assent for various treatments as well as who is allowed to receive protected health information. The EHR must distinguish who has provided such consent based on the presenting problem and the diagnosis.^{48,66} An adolescent should be able to provide such access in a noncoercive manner in a private setting.⁶⁸

User Perspective

No specific comments on privacy were abstracted, but users did repeatedly suggest that a typical pediatric EHR should have features to keep information private from parents and other providers. Providers reported that some EHR systems would print notes that did not exclude confidential sections. The staff in those cases has to manually select which sections to print. Some other specific features suggested by the reviewers:

- Privacy alerts on charts
- The ability to flag some notes as “confidential”
- The compliance with state-specific privacy regulations

Managing Pediatric Conditions

Summary of Recommended Functionalities and Issues Identified by Key Informants

EHR functionality to support managing a clinical subpopulation may take two forms: monitoring and managing an at-risk clinical subpopulation or supporting care of a specific patient in that subpopulation. The Centers for Medicare and Medicaid Services specify Stage 2 criteria to demonstrate meaningful use{Centers for Medicare and Medicaid Services, 2012 #172}; regulations include as an objective generation of patient lists by condition so that a provider may better care for a clinical subpopulation⁷¹ and Key Informants indicated that the ability to easily identify specific lists of patient populations is associated with physician job satisfaction when practices are able to schedule necessary and meaningful visits for these patients.

One subpopulation specifically identified by our Key Informants, but that did not appear prominently in the literature, is those children who are homeless or otherwise vulnerable. Other at-risk populations described included children in foster care and those with food insecurity or exposure to violence. An EHR could be a valuable resource to accessing and supporting this group by identifying individuals who are homeless and presenting them in a list to a provider or medical social worker. Additionally, Key Informants discussed the importance of accurate documentation of care for more traditional sub-populations such as children with long-term health conditions. Understanding “normal” for children with conditions such as cerebral palsy or chronic illness is important for recognizing and assessing change and requires a nuanced documentation of care.

Summary of Recommended Functionalities and Issues Identified in the Literature

Managing a Clinical Subpopulation

The EHR can support pediatric functionality to manage clinical subpopulations, such as patients carrying a specific diagnosis or with an associated risk factor, but little information is available in the published literature related to pediatrics, and specifically to outpatient-relevant situations. One study used the EHR to link maternal and infant medical charts to identify infants at risk of perinatal acquisition of hepatitis C.²¹ Generation of an annual list of exposed infants was among several interventions employed to help ensure children were subsequently screened for hepatitis C after 18 months of age, in accordance with AAP recommendations.

One additional study examined the effects of implementing CDS, reminding clinicians to assess for attention deficit hyperactivity disorder symptoms every 3 to 6 months. The system included a structured note template to record symptoms, treatment effectiveness, and adverse events.¹⁸ Implementation of this functionality was associated with improved documentation and an improved visit rate of patients with a given diagnosis of attention deficit hyperactivity disorder.

Finally, a study by Bell et al. showed improved prescribing of controller medications and generation of asthma control plans in a group with clinical decision support incorporated into their workflow as opposed to a group that was given the electronic tools only.⁷²

User Perspective

We did not identify specific comments on managing a clinical subpopulation or supporting care of specific patients in a subpopulation in the AAP EHR user review site; however, reviewers did touch on the ability of systems to provide features specific to premature infants or special populations such as children with Down syndrome. Reviewers also commented on needs specific to children born outside the U.S. Another reviewer commented on the adequacy and appropriateness of developmental questions

Medications and Computerized Physician Order Entry (CPOE)

Summary of Recommended Functionalities and Issues Identified by Key Informants

Medication management, including computerized physician order entry and weight-based dosing was noted as a core functionality for a pediatric EHR, albeit one that is not unique to pediatrics. Nonetheless, medication management in children is subject to increased safety risks for at least three reasons.⁷³ First, a child's continuously changing physiology presents an important complicating factor for medication management.^{73,74} Second, young children do not have communication skills to warn clinicians about potential mistakes in administering drugs or about the adverse effects that they may experience. Third, children, especially neonates, may have more limited internal reserves than adults with which to buffer errors.^{3,75}

Key Informants discussed safety issues inherent in medication management, noting that a lack of such functionality increases a child's risk of receiving the wrong medication or wrong dose. These issues are further complicated by the sometimes complex contraindications for children as the range of physical characteristics including vital signs, height, and weight in pediatric patients overall is much wider than that for adult patients (e.g., from a 500 gram

premature infant to a 100 kilogram in an obese adolescent). The pharmacokinetics and appropriate drug doses further depend on the maturity of a particular pediatric patient's renal and hepatic drug elimination systems. Given this developing physiology, a young child has relatively limited reserves to buffer the effects of improper treatment or disease, making him particularly vulnerable to adverse effects of medication variance when compared to an adult.⁷⁶

Such significant variation means that the definitions of “normal,” “standard,” and “wrong” dosages for pediatric patients change rapidly over time with the clinical parameters used to calculate the dosages (age, BSA, etc.). Key Informants commented on the need for flexible systems with robust rules for functions like dose rounding that take into account differences in the patient population and in the medication being administered.

Summary of Recommended Functionalities and Issues Identified in the Literature

Medication management

Using weight-based dosing and individually tailored dosing makes the task of ordering medications for children correctly a complex endeavor^{73,77} that could be substantially supported in EHRs. In accordance with the Institute of Medicine definition of an EHR, an effective system would improve medication prescribing to include “(3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for health care delivery.”^{48,78}

EHR systems have the potential to mitigate complexity with advanced decision support features, thus improving patient safety. Exploiting this potential calls for a specialized assessment of the unique challenges in providing pediatric care with EHRs, and in particular, unique features required of the EHRs. Pediatric medication dosing based on age and weight is more complex than dosing in adults and is prone to calculation errors.⁷⁴ The process is further complicated by a large selection of alternative routes (oral, rectal, intravenous, subcutaneous, intrathecal, intraosseous, via gastric tube) and significant variations in concentrations of the medications, which can be provided in a great variety of dispensed forms such as tablets, liquid, nasal, partial-tablet formulations, and combination prescriptions. Even if a provider calculates correctly the dose of the medication, the dose has to be translated into the correct amount of a particular concentration to be administered, which provides the opportunity for error.⁴

Amoxicillin clavulanate is typically used in one or two dose forms for adults, while there are 13 different formulations for pediatric use, which increase the chance for a prescribing error. Additional factors, including the need for individualized dilution of stock medications and pediatric compounding of medications with parenteral nutrition being the most complex medication,⁷⁹ place children at an increased risk of medication errors. With low-weight patients, sophisticated rounding strategies and accurate weight measurements are particularly critical to avoid over- or under-dosing.⁵⁶ For premature infants, even the patient's age is complicated by whether the system refers to the chronological age, which is based on birthdate, or the postmenstrual age, a reflection of gestational age.

One study compared the set of dosing eRules of the clinical decision support (CDS) integrated in a vendor-supplied ordering system with traditional dosing sources, deemed the gold standard. A significant gap was found between dosing rules in commercial products and actual prescribing practices of pediatric providers.¹³

In another study, the EHR provided chronological age by default, rather than facilitating a choice of corrected age, which influenced assessment and recommendations for care.¹⁴ One study evaluating prescribing of narcotic substances in children identified support in selecting the correct concentration as well as “show your work” or the display of all data that influenced the final dose and amount in the prescription an important design feature.⁸⁰ In an unmodified (vendor supplied) EHR, medication prescriptions for children generated a higher proportion of improper dosing alerts than prescriptions for adults, resulting in extensive dosing overrides and alert fatigue.¹⁵ In a study of pediatric dose range checking, minimum dose range checks were found to be of little value to pediatricians.⁸¹

Electronic prescribing

An electronic medication prescribing system can vary widely in implementation. It may range from a system that permits filling a few boxes and a printing mechanism without and decision support to a fully integrated e-prescribing system with full decision support including pediatric-specific drug references and cross checking of allergies and medication interactions, integrated formulary information, and longitudinal medication tracking.⁷⁶ The design and usability of such a system is important, as a very sophisticated and full-featured system may be of little use if it is too cumbersome, requires frequent workarounds, and lacks well-designed user interfaces.⁷⁴ The goal of medication prescribing in an EHR is to improve safety and ease the demands on pediatric clinicians without interruption of workflow and increase in workload.

Requirements for CDS to support electronic prescribing noted in the literature are summarized in Table 3 and include the following: weight-based dose calculations and range checks;^{9,11,48,56,82} automated dose rounding;^{9,48,56,77}; age correction and adjustment for infants;¹⁴ and optimized display options for medication orders.⁵⁶

Table 3. Requirements for CDS to support electronic prescribing

Feature	Specific details
Weight-based dose calculations and range checks ^{9,11,48,56,83}	<ul style="list-style-type: none"> • Uses specific units of measurements, preferably with allowance to switch between different systems of measurements (e.g., between metric and Imperial), and display of units of measure along with the data values. • Display normal pediatric ranges for reference and advise user when no pediatric references exist. • Use pediatric norms with respect to range and alert levels, citing patient weight / age with soft-stops for adult dose.
Dose rounding ^{9,48,56,77}	<ul style="list-style-type: none"> • System should allow rounding of medication doses to appropriate decimal precision in consideration of the Low-weight patients. • System must be able to accept weight in grams or to third decimal place when provided in Kg. • Similarly, the system must be able to accept age to the precision of days.
Age corrections / adjustments ¹⁴	<ul style="list-style-type: none"> • System should provide appropriate alerts for age correction for preterm infants, neonates, and small weight patients.
Optimized options for medications ^{56,80}	<ul style="list-style-type: none"> • This is based on the availability of medications in appropriate format or concentration. • Depending on whether this is inpatient or ambulatory setting, the EHR system may be parameterized to either available forms / concentration with the pharmacy or the most convenient forms / concentrations available in the market.
Special label printing ^{9,48}	<ul style="list-style-type: none"> • These options may be considered for more advanced systems • Specialized label printing for ‘School-day’ doses.

User Perspective

Overall, providers commonly stressed the need for effective e-prescribing. Specific suggestions included:

- Featuring weight-based dosing and utilizing an integrated calculator for that.
- Dose calculation should be automatic, pediatric specific, easy, provide soft-stops, and appropriate range-based alerts.
- A side-panel (or a hover-over pop-up) for brief description and justification of calculations to permit “Show your work”.
- Looking up a medication should be easy and comprehensive, by both generic and brand names.
- Selecting the appropriate concentration should be supported.
- It should be possible for med list to be viewed in chronological order, and to split current and past medications.
- E-prescribing for controlled substances should be possible if allowed by state.

Documentation and Billing

Summary of Recommended Functionalities and Issues Identified by Key Informants

Key Informants noted that clinicians routinely describe existing EHRs as too complex and cumbersome to use. Informants described the need to design systems with pediatric care workflow in mind as functionality not integrated into workflow will not be used in clinical practice. Key Informants also discussed documentation of care in terms of the ability to identify prior visits and visits at other centers. At present, data are often too fractionated across multiple systems to provide a useful picture of a patient’s care. Key Informants also commented on the lack of consistent, common nomenclature for coding elements of care. Lack of a common nomenclature limits interoperability and complicates clinical decision.

Summary of Recommended Functionalities and Issues Identified in the Literature

Pediatric requirements in regards to documentation and billing discussed in the literature appear to be similar to adult needs. These requirements include reducing workload during documentation by reducing the number of clicks and screens required. Clinicians desire a decreased burden in documentation of their specialty specific procedures and billing codes and desire an easier way to access these items. Codes, diagnoses, and procedures should be customized to ease access to pediatric-relevant information and reduce documentation workload.

User Perspective

Reviewers mentioned repeatedly that pediatric EHR systems should have the possibility of customization, often without explaining what to customize. Implied seem the notion that pediatric office visits often focus on a set of pediatric well or sick visits with a specific range of diagnoses, procedures, and tests that are used frequently. Increasing the ease with which these items can be retrieved during documentation (for example through a “frequently used list”) appears to be an important desire in regards to usability. One reviewer clarified that customizable data entry and problem lists would allow different doctors to meet their specific needs.

Data management was the focus of multiple reviews. Several reviewers suggested one EHR screen to display the pertinent information needed: names, a brief yet comprehensive problem list, and a descriptive updatable summary of patient's history. This requirement seems similar to the needs of adult providers with the exception that some data elements may be exchangeable.

The fact that pediatricians see large numbers of patients in a day is reflected in the fact that many reviewers addressed the need for EHRs to be integrated into the pediatrician's workflow. Several providers complained about EHR systems that lead to disruptions of the workflow mostly focusing on the ease of documentation and note taking. Another provider complained about software that requires going back and forth between screens in order to do visit documentation, which does not reflect the natural steps of information gathering in a clinical visit.

The support of Routine Health Care Maintenance (RHCM) was well addressed. The elements of these primary care visits are specific to pediatrics, and many EHR systems are not set up for such documentation. Other features of the documentation and workflow that reviewers mentioned include: 1) allowing for patient documentation; 2) allowing for digital signature; and 3) the need to support importing paper documents and the ability to scan them to patient's digital record.

Pediatric-Specific Norms and Growth Charts

Summary of Recommended Functionalities and Issues Identified by Key Informants

One essential area that differentiates pediatric and adult EHR requirements is the need to incorporate pediatric norms, an issue frequently noted by Key Informants. For example, the value of normal heart rate is not universal but depends on age. Most EHRs contain alerts and displays of upper and lower limit of normal based on adult normal values only,^{11,84} which may lead to the loss of their potential to provide clinically useful alerts or visual cues based on the range of appropriate norms for pediatric patients. The lack of pediatric norms may become dangerous when an EHR fails to identify and alert for abnormal values that may indicate life-threatening conditions (A heart rate of 60 is normal in an adult but should trigger an alert in an infant).

Childhood is a period of change, where growth and development advance not always at a linear acceleration, and special populations will have varying growth patterns. Attention to the special significance of children's growth in pediatric practice is also essential for a pediatric EHR and should manifest in graphic display and special calculations of growth patterns and comparison with normal velocity of change in typically and atypically developing children. Because small changes in growth parameters, such as weight changes in premature infants, may be important, systems should be able to store data scales that adjust the number of decimals to the total amount (three decimals for the display of weight for a premature infant, zero decimals for an adolescent) to demonstrate these changes.

Key Informants noted that the development of alternative growth charts to account for variations in growth patterns may be limited by poor availability of evidence strong enough to support their use and the fact that validated growth charts for special populations are lacking. Special population growth charts in commercial EHR systems, if available, may be derived from unknown data samples and using methods that may not have been clearly reported. Data sets used to derive the specialized charts are typically not accessible for testing.

Summary of Recommended Functionalities and Issues Identified in the Literature

Sensitivity to growth norms

A pediatric EHR is expected to support recording of measurements on a sufficiently granular scale to be useful for newborn or infant care. Reports in the literature have noted that EHRs should be able to compare vital signs with age-based normal ranges, accept provided normative values, and alter normal ranges to represent specific ethnic, or geographic populations.⁹ A Key Informant pointed out that pediatricians who are not affiliated with integrated health systems and whose EHRs lack pediatric norm functionality may not have adequate technical or financial resources to manipulate EHRs to account for specialized needs.

Flexibility in data formats

Pediatric-compliant EHRs are sensitive to numeric and non-numeric data.⁴⁸ Norms for almost all numeric data (such as laboratory results, body measurements, scores on standardized assessments, and vital signs) change as the child grows. The measurements of most of these data are continuous, and they depend on age and/or other variants. A limited number of reference ranges may not be enough, and pediatric EHRs should be able to define a normal reference range for each piece of data at any age or in the appropriate age group granularity. Depending on data distributions, providing percentile values and/or standard deviations from the means should be available in pediatric EHRs. For non-numeric data (e.g., the presence of an abnormal physical sign), an EHR should consider age in the interpretation of normality. For example, several routine physical exam findings for newborn infants are considered an abnormal finding in older children (e.g., open fontanel).

Although age and weight are the two variants that many pediatric data depend on, some normative data is related to complex variants.⁴⁸ Blood pressure, for example, has a reference range that is determined by age, sex, and height percentile. Another example is the peak flow meter norms, which also depend on those three variants. When a pediatric-compliant EHR flags an abnormal value of blood pressure, spirometry, or other pediatric data assessment, it should take into account all different related variants.

One challenge to the implementation of pediatric norms into EHR systems is in the case of laboratory values.⁵⁴ The reference laboratory and not the EHR usually supply the normal ranges for these values. The EHR should be able to allow users to both integrate normal reference ranges for age provided from the laboratory and to alter normal ranges to represent specific age and ethnic or geographic populations.

Flexible growth charts

The AAP Task Force on Medical Informatics has recommended growth chart functionality in EHRs including “Recording, graphic display, and special calculations of growth patterns, the ability to calculate, display, and compare a child’s growth percentiles and BMI with normal ranges, the ability to use different ranges for different patients, the ability to store data on a small enough scale to represent these changes.”⁵⁴

One study of growth chart functionality in an EHR system in a multispecialty pediatric clinic in an academic medical center described an electronic growth chart able to manipulate data, perform calculations, and adapt to user preferences and patient characteristics.⁸⁵ It used reference parameters and Z-score values for weight, height, and head circumference. The growth chart was

easily viewed and supported features including the calculation of growth velocity, superimposing mid-parental height points on height curves, and plotting height curve against skeletal age. After implementation, the number of documentation instances of weight, stature, and head circumference improved from fewer than ten total per weekday, up to 488 weight values, 293 stature values, and 74 head circumference values suggesting increased incentives to providers to record these data in the EHR.

Table 4 outlines desiderata for EHR system–based growth charts identified in this study via experiences with EHR users, discussions with members of the AAP Council on Clinical Information Technology, and discussions with members of the Health Level-7 Pediatric Data Special Interest Group.⁸⁵

Table 4. Desiderata for management and representation of pediatric growth in an EHR system^a

Workflow

- Use routinely gathered growth measurements
- Automatically generate growth charts
- Growth charts accessible from standard EHR system components
- Growth data and calculations reusable for other tasks (e.g., decision support, documentation)

Growth data

- Capture weight, height or length, head circumference
- Calculate body mass index and growth velocity
- Calculate percentiles and standard deviations based on population norms
- Capture data using different units of measurement (e.g., grams, kilograms, pounds)
- Capture context of measurement (e.g., lying or standing, ventilated, receiving growth hormone)
- Support automated data capture from measurement devices (e.g., digital scales)

Presentation

- Display growth data on standardized charts as the default view
- Display against standard population-based normal curves
- Display normal curves based on age, gender, and other demographic characteristics
- Display using graphical and tabular formats
- Display predictive growth curves or growth targets
- Display time and date of birth for infants

Functionality

- Calculate mid-parental height by gender-specific parent height percentiles
- Display bone age measurements with actual age measurements
- Display development states (e.g. Tanner stages) with actual age measurements
- Derive and display and the median age at which a given growth point is achieved
- Allow adding, deleting, and editing of growth points
- Enable varying the scale's level of detail (i.e., zoom in or out)
- Support printing and faxing
- Support user preferences (i.e., connected points, superimposed values, table or graphical chart)

Notes: ^a From: Rosenbloom et al., 2006⁸⁵ Abbreviations: EHR: electronic health record

Sub-population-specific growth charts

Growth may be altered or impaired in some conditions including prematurity and Down syndrome, and population-based growth charts may not accurately reflect development of these children. Despite the lack of validated alternative growth charts as discussed above, the AAP recommended that EHR systems incorporate syndrome-specific growth charts where feasible. Attempts to address some of these alternative growth charts are noted in the literature. One example is a study that generated new growth curves for weight in male and female children with Down syndrome that described an approach to develop standardized, EHR compatible, sub-population growth charts, along with a computable data table.⁸⁶ The study highlighted the need for using consistent approach or a standardized set of normative curves across processes to develop EHR-integrated growth charts. Without a consistent approach, different EHR systems will use different protocols for monitoring of growth in sub-populations, which limit inter-system communication, data exchange, and efforts to screen for growth abnormalities in children.

Another example is the application of pediatric Prader-Willi Syndrome growth charts of both genders, in two tertiary care facilities.⁸⁷ The authors noted some challenges in one of the two study centers that created barriers for application including the use of a commercially available EHR as compared to an in-house developed EHR and the lack of full application of a system-wide EHR that likely reduced the demand for Prader-Willi Syndrome growth chart.

Premature infants represent another challenge for the design of EHR growth monitoring. The use of chronological age instead of corrected age when plotting against growth charts may result in incorrect interpretations regarding the adequacy of a child's growth or developmental progress and has the potential to negatively affect care.¹⁴ The AAP and the Centers for Disease Control and Prevention recommended correcting age for all premature infants up to age 24 months. In one study of an EHR that used chronological age as a default setting, corrected age was used in only 24 percent of visits for infants less than 32 weeks gestation during their infancy outpatient visits in 31 primary care sites. The implications of this finding include an over-identification of developmental delay, and dietary changes including increase of caloric intake that were more likely to be done incorrectly or earlier than indicated. This study implied that EHR did not facilitate the choice of the corrected age in this population, and that default to chronological age may have contributed to the inappropriate choices by providers.

Growth monitoring decision support tools

Changes in growth trajectory or not being on a target growth curve can signal clinical problems developing in an infant or child; thus, support for growth monitoring is a helpful component of an EHR. Nonetheless, few growth monitoring decision support tools were developed and described in the literature. One group in Finland conducted a population-based pre-post intervention comparison study of a computerized and automated growth monitoring strategy integrated into EHR system in pediatric primary care setting.⁸⁸ The application of this tool statistically increased referral because of suspected growth delay from 0.22 percent in standard growth monitoring era to 0.64 percent in automated growth monitoring era. Although this EHR-integrated tool increased the workload in of specialists, it improved primary care sensitivity to the detection of growth disorders.

User Perspective

The Pediatric-Specific Norms and Growth Charts functionalities were mentioned in many reviews. The majority of pediatric providers who reviewed their own EHR systems on the AAP website expressed satisfaction with the fact that pediatric growth charts are available to them. However, a few reviewers reported using EHR systems that do not provide any growth charts at all. A few other providers complained about the absence of specific charts like a BMI chart, premature infant growth charts, and Down syndrome growth charts.

As a key element for tracking a child's health and development, growth charts are of major concern to pediatricians. The reviewers stressed the need for up-to-date and standardized growth data from reputable sources like World Health Organization or the Centers for Disease Control and Prevention as well as alternate charts for children with developmental issues such as being born prematurely or having Trisomy 21. Other concerns included:

- The need to have height, weight and BMI included on the same chart
- The need for alternate units of measurement
- The need for the parameters to be customizable by age
- The need for automatic percentile calculations
- General usability/readability of the plotting feature

GQ2. Description of the context in which EHRs are implemented

G2A. What is the potential value of pediatric-specific functionalities in the context of care transition, specifically from newborn care to pediatric primary care, from pediatric primary care to pediatric specialist care, and from pediatric primary care to adolescent care?

The provision of pediatric care occurs over the course of many transitions that may involve a variety of care providers against a backdrop of growth and development of the neonate to child to adolescent and to adult. They may experience additional transitions at any point, including from inpatient care to outpatient care or from primary care to specialty care. Frequently care is provided in nontraditional settings such as school health or camps. Many times communication for these transitions needs to be bidirectional, and if the patient has any special health care needs, transitions may be especially challenging. Our recently published technical brief on transitions of care from pediatric to adult care for children with special health care needs⁸⁹ documented a dearth of evidence on what works to support and facilitate this particular transition.

The AAP endorsed the Got Transition recommendations as an accessible resource for the development of EHR functionalities to support the transition of care for children, specifically children with special health care needs.⁹⁰ As with the description of Bright Futures, above, however, the available materials are unlikely to be immediately translated into a programmable form due to complexity, lack of disambiguation, and decidability; nonetheless, Got Transition can provide a potential roadmap for EHR developers.

Discussions with our Key Informants identified transitions as an important functionality of a pediatric EHR. Despite its importance, it is not easily tied to a specific function but instead is affected by the improvement of multiple functions and services provided. This is perhaps not surprising given the wide range of ages, clinical scenarios, and meanings encompassed by the concept. Transitions identified by the Key Informants are listed below with a brief description of their importance. Related functionalities described in the current literature will be discussed following the descriptions.

Age-based Transitions

For the transition of care from the fetus to newborn, newborn screening plays an important role. Virtually every infant born in the United States undergoes a series of screening tests shortly after birth to identify potentially debilitating or fatal conditions.⁹¹ States differ in how many conditions are tested during newborn screening, but diseases such as phenylketonuria, hemoglobinopathies, cystic fibrosis and several others are shared between all states.

In the proposed Model Format by Intermountain Health, an EHR “would include coded results of genetic, metabolic, and developmental testing and describe functionality for prompts for caregivers for regional, state, or other requirements.”⁷⁰ Due to the rare nature of the diseases being screened, “a typical physician may not have the opportunity to encounter even a single case of some conditions in their entire career.”⁹¹ Another study evaluated using the EHR to improve hepatitis C screening and followup. This example illustrates a clinical scenario where at risk children are identified around the time of birth by maternal history, but screening is not to take place until after the child is 18 months old. In that study, at risk children were initially

identified retrospectively through manual chart review, but the EHR intervention used automated prospective identification and improved hepatitis C screening tests from 8 to 50 percent.²¹

The transition from infancy into childhood is now a period marked by frequent well-child visits and frequent immunizations. Specific EHR functions to support this transition thus depend on an EHR’s ability to send, receive, integrate into a patient’s record, and prompt physicians to act on vaccine data or lack thereof. In addition to vaccinations, preventive care information that is appropriate to a patient’s age and developmental stage should be provided at every well visit. As the body of evidence-based recommended guidelines keeps growing, it becomes more difficult to determine which guidelines may apply to a specific patient. One study applied a Bayesian learning method to an existing patient information and screening tool in order to provide physician prompts and patient education better suited for that individual.⁹²

Adolescence marks the physical transition of a child into an adult and an EHR should facilitate this. Developmental screening, anticipatory care in the form of patient handouts including high risk behaviors, and vaccinations continue to play an important role during adolescence, but privacy becomes a much larger focus than in previous stages of a child’s life. The Society for Adolescent Health and Medicine recommends that an EHR needs to take into account the special needs of adolescents to access health information and the vigorous protection of confidentiality.²² The American College of Obstetrics and Gynecology also provided recommendations in the form of a committee opinion. They note that institutions establishing an EHR system should consider systems with adolescent-specific modules that can be customized to accommodate the confidentiality needs related to minor adolescents and comply with the requirements of state and federal laws. Confidentiality concerns are heightened during adolescence and can affect the quality of care. Security measures must be put in place at the systems level, and the committee opinion even recommends that if the EHR system does not allow for procedures to maintain adolescent confidentiality, the provider should inform the patient and offer to refer to a provider who is required to provide confidential care.⁹³

Table 5. Key age-based transitions relevant to EHR development

Transition	Challenges	Relevant Functionalities
Fetal to Newborn	Involves physiologic changes of the infant as well as a physical transfer from hospital to home to clinic. A parent or infant may change providers during this time creating additional transitions from one facility, provider, or state to another.	Documentation (specifically growth tracking and screening tests as well as mother baby link to allow maternal labs to be linked to the infant) Development
Newborn to childhood	Development encompasses changes in physical, emotional, intellectual, motor, neurological, and psychological health. Vaccinations are important in this time period. Most required vaccinations are completed by 15 to 18 months with nearly all required immunizations completed by 4 years. ⁹⁴	Vaccines Development Anticipatory guidance Population Management
Childhood to adolescence	Begins the transition to adulthood and creates new challenges not only for the patient and parents, but also for the providers and the EHR. Privacy laws and definitions of autonomy create a unique interplay between patient autonomy and privacy concerns. Significant development continues to occur during this time. Providers must achieve appropriate health maintenance while also promoting responsibility and self-interest in the adolescent’s own health.	Development including risk behaviors Medications and CPOE Population Management Privacy

Adolescence to adulthood	This transition will be unique for each patient. A major goal is assessing a patient's readiness for transition out of pediatric care and into adult care. Complexity of medical history, ability to manage one's own care, or ability of an adult provider to manage an uncommon childhood condition are possible modifiers for readiness.	Privacy Population Management
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Inpatient and outpatient

Some patients transfer to and from clinic multiple times. These facility transfers often involve different EHR systems and highlight the need for improvement in interoperability of data between EHR systems. Basic requirements for an EHR “must support patient-care transitions between medical homes via universal (i.e., vendor/technology-neutral) portability standards for patient records among different medical home information systems”.⁹⁵ As of the time of this report, it is critical to note that such universal interoperability is for the most part still dependent upon paper transmission due to a lack of Health Information Exchange. Hospital discharge after admission for asthma carries its own set of mandates from the Joint Commission and is thus an increasingly studied example of this transition.

Key Informants and literature review also identified the transition from one facility to another as an important function for an EHR to perform. Methods of data transmission and interoperability are shared between pediatric and adult EHRs. Nevertheless, asthma appears in the literature as a special case of this transition likely due to mandates put in place by the Joint Commission. In 2003, the commission developed three specific measures to help reduce high re-admission rates for patients with asthma. Two of the three measures have maintained greater than 95 percent compliance nationwide. Those involve the use of relievers and corticosteroids for inpatient admissions. The third measure focuses on self-management by providing a home management plan of care or “asthma action plan”.⁹⁶ Due to regulation and assessment by the Joint Commission, there is a growing body of literature on methods for improving compliance. While this asthma action plan is a discharge requirement for patients admitted with asthma, many clinics are using the same form as an informational handout following clinic visits. Enhancements in EHRs should support pediatric asthma management by reinforcing physician adherence to guidelines and improving patient follow-up. The group anticipates that improved EHR support will increase the level of evidence-based care patients receive.⁹⁷

Similar to asthma action plans, the literature search identified forms known as “emergency information forms” (EIF) as an important function to facilitate transitions of care. The AAP and American College of Emergency Physicians (ACEP) endorsed the EIF as a minimum data set for use in emergencies. These forms are designed for “special-needs” children to provide a minimum amount of data about diagnoses and medications the patient carries as well as procedures a patient should or should not receive in emergencies. One study created a database for storing the EIF for a patient and stated that an accurate emergency summary should help to prevent medication errors at the time of transitions of care.⁹⁸ Even though the Key Informants did not specifically address this topic, the AAP and ACEP specify that optimally, the EIF is created in the child’s primary site of medical care (designated the Medical Home by the AAP) and thus is an important consideration for the development of a pediatric EHR.

The Particular Challenge of Identity

A Key Informant singled out transitions of identity as one of the most important functions of an EHR. The identity of a child changes when there is a divorce and one parent is assigned custody. Movement to a different state, home, or insurance carrier affects the whole identity of a

child. Foster care, emancipation status, and identity protection are just a few facets of all the features that truly make up a child's identity. These issues are admittedly hard to quantify for inclusion and certification in a pediatric EHR but are important functions to think about in the scope of this review.

Although our Key Informants were adamant that transitions of identity, including through acquisition of a name after birth, through divorce and adoption and in the foster care system are critical for EHR implementation, little is available in the literature to guide best development of the EHR in this regard.

As noted by the AAP, "A universal patient identifier is a desirable but as yet unachieved goal."⁵⁴ Thus, an optimally functional EHR will need to provide assignment immediately at the time of birth or even before if prenatal procedures are to be performed. EHRs need to accommodate temporary data for this field and flexibility of search functions as well as maintaining records of multiple names used by the patient. "Limited ability to communicate with pediatric patients increases the reliance on the EHR to accurately identify patients, detect erroneous assumptions, discover symptoms, and access historical information."⁵⁶

In summary, a child can be discharged from the hospital with one name and arrive in clinic the following day under a new one. Separately or in conjunction, the payer relationship often depends on custody, employment status, or the ability to submit paperwork on time to the correct offices. Key Informants mentioned that sensitive issues such as adoption, foster care, or egg/sperm donation can also play a deterministic role in the identity of a child. For reasons of marriage, parenthood, or financial security children can obtain emancipation status prior to the age of 18. Current EHR systems are rarely adequate for representing this. As mentioned, literature review did not provide a solution, but the paucity of evidence should be an impetus for ongoing research.

GQ2B. Are certain pediatric-specific functionalities beneficial for a pediatrician to conduct her work including sick and well-child visits? If so, does this vary by health care setting (e.g. primary care office, specialty care office, school health, and alternative care settings) or by type of visit (e.g., preventive vs. acute care)?

The available literature to date provides little suggestion of the ways in which particular functionalities are beneficial within the context of pediatric care overall, or the degree to which they affect workflow and day-to-day processes. Key Informants note that while the literature to date has focused on functionality, in particular as it pertains to meeting requirements and improving health, substantially less attention has been paid to issues of the user interface and workflow as they are specific to the care of children. This is clearly an area for future examination and consideration as pediatric EHRs are developed and disseminated more broadly.

Nonetheless, it is an area where we gleaned input from Key Informants. Key Informants noted the importance of tying functionalities to supporting pediatric providers in meeting Meaningful Use requirements and measuring quality. A particular characteristic of the well-child visit is the degree to which it is highly structured. Components of that visit and parts of the physical exam for example, may or may not be associated with a quality metric or longer-term health outcomes.

Key Informants suggested that pediatric quality measures be incorporated into the development of the EHR such that reporting becomes part of the workflow and not an additional burden to the provider. In this way, decisions about what to build into the EHR are driven by two things – our empirical knowledge about what issues are tied to hard health outcomes (e.g. vaccinations and smoking status), and established quality metrics that will need to be gathered in a clinical practice.

For example, one particular area that is difficult to integrate into the workflow was noted to be tracking and care around child development, particularly in a busy environment with short visit times. By the same token, while tracking development in an EHR may be a worthwhile endeavor and desirable to pediatricians, evidence that such incorporation affects clinical outcomes is largely lacking. Our Key Informants noted aptly that physicians have met needs such as vaccination logic in the absence of an electronic health record for many years. Thus of key importance is that the EHR fit easily into the clinician's workflow with a focus on usability. Interestingly, as noted in Guiding Question 4 below, despite the centrality of this issue, particularly in pediatrics, evidence is trailing.

Appropriate CPOE integrated with clinical decision support (CDS) for dosing and relevant alerts make it easy for the pediatrician to conduct her work. Appropriate weight and age based dose calculations, appropriate dose ranges, and corresponding alerts to indicate improper dosing expedite the medication use workflow for the pediatric providers.

GQ2C. What are the challenges to implementing specific functionalities? Are some harder than others to implement by a) vendors; and/or b) pediatric providers?

Per our Key Informants, any implementation of an EHR needs to be mindful that pediatrics is a high volume practice, and adding time and complexity to the day in a field with an already relatively low margin will be problematic for physicians. Ironically, implementation of all of the noted functionalities may actually create a challenge for pediatric providers to successfully see enough patients while documenting adequately and using the fully functionalities available in the EHR. Key Informants noted that taking the time to record additional information than might have previously been recorded comes at potentially significant cost if it requires fewer visits take place. Indeed, one study in our review documented the time that it took for a pediatric practice to return to baseline volume after implementing an EHR and it was substantially longer than the vendor had indicated.⁹⁹

Implementation Challenges: Vaccines

Vaccine functionality in EHRs is hindered by factors such as non-centralized, proprietary databases that cause fragmentation of vaccination records. Clinical decision support does not perform well when documentation is incomplete and in fact can prompt physicians to give immunizations unnecessarily. Thus, finding ways to ensure that various databases communicate well and that one complete and correct record is available are particular challenges to properly implementing vaccination procedures in the EHR. Without being able to consistently demonstrate compliance with vaccinations in the patient population, physicians risk over or under vaccinating, and indeed multiple authors note this challenge.¹⁰⁰ In addition to this core challenge, many systems have inefficient forms of data entry requiring scanning of paper records or electronic submission to a state registry that does not interface with the native patient record. Finally, different immunization formulations and manufacturers create deviations in the way a patient can be delinquent and change the number of doses needed to be considered up to date.

Implementation Challenges: Privacy

Those who do not care for adolescent patients regularly may consider adolescent privacy as a niche issue.^{67,68} However, the same techniques employed in protecting an adolescent's privacy can be expanded to many other situations including ill adults who desire to protect certain health information from their children or caregivers. Also, these issues are now extended with the observation that some adolescents can also remain on their parents' insurance policy through the age of 26.⁶⁷

Implementation of privacy controls in the EHR focus on maintaining granularity and consistency across the privacy implementation. For a relatively small EHR implementation, having a single default privacy setting with minimal customization may be adequate and may help to improve utilization by minimizing confusion.

Allowing default privacy settings is easiest when information is stored in structured data fields. Many providers currently use adolescent risk assessment screening tools that contain copyrights that present a barrier to direct integration into an EHR. Paper copies of these forms are currently being scanned into medical charts, which can add complexity to controlling the protected health information.¹¹

Implementation Challenges: Managing a Clinical Subpopulation

An EHR that supports management of clinical subpopulations will support generation of a list of patients with a unifying feature as well as decision support to improve care of each individual patient¹⁸. Generation of such lists must be done in the context of respect for an adolescent's privacy in cases of potentially sensitive health information.²² An EHR can support the adoption of practice guidelines and clinical recommendations by incorporating decision support models that fit into a clinician's workflow when most needed.⁷²

Implementation Challenges: Medications and CPOE

Enhancing an adult-focused CPOE system for a safe pediatric medication management is an intense and sophisticated task and has limitations.¹⁰¹ Such efforts require high-level sponsorship, involvement of clinicians, and round-the-clock support.¹⁰² Nevertheless, these efforts are seen as necessary and beneficial in reducing medication errors.^{83,103} In particular, vendors face the challenge in the context of detailed dosing options of integrating alerts that are appropriate and improve safety but that do not generate fatigue, which commonly leads to the practice of physicians ignoring alerts as a nuisance.

Implementation Challenges: Development

A particular challenge of integrating developmental tracking in an EHR is a lack of agreed upon standards, and lack of computability of those standards that do exist. For example, the AAP has approved nine different development screening instruments – all which vary in format, sensitivity, specificity, and modality.¹⁰⁴

Even after selecting what to implement, many guidelines lack computability, meaning that they are not directly implementable in an actionable way. This is particularly the case for recommendations such as “learning to manage conflict nonviolently”, “avoiding situations in which drugs and alcohol are readily available”, and “avoiding risky situations”.⁶³

Implementation Challenges: Growth Charts and Norms

One thing that is very pediatric-specific is the lack of standards for clinical circumstance (e.g., alternate growth charts). Alternative growth charts do not exist, yet many vendors sell them or claim they have them. AAP's position is that there are two growth charts with data (the Centers for Disease Control and Prevention and World Health Organization). Vendors attempt to create a feature for which each pediatrician wants. But if there is no source of official formal data, vendors are effectively making up data and putting it in their EHR. Vendors then either have to either contradict the AAP's position, because it is in writing that you should be using the World Health Organization or Centers for Disease Control and Prevention growth charts for these clinical circumstances, or to make sales, build something that may not be valid. It would actually be easy for most vendors to produce the features; however, we do not have the ability to make up the standards.

Evidence Map (GQ3A and GQ3B)

GQ3A. Is there any evidence that using an EHR adapted for the specific needs of pediatric providers compared with using a “regular” EHR or not using an EHR at all produces a) better quality, including safety and cost outcomes for patients; and/or b) improved workflow or job satisfaction for providers?

GQ3B. Which pediatric-specific functionalities influence a) patient outcomes (including safety; quality; cost; equity; standardization of care; and/or efficiency); b) the ability of a pediatric provider to conduct work within the EHR; c) improvement of workflow and provider satisfaction; and/or d) involvement of patients and families (including their education and shared decision making)?

Evidence

The evidence base that we identified for guiding questions 3a and 3b consisted of targeted existing systematic reviews, supplemented by original studies published since completion of those reviews. For these guiding questions, we were assessing the state of the empirical literature focusing on the specific outcomes noted in these questions and to determine the degree to which it could support or provide information on implementation of those elements. As this is a technical brief, and not a systematic review, we do not assess the rigor of individual studies or assess the strength of the evidence. Of note, the available literature did not directly answer the two guiding questions. Therefore, we describe the empirical literature that is available in order to attempt to provide indirect evidence around these issues. For example, studies do not compare non-pediatric to pediatric EHRs, as would be ideal for Guiding Question 1; rather, there are a number of studies that describe the de novo implementation of a pediatric EHR altogether using a pre-post approach. Therefore, we combine the answers to these guiding questions to provide as complete a view of the available literature as possible. We have organized the literature around the functionalities described in Guiding Question 1.

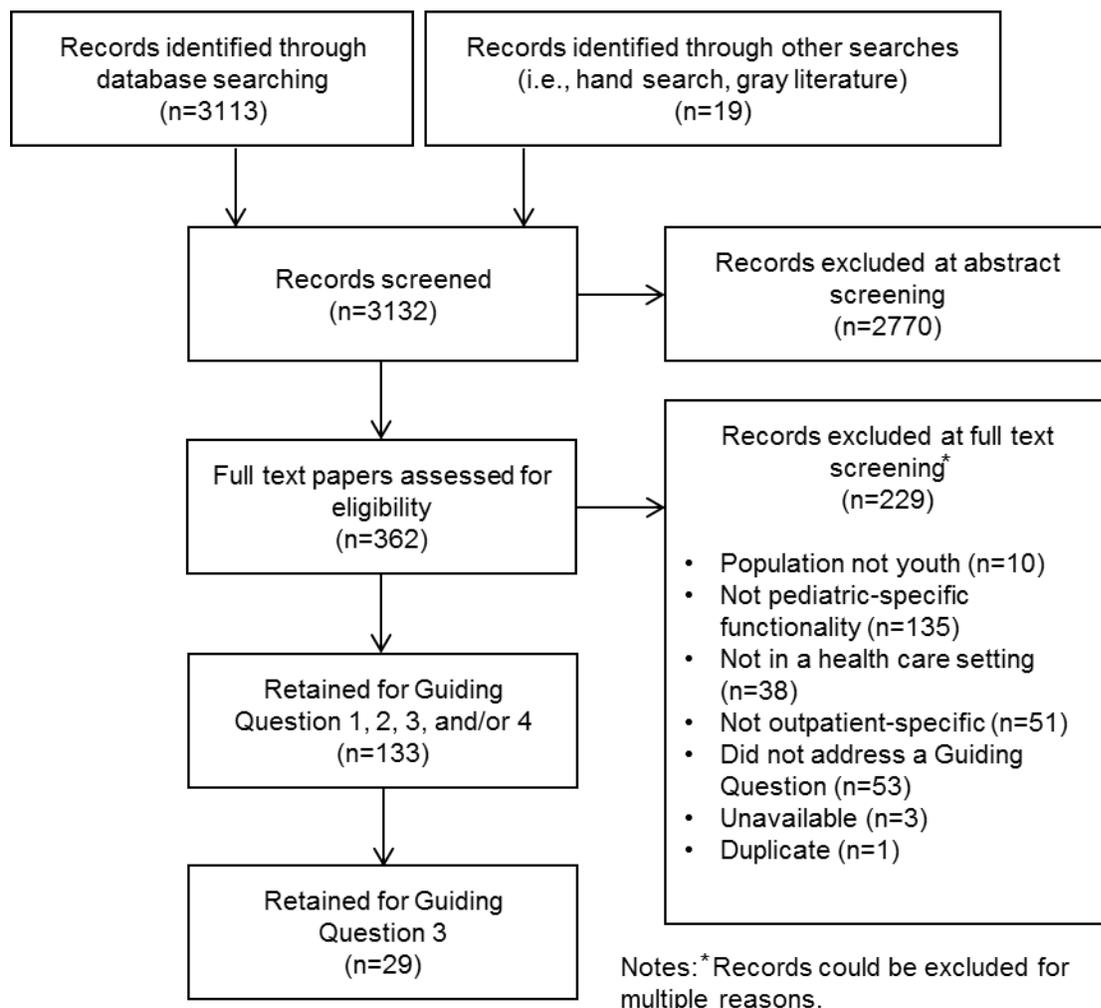
We included in our summary studies that used noncurrent comparators and retrospective studies, but note that these have inherent weaknesses in rigor for assessing effectiveness. We sought studies that measured effectiveness for better quality, including safety and cost outcomes for patients and improved workflow or job satisfaction for providers. Studies needed to address an evaluation of an EHR generally or specific functionalities in a pediatric setting and had to evaluate an intervention that either was focused in the outpatient setting or that, if studied in the inpatient setting, would also apply in the outpatient setting. We identified four recent systematic reviews addressing EHRs or EHR components in pediatric settings. Three primarily addressed CPOE and medication errors,¹⁰⁵⁻¹⁰⁷ and one assessed pediatric-focused health information technology.¹⁰⁸

The amount of empirical literature meeting our questions is limited. Nonetheless, it can be grouped thematically into efforts to improve vaccination rates, reduce medication errors, increase accurate diagnoses (primarily of obesity) and other studies (most commonly focused on

screening and preventive care). We identified no studies that specifically compared a pediatric specific EHR to one developed for an adult population.

Across all clinical topics, we examined 29 studies that evaluated the implementation of an EHR with large or modifications to or additions to an existing EHR.^{8,16-19,58,60,72,83,99,109-127} One study¹⁹ reported on outcomes related to workflow, including satisfaction, but most studies reported on clinical outcomes (e.g. vaccination rates and medication errors) or documentation (proportions of children for whom diagnoses were correctly documented). See Figure 1 for detailed reasons for exclusion.

Figure 1. Literature flow diagram



An AHRQ review assessed pediatric health information technology broadly and noted some evidence to support CPOE and CDS from a small number of studies, largely conducted in academic medical centers.¹⁰⁸ Some studies reported improvements in documentation and antibiotic prescribing and some reductions in medication errors. Evidence for changes in vaccine adherence was mixed, with small improvements in adherence to one vaccine in one study in a

general pediatric population and improvements in flu vaccine in children with asthma in another. Timeliness of drug administration and diagnostic testing was improved in one NICU study.¹⁰⁸

Vaccination-specific functionality

As described in Guiding Question 1, the availability of vaccine services support in a pediatric EHR is consistently described as core functionality. The prominent role of the vaccination schedule in well-child care makes it unsurprising that a bolus of work exists evaluating systems of increasing systems to improve vaccination rates in a variety of populations. The studies most commonly used clinical decision support and most often targeted rates of influenza vaccine, often in vulnerable populations.

We sought primarily studies that took place in outpatient settings as those are most relevant to this technical brief. All of the vaccination studies used some sort of decision support in an existing EHR (Table 6). Most were retrospective, although two were cluster RCTs, randomized at the practice level and conducted by the same group.^{17,112} In all studies, vaccination rates increased, although without true comparator groups, the degree to which the increase is associated with the EHR implementation or to some degree, learned behavior is unknown. Nonetheless, vaccine support is consistently described in the non-empirical literature and by our Key Informants as essential and the body of literature provides a basis for feasibility and effectiveness of using clinical decision support to increase vaccination rates and support the documentation process.

Table 6. Selected evaluation and outcomes studies on interventions to increase vaccination rates in pediatric care

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
Fiks et al., 2013 ¹¹² RCT, cluster (randomized at the practice level) 22 hospital-owned primary care practices	All girls ages 11 to 17 years due for at least one HPV vaccine in the study period	Clinician and family directed decision support, using an existing EHR Clinician intervention: EHR-based alerts for all routine adolescent vaccinations; 2) 1 hour presentation and 3) quarterly performance feedback reports Family intervention: automated telephone calls based on an EHR-generated roster. HPV vaccination rates (cumulative incidence) and time to vaccine receipt.	The combined intervention group demonstrated the greatest effect in both vaccination rates and time to vaccine, compared to the control group. Effects of individual components or of either the clinician or family group alone were not significantly greater than control.
Nelson et al., 2014 ⁵⁸ Pilot retrospective design with a convenience sample Outpatient specialty	Pediatric systemic lupus erythematosus Pre: 40 charts Post: 20 charts	CDS in existing EHR Rates of compliance with infection and cardiovascular disease preventive care quality indicators	PVX vaccine (%) Pre: 31.3 Post: 81.0 Influenza vaccine (%) Pre: 33.3 Post: 95.0 Lipid panel (%)

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
clinic			Pre: 25.0 Post: 76.0
Patwardhan et al., 2012 ^{57,120} Pre-post; stakeholder survey Pediatric hospital rheumatology clinics	Medical records from rheumatology patients aged 1 to 22 years, 3 cohorts (2007, 2008, and 2009)	Automatic best practice alert reminder in the record introduced from September 2009 to April 2010 Claims-based reporting of influenza receipt over 3 years	Vaccination rate (%) 2007: 9.0 2008: 7.8 2009: 25.5 Rates of vaccination differed significantly by attending physician.
Pollack et al., 2014 ¹²¹ Pre-post, retrospective Seattle Children's Hospital	All children 6 months of age and older hospitalized between 2003 and 2012 Admissions: 20,651	System integrated into EMR to determine flu vaccine eligibility, conduct screening and order appropriate formulation Screening status and vaccination status	Screening rate (%) Pre: 19.8 Post: 77.1 Vaccination rate (%) Pre: 2.1 Post: 8.0
Bundy et al., 2013 ⁸ Interrupted time series Urban, hospital based pediatric primary care clinic	children seen by pediatric residents and selected from 3 age groups	CDS prompt to providers to administer vaccines that were overdue Proportion of children up to date at index birthday; proportion of children up-to-date within one year of index birthday	Up-to-date on index birthday No clinically meaningful change Up-to-date within one year of index birthday No clinically meaningful change
Fiks et al., 2009 ¹⁷ RCT, cluster 20 Primary care sites (2006-2007)	Children ages 5 to 19 years with asthma Participants (visits) Pre-intervention: 10,667 (21,422) Year 1: 11,919 (23, 418)	EHR-based clinical alert for influenza vaccine Captured vaccination opportunities	Change in captured vaccination opportunities (%) Intervention sites: 4.8 Control sites: 3.2 95% CI: -2.4 to 4.9
Fiks et al., 2007 ¹⁶ Pre-post 4 urban primary care centers affiliated with an academic medical center	All children younger than 24 months during a 1 year intervention (2004 to 2005) Visits: 15,928	Electronic reminders programmed to appear at every visit where a vaccine was due Rates of captured immunizations opportunities and overall immunization rates at 24 months	Captured immunization opportunities at well-child visits (%) Pre: 78.2 Post: 90.3 Captured immunization opportunities at sick-child visits (%) Pre: 11.3 Post: 32.0 Up-to-date, adjusted (%) Pre: 81.7 Post: 90.1

Abbreviations: CDS: clinical decision support; RCT: randomized controlled trial; EHR: electronic health record; EMR: electronic medical record; HPV: human papilloma virus;

Medication and CPOE- specific functionalities

Most studies of weight-based dosing and the use of CPOE to reduce errors have been conducted in inpatient settings, particularly in the NICU or PICU. No studies have used

concurrent comparators. Of the four recent systematic reviews addressing EHRs or EHR components in pediatric settings, three primarily addressed CPOE and medication errors.^{105,106,107} CPOE was typically associated with reductions in medication errors and some improvements in vaccine adherence and timeliness of care.^{16,57,58,112,121} Potential associations between reduction in errors and patient outcomes are not clear, and across reviews, studies assessed heterogeneous implementations.

Studies were often conducted in academic medical centers or in specialized populations (NICU, children with asthma), thus generalizability to other settings and contexts may be limited. Moreover, technologies are implemented in unique and complex systems of care, and disentangling the effects of an individual technology from the overall system of care is challenging. We summarize these prior reviews below from recent to oldest in Table 7.

One review and meta-analysis published in 2014 included eight pre-post studies addressing CPOE implemented in the PICU setting. In seven of eight studies, medication errors were significantly reduced after implementation. The review also reported positive effects of electronic decision support and documentation tools on prescribing errors and delay in medication delivery. CPOE with CDS was positively associated with error reduction in meta-analysis (RR=0.47, 95% CI: 0.28 to 0.79).¹⁰⁵

Another review included eight studies of CPOE systems in the NICU or PICU. Medication prescription errors and/or adverse drug events decreased in three of five studies and decreased in another, though potential adverse drug events increased. Mortality results were mixed with a significant decrease post-implementation in one study, significant increase in another study, and non-significant decrease in third. In meta-analyses, potential and actual adverse drug events showed a non-significant decrease after CPOE (RR=0.65, 95% CI: 0.01 to 0.77), and mortality rates were not significantly influenced by CPOE (RR=1.02, 95% CI: 0.52 to 1.94). In the one study reporting an increase in mortality after CPOE introduction,¹² mortality risk associated with CPOE was elevated (OR=3.28, 95% CI: 1.94 to 5.55).¹⁰⁶

One systematic review evaluated interventions to reduce dosing errors in children and included 14 studies of CPOE. Most studies were pre-post designs and most reported reductions in total error rates after CPOE implementation, though as noted in the systematic review previously described, one study¹² reported an increase in mortality following implementation of CPOE. The investigators note that systems classed as CPOE likely varied considerably in functionality.¹⁰⁷

In addition to the systematic reviews, we sought original research published since the end date of the systematic reviews. Only one directly relevant study (i.e. in the outpatient setting) was identified.⁸³ Nonetheless, we provide an overview of inpatient studies under the view that those systems of care would also be relevant to outpatient medication processes, where issues such as weight-based dosing are also in play.

In the outpatient study, an automated weight-based dosing calculator added to an existing EHR was associated with significantly fewer medication errors after implementation in multiple family medicine clinics. The study focused specifically on the use of ibuprofen and acetaminophen in children ages 12 and under.⁸³

Studies examined either the implementation of a CPOE or CPOE with and without CDS. Among those that studied all potential iterations, those that separately addressed the issue of CDS in addition to the CPOE consistently reported that while implementation of CPOE generally did not lead to significant change, the addition of decision support around dosing did.

Table 7. Selected evaluation and outcomes studies on CPOE and weight-based dosing

Author, Date Study Design Setting	Population / Groups	Intervention Target outcomes	Results
McCrary et al., 2014 ¹¹⁹ Pre-post, retrospective Academic children's hospital	Patients in a PICU who received manual red blood cell exchange	Introduction of a CPOE system (Eclipsys Sunrise Clinical Manager) Protocol compliance and effectiveness of the manual red blood cell exchange procedure	Protocol violations (n) Pre-intervention: 20 Post-intervention: 3 Sickle hemoglobin reduction (%) Pre-intervention: 55 Post-intervention: 70 Prep=0.04 Peak hemoglobin (g/dL) Pre-intervention: 12.0 Post-intervention: 11.5 p=0.25
Bissinger et al., 2013 ¹¹⁰ Pre-post, prospective quality improvement study Academic NICU	All infants who had antibiotics initiated for a suspected healthcare-associated infection Phase I: Baseline Phase II: Implementation of a CPOE	Development and introduction of a CPOE system, after a period of quality improvement projects Improvement between Phase I and Phase II in time to antibiotic	Antibiotic timing, mean (SD) Pre: 150 (85.1) Phase I: 113 (70.4) Phase II: 74 (43.4) Phase I vs. Phase II: p<0.001 Administration within 2 hours (%) Pre: 45 Phase I: 66 Phase II: 85 p<0.001
Maat et al., 2012 ¹¹⁸ Interrupted time-series simulation study Academic NICU	All neonates hospitalized for one or more days between 2001 and 2007 with one or more risk factors for hypoglycemia or hyperglycemia (n=2040)	System combining CPOE and parenteral and enteral nutrition ordering (CPOE system with additional CDS for glucose calculations) Hypoglycemic and hyperglycemic episodes and prescribing time efficiency	No significant pre-post difference on numbers of hypo- and hyperglycemias per 100 hospital days of patients in every 3 month period (p=0.88; p=0.75) or per 100 glucose measurements (p=0.91; p=0.74) Stratification for SGA also showed no effect. Physicians completed the three simulation cases correctly with a significant reduction in time with CPOE vs. calculation of 1.3 minutes for simple and 8.6 minutes for complex cases.
Kazemi et al., 2009 ¹¹⁵ Pre-post with three periods Iranian neonatal ward	P1: no CPOE P2: CPOE without decision support P3: CPOE with decision support	CPOE with and without decision support Non-intercepted dosing errors in antibiotics and anticonvulsants	There was no significant difference in error rates pre and post CPOE without decision support. Errors were significantly reduced after decision support was added to the CPOE (53% to 34%; p<0.001) Dose errors were more frequently intercepted than frequency errors. Notably, physicians ignored alerts when they did not understand why they appeared.
Longhurst et al.,	All non-obstetric inpatients	CPOE (locally modified)	Change in mortality rate,

Author, Date Study Design Setting	Population / Groups	Intervention Target outcomes	Results
2010 ¹¹⁷ Pre-post Academic children's hospital (quaternary care center)	admitted 2001 to 2009 Discharges (n) Pre-intervention: 80,063 Post-intervention: 17,432	functionality within a commercially sold EHR to support CPOE and electronic nursing documentation) Mean monthly adjusted mortality	adjusted mean monthly Post-implementation: 20% reduction (95% CI: 0.8 to 40), p=0.03
Kadmon et al., 2009 ¹¹⁴ Pre-post with four periods Tertiary care medical center, PICU	1250 orders from each of the 4 periods P1: no CPOE P2: CPOE without decision support P3: CPOE with decision support P4: CPOE with decision support after a change in prescription authorization	CPOE with and without decision support that included dosage recommendations and limits on prescriptions Prescription error rates	Total errors (%) P1: 8.2 P2: 7.8 P3: 4.4 P4: 1.4 p<0.0001 Potential adverse drug events (%) P1: 2.5 P2: 2.4 P3: 0.8 P4: 0.7 p=0.82 MPEs (%) P1: 5.5 P2: 5.3 P3: 3.8 P4: 0.7 p=0.0001 RVs P1: 0.002 P2: 0.001 P3: 0 P4: 0.7 p=1.0 Significant decreases in errors occurred only after the addition of decision support to the CPOE
Yu et al., 2009 ¹²⁷ Case control study Data from the health information management systems society analytics database linked with the national association of children's hospitals database (2005 – 2006) Children's hospitals	Cases: 4,625 Controls: 18,040	Presence of a CPOE (hospitals that implemented electronic order entry in all clinical domains)	Adverse drug events Odds of experiencing an ADE were 42% higher in hospitals without CPOE

Author, Date Study Design Setting	Population / Groups	Intervention Target outcomes	Results
Ginzburg et al., 2009 ⁸³ Pre-post Multiple family medicine clinics	Children ages 12 and younger receiving either ibuprofen or acetaminophen prescriptions Visits (n) Pre-intervention: 316 Post-intervention: 224	Automated weight-based dosing calculator within the EHR Medication and overdosing errors	Pre- vs. Post-intervention Medication errors: p=0.002 Strength overdosing errors: p=0.028

Notes: ^a See: “Improving Antimicrobial Prescribing Practices in the Neonatal Intensive Care Unit” (5R01NR010821)
Abbreviations: CPOE: computerized physician order entry; EHR: electronic health records; NICU: neonatal intensive care unit; PICU: pediatric intensive care unit;

Obesity Diagnosis

A body of literature exists on methods for encouraging the recording of BMI and presumably, appropriate follow up, including a prior systematic review on the use of information technology for screening and treating obesity that includes studies through April 2012.¹²⁸ All but one of the newer studies identified was used a pre-post design (Table 8). Newer studies consistently reported higher rates of diagnosis and documentation, but given substantial attention paid to issues of obesity in children, it is not entirely clear that increases may not have been associated with secular trends. No studies describe patient health outcomes or directly address workflow issues.

As noted in a study published in 2012, in which there was a concurrent comparator, the predicted probability for a diagnosis of obesity increased in both groups (with and without a structured progress note) but the increase was greater in the intervention group. In this study, the effect of a point of care alert with clinical decision support was studied in two group practices in Massachusetts.¹⁰⁹ One implemented the alert, and the other did not. The decision support tool was activated in the intervention set of clinics for children whose age and sex-specific BMI was equal to or greater than 95 percent. The baseline rate of documenting an ICD-9 code for obesity was significantly lower in the intervention group at baseline than in the comparator group, and this group demonstrated significantly greater improvement in documentation over the course of the study. While this study demonstrates a case in which a decision support tool was able to increase documentation, additional study is necessary to understand the degree to which documentation leads to appropriate care and patient-centered outcomes. All other studies were pre-post with the inherent risks of bias associated with that design.

Table 8. Selected evaluation and outcomes studies on use of documentation functionalities to improve identification of obesity

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
Shaikh et al., 2014 ¹²⁴ Pre-post UC Davis Health System	36 pediatric house staff and 12 attending physicians; 432 overweight/obese children (574 total visits)	An alert for high BMI, a checklist and standardized documentation template Adherence to clinical recommendations for overweight and obesity	Diagnosis of overweight/obesity increased from 40% to 57%. Proportion of children scheduled for followup visits increased from 17% to 27%.

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
Bode et al., 2013 ¹¹¹ Pre-post Academic military medical center, adolescent clinic	All adolescent patients, ages 12 to 19 presenting for well-child care	Inclusion of BMI percentile and BMI growth curve by the medical screener	Rates of BMI Pre: 30.0 Post: 30.5 Correct diagnosis rate (%) Pre: 40.0 Post: 64.0 Pre vs. Post: OR=3.36, 95% CI: 1.7 to 6.7
Savinon et al., 2012 ¹²² Pre-post Federally funded, privately owned community health center	All children ages 7 to 18 years presenting for a well-child visit for a total of 74 records (40 written and 34 electronic)	Customized EMR including data entry for BMI calculation, risk assessment questionnaire for parents, diagnosis prompt, and an obesity-specific followup visit. Frequency of recording BMI, completing growth charts Number of children diagnosed with overweight or obesity	Rates of diagnosis no change BMI recorded in EMR patients were significantly more likely to have a BMI recorded in the record after the intervention
Keehbauch et al., 2012 ¹¹⁶ Pre-post Two community-based family medicine residency clinics	Family medicine residents, pediatric and family medicine faculty Pediatric patients aged 2 to 18 years	EHR upgrade to include BMI by gender and age, plus physician education versus EHR upgrade alone Site 1: EMR upgrade plus physician education Site 2: EMR upgrade alone	Correct documentation of overweight or obese status (%) Site 1: Pre: 29.7 Post: 40.2 Site 2: Pre: 19.4 Post: 27.5
Ayash et al., 2012 ¹⁰⁹ Quasi-experimental (natural) experiment Multisite group practices	Children ages 2 to 18 years seen for well-child care between 2006 and 2008 Intervention: 34,908 Comparison: 123,446	Computerized point of care alert with clinical decision support; physicians at one system were led to a structured progress note Predicted probability of diagnosis of childhood obesity	Predicted probability of an obesity diagnosis increased significantly more in the intervention group than in the control.

Abbreviations: BMI: body mass index; EHR: electronic health record; BMI: body mass index; EMR: electronic medical record;

Other functionalities including prevention and counseling

A growing body of literature is assessing additional services, including preventive care and counseling. Much of this literature focuses on populations with special health care needs and thus provides support for the use of EHRs in population management. Populations studied included children with asthma and attention deficit hyperactivity disorder (Table 9). Screening and prevention topics included increasing appropriate Pap smears in young women, screening for anemia and tuberculosis on the basis of family triggers, and behavioral screening.

A recent study assessed whether the rates of preventive counseling delivered at well-child visits is different for practices that use a basic EHR, a fully functional EHR, or no EHR.¹⁹ This study provides the best estimates to date of national rates of EHR use as they relate to preventive care. The authors conducted a cross-sectional analysis combining data from the National

Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) Electronic Medical Records Supplement from 2007-2010. NAMCS provides information about the use of ambulatory medical care service and NHAMCS provides details about hospital-based outpatient and emergency departments in the United States. These two surveys include information provided by physicians or staff members that include patient demographics, counseling topics discussed, ICD-9 codes, and visit duration.

Overall 77 percent of preventive visits were performed with no EHR, 14 percent with a basic EHR, and 9 percent with a fully functional EHR. When comparing basic to fully functional EHR's, visits take 3.5 more minutes (18%) for fully functional EHRs than those with basic EHR's (p=0.05). In practices with fully functional EHRs, 34 percent more counseling topics were covered in during the visit. When time is considered in the model, visits utilizing fully functional EHR's provided 36 percent more counseling than those without an EHR (p=0.009) and for each 10-minute increase in time spent, the average number of topics increased by 12 percent (p=0.01).

One study described the time needed to learn a new system and return to baseline visit numbers after implementation of an EHR.⁹⁹ This study reported simultaneously that outcomes were positive in terms of increasing presence of problem lists, decreased medication and forms turnaround time and decreased need for medical support staff. However, appointments had to be restricted for 3 months rather than the expected 4 weeks as staff learned the system.

Table 9. Selected evaluation and outcomes studies of other functionalities

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
Rand et al., 2013 ¹⁹ Cross-sectional Analysis of NAMCS and NHAMCES data (2007 – 2010)	National comparison of practices with and without EHRs Well-child visits	Presence of an EHR Preventive counseling at child and adolescent well-child visits	Practices with EHRs documented 34% more preventive topics than those without Well-child visits with a fully functional EHR lasted 3.5 minutes longer than those with a basic EHR
White et al., 2013 ¹²⁵ Pre-post, retrospective review of data Academic medical center	374 adolescents, median age 19 (range: 14 to 20) years; 71 providers	CDS revised to reflect current guidelines for screening in adolescents, including raising reminder age to 21 years, and providing guidance about which test (Pap only) is appropriate for young women. Physicians cervical cancer screening patterns for adolescents	Number of pap smears decreased significantly overall (34%, p<0.0005) by 60% among OB/GYNs (p<0.005) and by 20% (p=0.08) among primary care physicians. The proportion of pap smears that were indicated did not change significantly overall or in any department. Most pap tests in both periods were not supported by the guideline-concordant algorithm.
Hacker et al., 2012 ¹¹³ Pre-post Academic pediatric	Seven pediatricians, serving 6,000 patients	Implementation of an EHR (transition from paper records) with a questionnaire for entering results from paper forms previously used to screen for mental illness	Rate of behavioral screening increased in the baseline period from 70% to 91%, but decreased in the training period by 28%.

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
practice			Half of eligible youths were screened in the month after implementation and screening did not return to baseline levels until 3 years after implementation.
Carroll et al., 2011 ⁶⁰ RCT General pediatric practice	2239 children	CHICA decision support and EMR system Implementation of screening for iron-deficiency anemia and tuberculosis based on family response to trigger questions	Physicians were more likely to screen in the presence of risk factors in the intervention group. Anemia: 17.5% vs. 3.1%, p<0.001 Tuberculosis: 1.8% vs. 0.8%, p<0.05
Co et al., 2010 ¹⁸ RCT, cluster General pediatrics; 12 primary care practices	Children aged 5 to 18 years with a prior diagnosis of ADHD; 79 pediatricians	EHR-based decision support, including a) clinician reminders to assess symptoms; and b) and ADHD note template Proportion of children with visits in the study period in which ADHD was assessed and quality of documentation of ADHD assessment	Patients in the intervention practices were more likely to have had <u>any</u> visit at which ADHD was discussed (p=.04); however, they did not have an increased likelihood of a non-well-child visit with ADHD discussion (.p=.27) or a well-child visit with ADHD discussion (.33). 33% of eligible physicians in the intervention group used the ADHD template over the study period. The template was never used for any visit other than one specifically for ADHD.
Bell et al., 2010 ⁷² RCT, cluster Children's Hospital of Philadelphia system, 12 primary care sites in the	stratified on urbanity	CDS alerts embedded in the EHR to encourage physicians to use available asthma management tools Proportion of children with persistent asthma with 1) at least one prescription for controller medications; 2) up to date ACP; 3) for ages 6 , documentation of spirometry	Urban intervention practices had statistically significant increases in controller meds and spirometry compared to controls. Although suburban practices had significant increases pre-post overall, there was no significant difference between intervention and control groups. Of note, urban practices had higher rates of compliance prior to the intervention.
Samaan et al., 2009 ⁹⁹ Pre-post Urban pediatric academic practice	20 attending physician and 26 transient physicians; residents and medical students seeing 14,000 patients with 35,000 visits annually	General Electric Logician 5.5 Version EHR Documentation, medication refill turnaround time, medical record support staff time, billing practices, patient volume and access to appointments, and patient cycle time	Presence of a problem list improved from 29% to 84% within 6 months. Medication turnaround time improved from 48 hours to 12 hours. Forms' turnaround decreased from 7 to 10 business days to 3 to 5 business days. Medical support staff needs decreased from 1 to 0.5 full

Author, Date Study Design Setting	Population	Intervention Target outcomes	Results
			time employee . Although the vendor suggested that patient volume would be returned to baseline after 4 weeks, appointments had to be restricted by 10% for an additional 3 months. This led to an increased wait for the third next available from 3 to 50 days, which returned to baseline in 1 year.
Schriger et al., 2000 ¹²³ Interrupted time series with ITT Academic emergency medicine department	Febrile children less than 3 years of age presenting to the emergency department	CDS based on guidelines for the care of febrile children without known cause Quality of documentation of the medical record and after-care instructions; Appropriateness of testing and treatment decisions and diagnoses; Percentage of testing and treatment charges associated with indicated activities; Per-patient charges per visit	Documentation increase of 21 essential history and exam items from 80% in the control to 92% during the intervention. Percentage documentation of after-care items increased from 48% to 81% Documentation decreased to baseline when the computer system was removed.

Abbreviations: ADHD: attention deficit hyperactivity disorder; EHR: electronic health record; CDS: clinical decision support; CHICA: Child Health Improvement through Computer Automation; NAMCS: National Ambulatory Medical Care Survey; NHAMCS: National Hospital Ambulatory Medical Care Survey

Another study demonstrated that EHRs have the potential to improve counseling and screening at well-child visits.⁶⁰ The Child Health Improvement through Computer Automation (CHICA) system is a decision-support and EHR system pediatric health maintenance and disease prevention. This study focused on screening for two specific conditions: tuberculosis and iron-deficiency anemia. When a patient checks into the clinic, the CHICA system prints a prescreening form. While waiting to see the provider, the patient or parent completes a prescreening form. The responses to the questions on the form are used to generate a provider worksheet that the clinician uses during the visit. In this study, patients were randomly selected to receive questions on the prescreening form about risk factors for tuberculosis and iron-deficiency anemia. If there were concerns, the provider worksheet would then reflect the increased risks with tailored alerts and encourage them to explore this area more thoroughly with the patient and perform risk-based screening tests if appropriate. The study included a control group in which the parents did not receive questions to answer and the provider worksheet contained only a generic reminder to inquire about these two conditions.

This study resulted in significant findings for the detection of risk factors for tuberculosis and iron-deficiency anemia. In the intervention group, significantly more people reported positive risk factors for iron-deficiency anemia as compared with the control group (OR=6.6, 95% CI: 4.5 to 9.5). In the tuberculosis group, there were also significantly higher detection rates of positive risk factors (OR=2.3, 95% CI: 1.0 to 5.0). The authors demonstrated that the CHICA system performs well in assessing risk directly from parents and patients to determine who should receive risk-based screening for tuberculosis and iron-deficiency anemia.

Ongoing Research

It is clear that research that is more rigorous is needed to inform development and implementation, and indeed a number of studies have been identified as being in progress. Studies that are currently registered as ongoing are documented, including their populations, interventions, and outcomes under study in Appendix G. We identified 17 ongoing studies, most of which are being conducted at academic centers, on a range of clinical topics, including improving asthma care, increasing vaccination uptake, weight-based dosing and care for premature infants.

GQ4. Dissemination and future developments

GQ4A. How does testability and usability of core functionalities promote or impede dissemination and future development of pediatric EHRs?

There are a number of challenges associated with the development and implementation of core functionalities for pediatric EHRs.

Implementation of health information technology projects has a very high likelihood of failure – some estimates place failures of software development and implementation as high as 70 percent. Adding pediatric functionalities to existing EHRs may both have a positive effect or negative on implementation success. Among the anticipated positive effects, is the possibility that adding functionalities to EHRs that support workflow and required tasks that pediatricians need to perform will increase provider willingness to adopt these systems. Presumably, under this scenario, they will perceive the value of the improved workflow, reduced documentation burden, and secondary utilization of data, including school physical exams or immunization records.

Negative effects through additional pediatric functionalities may be linked to poor implementation into workflows, inclusion of functionalities that have little value to pediatric providers, and unintended consequences of new pediatric functionalities such as increased documentation burden or increased liability.

Introducing a new pediatric functionality to an EHR should, therefore be done thoughtfully and is ideally done in consideration of utility, testability, and usability principles. Understanding the importance of computability and specificity of guidelines as well as motivations for development pediatric-specific functionalities provides further insight into how dissemination and development will be driven in the future.

Utility

Utility refers to the usefulness of a specific function to both the pediatric provider and the patient. If a pediatric function is added to the EHR that rarely provides value and is associated with a significant burden, for example underdosing alerts,⁸¹ then its utility must be considered as low and vendors and providers should refrain from implementing it into pediatric EHRs.

We identified no specific literature to the topic of utility of pediatric functionalities, although Key Informants identified a number of functionalities that they perceived to have high immediate utility for pediatric providers. These included such as dosing support, immunization documentation and forecasting, documentation of pediatric development and physical exams, anticipatory guidance, and pediatric growth charts, as described in Guiding Question 1. Also, certain high volume diseases and their pediatric specific management needs were identified as targets for functionalities with high value (e.g. subpopulation management of children with asthma).

Testability

Testability or validity refers to the finding that a pediatric functionality actually performs the function it purports to perform. For example if immunization forecasting is added to an EHR, it has to be validated that it actually provides the correct recommendation to a provider. For this scenario, the Centers for Disease Control and Prevention recognized the complexity and provide

a testing framework that allows developers to test their forecasting results against expected results (<http://www.cdc.gov/vaccines/programs/iis/interop-proj/cds.html>)

No papers were identified that focused on testability of pediatric EHR functionalities. The paucity of pediatric specific features in EHRs explains this finding. However, indirect evidence exists that there is a need to validate pediatric functionalities as indicated by the Centers for Disease Control and Prevention effort to allow developers of immunization forecasting to evaluate the validity of their clinical decision support. Anticipating the increased implementation of “Bright Futures” in pediatric EHRs, we also anticipate the need for a validation process. The need is not only determined by the ambiguity and decidability of some Bright Futures recommendations⁶³ but also by the complexity of the decision support required to select the appropriate developmental questions and exams based on age, gender, and prior knowledge of the patient’s state.

The phenomenon of system testability is extremely new and generally poorly understood. Testability is typically relevant to core functionalities that utilize patient-specific data (age, weight, height, immunizations received) and contextual variables (date, planned medication order) to detect out of range or abnormal values (delayed growth, delayed immunizations, inappropriate medication doses for age) to recommend changes in plans (revised immunization administration plans, age-appropriate medication doses) and to compute higher-level patient data (e.g., body mass index.) Systems employing computational approaches to provide these recommendations may be at risk for causing medical errors. These components may, however, be tested against use cases. A Key Informant stated that “testing has been a part of certification the implementation of Surescripts® electronic prescribing messaging standards for more than 10 years.” Testing also has been employed in immunization ordering and status checking¹²⁹⁻¹³¹ and in tools to calculate weight-based dosing of prescription medications.¹³²

These papers demonstrate the need for rigorous assessment of core functionalities amenable to testing, with publication of those results in a way that allows adopters of these patient data to factor these data in their purchasing decisions. However, the literature search returned no papers summarizing the value of testability, researching variation in computation among vendor systems for pediatrics, and assessing the impact of exposing any test results to purchasers.

Usability

Usability describes how well functionality integrates into the workflow of a clinician and can be used at the right time during a visit without interrupting other processes. The implementation alone of desired pediatric-specific functionalities is not necessarily associated with an improved pediatric EHR to support pediatric care, as it is the *usability* of the functionality that drives acceptance. Building pediatric functionality is not enough to assure that the EHR is being used by pediatric providers.

Several comments from Key Informants emphasized the importance of new functionalities being able to support workflows in an efficient manner, at the risk of being underutilized. Among the comments:

- "Frequently, pediatricians report that the core functionality takes too long or is too complicated. Usability is the issue, and is one that is difficult to measure."
- "Software can be designed with the functionality, but if it is not in a workflow-friendly user interface, it does not matter that the functionality exists. A feature list without a gauge of usability is not helpful."

- "One of the chief complaints that you hear from the users is that it is too hard to use plain and simple. If they are too hard to use, then the full benefit of what is the actual functionality is lessened."

One suggestion to increase usability of new functionalities was to recommend that vendors provide real-time, contextual support features to optimize the use of pediatric tools. Usability of EHR functionalities has been recently reviewed by AHRQ.¹³³ There are a number of core functionalities whose usability in the adult literature has affected adoption and dissemination.

However, a literature search did not identify any articles specific to pediatric core functionalities. It is clear from feedback provided to the AAP EMR review site that there is a difference in perceived usability of core functions across the spectrum of commercially available EMRs. Feedback on that site is designed to both steer pediatric practices toward more usable systems and to "raise the bar" of functionality in those systems found less usable. Given the wide variation in perceived usability, it would be useful to understand how these perceptions affect dissemination and future modifications by these vendors. There was implied consensus through the categories evaluated in the EMR review site and expressed consensus by the Key Informants that usability evaluation/research in pediatric EHRs is needed to improve experience, workflow, and incentives for EHR use.

Specificity and Computability

Proposed functionalities should be clearly defined, using specific guidelines and standardized data when applicable to reduce vendor interpretation and translation.

A Key Informant representing a pediatric EHR vendor stated that, "The more concrete and computable, the more likely a vendor is going to pay attention." The same informant gave an example of two different sets of data for pediatric growth charts - one from the Centers for Disease Control and Prevention and one from the World Health Organization - and explained that, "If there is no source of official data, vendors effectively make up the data and put it in their EHR. In practice, vendors can easily produce the features; however, vendors cannot make up the standards."

Key Informants suggested that organizations such as the AAP and other key expert organizations should work with vendors to aid in the creation and dissemination of guidelines and standardized data similar to the work currently performed by the Partnership for Policy Implementation at the AAP.

Incentives for Developing Pediatric Functionalities

Incentives for developing pediatric functionalities for EHRs are currently driven by 1) meaningful use requirements and the patient-centered medical home; 2) a desire to support and maintain patient safety; and 3) the increasing presence of pediatric-specific clinical quality measures.

Meaningful Use (MU) and the Patient-Centered Medical Home (PCMH)

Currently, EHR vendors have been concentrating their development resources on meeting the stages of Meaningful Use requirements, so that their products can become certified and available to providers and hospitals that want to use those products to take advantage of financial incentives. Per one former vendor and Key Informant for this technical report, vendors' ability to respond to customer demands for new features and improved usability has been reduced by half in response to the federal legislation.

Key Informant discussions on how to continue to prioritize and promote/incentivize vendors to develop specific core functionalities for pediatrics focused on the following strategies: patient safety, clinical quality measures, Meaningful Use, and the Patient-Centered Medical Home.

A Key Informant representing a pediatric EHR vendor stated, "for the near future, anything that is in the model pediatric data format that lines up with Meaningful Use or the Patient-Centered Medical Home is much more likely to get done than those that do not. The Patient-Centered Medical Home and Meaningful Use certification are driving development." Increased survival of complex pediatric patients, as well as the increase in chronic illnesses such as diabetes, hypertension, and obesity in pediatric populations, make the care coordination functionality an increasing priority.

Patient Safety

Key Informants suggested that the safety aspect of dealing with pediatric patients is an important consideration. Specifically, pediatric patients have different standards for vital signs. Heart rates and blood pressures that may be considered normal for most individuals are significantly abnormal for certain age ranges. Pediatric patients require weight-based dosing, which is prone to calculation error. Automated calculations remove some of the human check factors leading to the potential for more error. Pediatric EHRs must according to the Key Informants and the literature reviewed in Guiding Question 1 assure that providers receive help in the complex decision making process required in pediatrics especially in the domains of medication management and immunization forecasting.

Clinical Quality Measures (CQMs)

As more CQMs are recommended specifically for the pediatric population,¹³⁴ it will become increasingly important for EHRs to have the capability to support these recommendations, including the collection of required data elements and generation of relevant reports. The literature demonstrated improvements in population health associated with core measures in asthma management.⁷²

Testability of Core Functionalities

As noted above, clearly specified functionalities, which include computable guidelines and data standards where applicable, are preferred by vendors, and such functionalities would be more straightforward to test. However, the usability of the functionalities was clearly presented as a high priority, and testing for usability can be difficult and time-consuming. One Key Informant asserted that "usability and being specific about how to design a function that has conformance criteria are orthogonal concepts or perhaps even contradictory."

An Investigator noted that this issue is currently being discussed in another venue overseen by the Centers for Disease Control and Prevention where features for improving immunization functionalities in EHRs are being addressed, including testing for usability. Knowledge obtained from those efforts would be relevant and provide useful input to this topic.

Summary and Implications

There is expert consensus in the literature that EHRs used in the care of children require specific pediatrics functionalities to support the work of child health care providers and to assure the delivery of quality care to pediatrics patients. These functionalities relate to a child's evolving physiology and maturity and the conditions that are associated with those.^{73,74} Key areas include vaccination, development, physiologic medication dosing, pediatric disease management, pediatric norms, and the relationship between pediatric patients and their caregivers, including adolescent privacy.

Vaccine forecasting and management is generally considered a critical pediatric functionality of an EHR. Forecasting is complex and must reflect local and regional immunization requirements. It must support documentation and appropriate handling of combination vaccinations. In accordance with meaningful use requirements and to support the pediatric clinician, the EHR must have the ability to communicate with one or more vaccine registries and exchange data bidirectionally.

The EHR needs functionalities to support longitudinal assessment of growth and development and counseling regarding injury prevention, proper nutrition, and lifestyle choices. Bright Futures is the primary guideline used by most pediatric clinicians for development and growth as well as screening for abnormalities and anticipatory guidance.⁶¹ Bright Futures recommendations are incorporated into few pediatric EHR's in part due to the large number of items that are neither decidable nor actionable.⁶³ The EHR could maximally support development recommendations by providing tailored longitudinal recommendations for individual patients using clinical decision support.⁹²

A pediatric friendly EHR must support medication dosing based on dynamic physiological parameters such as weight, age, body surface area, and metabolic function. Medication ordering is additionally complicated by a wide array of available tablet strengths and liquid concentrations. The appropriate dose and medication interactions can also change by the route of administration. EHRs should facilitate weight and body-surface based dosing that supports appropriate rounding based on a medication's safety and efficacy margin, which may change based on route and patient's physiology such as hepatic or renal function. Prescribing should also incorporate common features of adult medication management such as drug-drug and drug-allergy checking, provision of an indication and diagnosis associated with each medication, and the ability to provide comments with salient prescription information that should be made available to pharmacists and others downstream. In summary, the EHR prescribing system should provide assistance in selecting appropriate dose and dispensing amounts given the specific patient's physiology and maturity and diagnoses.

The pediatric EHR should support functionality that assists with care and management of common pediatric conditions, such as asthma, attention deficit hyperactivity disorder, and perinatal exposures. On the macro scale, the EHR should support management of clinical subpopulations by allowing creation of customized lists based on condition or feature. On the individual scale, the EHR incorporate clinical practice guidelines and recommendations into the standard clinical workflow, including generation of pediatric specific billing codes and documentation.

A key functionality related to the child's changing physiology and maturity is the incorporation of pediatric specific norms and growth charts into the EHR. A pediatric provider must assure adequate, on-target growth and development. This work requires the EHR to support longitudinal documentation of growth and developmental patterns with adequate age and

granularity specifications. The growth chart should be readily available in the EHR and must capture weight, height or length, head circumference and calculate body mass index, growth velocity, percentiles and standard deviations based on population norms. Display should be available in a variety of formats that vary based on gender and condition (e.g. trisomy 21). The growth chart should support adjustments for gestational age, mid-parental height, bone age measurements, and the ability to manipulate, display, or disseminate data in a variety of ways to suit the clinician's needs.

The pediatric patient is cared for in the context of a dynamic family and social structure. For the young child, this includes linking complex family structures and promoting anticipatory guidance and screening that is tailored to the individual in the context of that structure. As the child become and adolescent, the EHR must support robust privacy controls that may have many complexities. Reports in the literature and Key Informants advocate default privacy functionality that can then be customized to allow differential access to various portions of the adolescent electronic health record. Such privacy settings must be in accordance with state laws that require confidentiality. With granularity and customizability, a successful implementation has the potential to provide even more security than classical paper records and may allow clinicians to better care for the unique needs of the adolescent patient population.⁶⁵

While many of these functionalities are not purely pediatric, their key role in the care of children in contrast to their minimal role for adults could mean they can get overlooked if an EHR is designed primarily for adult care.^{48,54} Yet, if these functionalities are implemented well, the EHR will also undoubtedly better support the care of all patients.

Next Steps

Through discussion with our Key Informants and review of the literature, we have enumerated a list of desirable functionalities that will support the pediatric clinician in caring for children. This list is focused on elements that are unique to children and support the longitudinal changes in physiology and maturity that occur from birth through adolescence and into adulthood. What remain to be measured through rigorous study are the measurable improvements to value of pediatric care that we expect these EHR functionalities to add. As pediatric-specific functionalities are added to more EHRs, we expect to see a great improvement in satisfaction of pediatric clinicians and in the quality of care provided to children.

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