Design of an Interactive Crowdsourcing Platform to Facilitate User-Centered Information Needs Evaluation

By

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Background
Effective medical software is designed to fit the needs of the end users, translating their work into action. User-centered design seeks to involve users at all stages of the design process, but the process itself can be tedious, leading to variable degrees of implementation amongst vendors. This research seeks to create a new method of involving multiple end users remotely in the user-centered design process in order to establish the features and design required for clinicians need to perform effectively.

Objectives
The objectives of this research are to summarize currently identified necessary pediatric-specific EHR functionalities and create an online software platform to delineate further needs and functionalities, contributing to remote user-centered design of electronic medical record software.

Methods
We created Vanderbilt Active Interface Design (VandAID), a novel web-based software platform for crowdsourcing user interface design. The platform provides immediate real-time feedback on user interface design and layout decisions using example patient scenarios. The scenarios can pull information from a variety of sources using standards such as a Fast Health Interoperability Resource (FHIR). The design platform allows the selected options to be sent to a REDCap project for statistical analysis or viewed directly in the VandAID platform. We performed a randomized controlled trial to test the usability and utility of this software platform for the design of a neonatal handoff tool.

Conclusions
This research advances scientific approaches to user-centered design of health information technology by creating a means of collecting remote feedback from multiple users. Results from the randomized controlled trial in the first use case demonstrate this software platform to be a highly usable and effective means of performing cooperative user-centered design.

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CHAPTER I

Introduction

Background

Classical methods of software design focus on implementing specific functions and requirements so that the software can perform a specific purpose. Optimal software design will support the user by translating their work into actions and outcomes.[1] User-centered design seeks to involve end users in all stages of the design process in order to help build software that is more congruent with the work that needs to be accomplished.[2] Current electronic health record (EHR) certification requirements from the Office of the National Coordinator for Health Information Technology (ONC) require EHR vendors to attest to implementing user-centered design principles, but compliance remains variable.[3–5]

Effective pediatric care requires specific EHR functionality which may not be emphasized in other areas of care. It is neither effective nor safe simply to take an EHR designed for adult patients and apply it to the pediatric population.[6,7] One of the main reasons for this is the child’s evolving physiology and maturity associated with growth and development. Some key problem areas include weight-based medication dosing, age-based vital sign reference ranges, key developmental transitions, and well-child care functionalities. In many of these areas, best practices and the key functionalities have not been rigorously evaluated in the medical literature.

This research seeks to identify the needs and requirements for effective care of pediatric patients and to develop new approaches to understand and collect end user technology needs. The research begins with a broad overview of the needed functionalities for general pediatrics with a technical brief examining the current literature, then it shifts on those functionalities that are needed specifically for neonatal medicine. The major body of work in this research focuses on a novel technique to elucidate the needs and functionalities of a specific electronic health record component, which in the initial use case was a neonatal handoff tool.

Objectives

The objectives of this research are to summarize currently identified necessary pediatric-specific EHR functionalities and create an online software platform to delineate further needs and functionalities, contributing to remote user-centered design of electronic medical record software.

Specific Aims

Aim 1: Specific Aim 1 of the research seeks to establish a baseline of current needs and requirements of a pediatric electronic health record. The methods for this portion consist of a Technical Brief for pediatrics in general and a review of the literature for neonatology. A Technical Brief includes a limited systematic literature review and discussions with key informants. Its goals are to provide an objective description of the state of the science, identify a framework for analyzing interventions, and summarize ongoing research and identify research gaps.


**Aim 2:** Specific Aim 2 of the research seeks to develop and evaluate a software platform to facilitate user-centered medical software design. The methods for this portion are largely technical and include web-based software development using JavaScript and the AngularJS development framework. Evaluation includes a randomized controlled trial comparing use of the new design platform with classical user-centered design techniques. The first use case of this software is to evaluate the information needs for an EHR-integrated handoff tool for neonatal intensive care unit (NICU) clinicians.


**Aim 3:** Specific Aim 3 of the research seeks to use the data from the randomized controlled trial in Aim 2 to evaluate the information needs and features necessary for creating a NICU handoff tool. The methods for this analysis will include a variety of ethnographic techniques, including both statistical analysis and visual analysis. Dufendach KR, Unertl KM, Gadd CS, et al. NICU Handoff Information Needs. *(in progress)*
CHAPTER II

Core Functionality in Pediatric Electronic Health Records


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 Children’s EHR Format created almost 700 requirements pertaining to pediatric functionality. While the report included multiple desired functions, the large number of requirements as well as the lack of prioritization may have had a paralyzing effect on most 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, child 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 omitted 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 of pediatric-specific functionalities provides further insight into how dissemination and development will be driven in the future.

FOR FULL TEXT, SEE APPENDIX B
CHAPTER III

Topics in Neonatal Informatics: Essential Functionalities of the Neonatal Electronic Health Record


**Abstract**

Despite the increased use of electronic health records (EHRs), many pediatricians use EHRs that do not contain pediatric functionalities, and no recent attempts to define neonatal functionalities have been made to date. This article describes the fundamental functionalities required in an EHR to provide safe and effective care to neonates, including neonatal data requirements and appropriate display of neonatal data; the need for the mother-infant dyad in the EHR; neonatology-specific scores; and special considerations for medication ordering, nutrition, newborn screening, transitions of care, and documentation. Many EHRs currently lack the functionalities required to provide safe and effective care to neonates. Neonatologists must lobby for better tools to ensure quality and safety for their patients.

FOR FULL TEXT, SEE APPENDIX C
CHAPTER IV

An Interactive Crowdsourcing Platform to Facilitate User-Centered Design

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Abstract

Background
Involving stakeholders early in the design of medical software is particularly important due to the need to incorporate complex knowledge and actions involved in clinical work. Standard user-centered design methods include focus groups and participatory design sessions with individual stakeholders, which generally limit user involvement to a small number of individuals due to the significant time investments from designers and end users.

Objectives
The goal of this project was to reduce the effort for end users to participate in co-design of a software user interface by developing an interactive web-based crowdsourcing platform.

Methods
We developed an interactive, modular platform that allows responsive remote customization and design feedback on a visual user interface based on user preferences. The responsive user interface canvas is designed as an HTML template that connects with the preferences and is updated dynamically through an AngularJS interface. Preference options are defined in a JSON configuration file. Final user preference selections are provided to the design team through an interface with REDCap.

Results
The user interface canvas responds in real time, giving users immediate feedback on the impact of their design choices. Because the interactive canvas is built as an HTML template, the software can be used to design a wide variety of visual interfaces. Invitations to use this design software can be sent via email, and potential end users may then provide their feedback quickly, asynchronously, and if needed, anonymously.

Conclusions
This new web-based crowdsourcing platform can involve multiple users in user-centered design simultaneously and provides means of obtaining design feedback remotely. The software can provide design feedback at any stage in the design process, but it will be of greatest utility for specifying user requirements and evaluating iterative designs with multiple options.
Background

One of the goals of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act was to improve the safety of medical care through the investment in electronic health record systems. However, safety results vary significantly between specific systems and locations.[8] E-iatrogenesis — the unintended negative consequences of implementing health information technology — had been described as early as 2007.[9] If not implemented carefully, unintended consequences of automation can contribute to patient errors.[10] By applying human factors principles into the design of medical software alerts, Russ et al. demonstrated improved usability and decreased prescribing errors in a simulated crossover trial.[11]

Despite advances in existing technology, clinician dissatisfaction with the EHR increased from 24% in 2010 to 39% in 2012.[12] A significant proportion of end user dissatisfaction in healthcare systems is attributable to poorly designed interfaces unresponsive to user workflows and needs. Change management knowledge mandates that end users must be included in the design process and that “workflow and information needs of end users must be studied and analyzed, and the effect of the new intervention must be modeled on workflow, new work demands, interruption of other tasks, and local culture and conditions.”[13] Development of health information technology software requires development of a common ground within the work team of the clinical work that needs to be performed.[14] Medical software design requires input from real users, who “alone have the relevant knowledge and understanding of the actions, and the consequences, of their work.”[14]

User-centered software design seeks to involve end users throughout the design process in order to create an end product that better matches the user’s expectations and experience. By developing the design based on the user’s needs and requirements (for example, by including all data elements required by a user to complete a task on the screen), the software product can better match the end user’s existing workflow as opposed to forcing the user to change their behavior to accommodate the design of the product (like having to interrupt the task and search for the required information elsewhere only to come back to the incomplete task).[15]

Current EHR certification requirements from the Office of the National Coordinator for Health Information Technology require EHR vendors to attest to implementing user-centered design practices in the creation of their software products.[3] However, a recent study examined the user-centered design processes of eleven EHR vendors from February to August 2013 and found a wide range of user-centered design practices ranging from full in-depth contextual analysis to providing methods of receiving requests from users.[4] Whether EHR software designers have a robust or basic user-centered design strategy, they all indicated that they felt user-centered design to be important and wished they had more resources to pursue it further. Yet, a recent examination of usability practices of 50 top electronic health record vendors found that fewer than half used the recommended 15 participants in usability testing, and only about half of those used at least 15 individuals with a clinical background.[5]

Traditional approaches to user-centered design used interviewing and surveying users, but these techniques can prove inadequate, as users often neither know their own requirements nor can they articulate them in ways computable to the design team.[14,16] Involving users in cooperative design or guided user-driven innovation allows end users to becomes a source of innovation in the design process, but such methods have limitations due to the time and expertise demanded on both designers and end users, alike. Due to these demands, end user involvement is often limited to just
a small number of stakeholders, which may not encapsulate the complexity in healthcare information technology systems, which often involve multiple stakeholders in varying contexts of use.[17]

Methods

We developed an interactive web-based platform that allows responsive remote customization and feedback of a visual user interface (Figure 1). Users can express their preferences in the software’s dynamic canvas, where the user interface is built. This canvas responds to settings and preferences from a toolbox available to users.

![Figure 1 - VandAID interface. On the left hand, the user selects content and formatting design decisions from the toolbox. On the right the user experiences the results of all selections in real time on the dynamic canvas.](image)

The platform is built with heavy reliance on the model-view-controller (MVC) software architectural pattern.[18] MVC is a software design pattern that divides the software into three parts. The “model” directly manages the underlying data and logic for the application. The “view” displays an output to the user based on the data contained in the model. The user then interacts with the “controller” to provide input back to the software to modify the model.

The web-based platform is written as a single page application using hypertext markup language (HTML) and JavaScript with the AngularJS 1.5.x framework.[19] AngularJS facilitates data binding between HTML elements and settings stored in the JavaScript data model.

Canvas

Throughout the interface design process, a design team must make decisions about what data elements to display and how to display them in regards to color, font, location on the screen, and other design choices. The canvas allows the design team to test different possible displays and
allowing the users to select the one that best matches their expectations and workflow. The canvas itself acts as the “view” in the MVC pattern. It can respond dynamically to the selections and preferences made by users, giving them direct feedback on the results of their selections.

The dynamic canvas is an HTML document that leverages the power and customizability of HTML 5 and JavaScript. Any graphics, formatting, and even scripts that can be included in a web page can be built directly into the dynamic canvas. This makes this platform ideal for designing custom HTML-based software, such as might be done in creating a SMART (Substitutable Medical Apps, Reusable Technologies) on FHIR (Fast Healthcare Interoperability Resource) application that can be embedded into an electronic health record (EHR) [20].

The canvas responds to the user’s selections and preferences by accessing the values of the preference fields through interfacing with a JavaScript field manager. Although any JavaScript can be used to access the field values, this platform is optimized to use AngularJS directives that allow direct manipulation of the HTML document object model (DOM) based on the values of fields.

Preferences pane

The preferences pane acts as a toolbox from which the user builds the application by first selecting which elements should appear on the canvas and then setting specific element option fields, such as whether out of range values should be bold or how numerical data should be displayed. The options fields are defined in a JavaScript Object Notation (JSON) file and are based on standard survey form elements such as multiple choice, checkbox, yes-no, text, and other options. A separate JSON preferences file allows the elements in the preferences pane to be grouped into categories which can be accessed directly as the user builds the interface.

In the MVC architectural pattern, the preferences pane acts as the controller. The user interacts with the controller to make changes to the values in the underlying model which are then reflected in the view on the canvas.

Integration with REDCap

One of the strengths of this platform is its close integration with REDCap [21]. Using the REDCap API, the platform can import data collection instrument fields directly into the software for use in the preferences pane. The user then modifies the values of these fields directly in the preferences pane. When the user is satisfied with the interface they have created on the canvas, they save and submit their selections which then are transferred to the design team, again through an interface with the REDCap API. REDCap can also be used to create automated email invitations to users. This can allow anonymous feedback submission on the interface being designed as well as end user voting on preferred interface settings.

Results

We have created a software platform that allows users to customize a user interface and see the results of that customization in real time, receiving immediate feedback on the impact of their choices. Our initial test case for this platform seeks to establish the list and formatting necessary to create an effective neonatal patient list for use in a handoff between neonatal clinicians. By allowing the users to select from a menu of items and have them populate the service list in real time, the users are better able to weigh the balance of adding more information with the space required to present that information and the review effort.
The first use case demonstrates the effective use of AngularJS directives to customize the information displayed and the formatting of that information (available at https://vandaid.azurewebsites.net).[22] For example, a user can select the electrolyte panel to appear on the list and can then customize the presentation of the lab data by indicating whether or not out of range labs should appear in bold, and indicating whether or not new labs should appear in italics. Users also have the ability to select if labs are displayed as lists or in graphical format.

This first use case also demonstrates the versatility of this platform in incorporating additional technology into the canvas by incorporating example patient information from a fast healthcare interoperability resource (FHIR).[23] In this case, the laboratory information for each patient is stored in a FHIR-formatted JSON file and loaded into the view asynchronously via a remote procedure call. This is possible because the platform itself acts only as a service interface to provide the canvas with the values in the preferences pane. The view may include any other custom JavaScript and make any additional remote procedure calls as necessary. This same design platform could potentially be incorporated into a live EHR to allow end users to create a custom views or dashboards for their patients.

Twenty-nine (29) neonatal clinicians used the VandAID platform to design and customize a neonatal handoff tool. Users successfully created customized views to their own specifications. Other than a short prompt at the top of the canvas pointing them to the left-sided toolbox and the save and submit button, users received no instruction on using the tool itself, and at no time did any of the clinicians request additional instruction on using the tool from the research team. Designs included details not easily captured in classical pen and paper participatory design sessions, including font size and italicized or bold labs. Participants saw the effects of their selections in five example patients, and several left valuable comments. Following the use of the tool, participants completed a system usability scale survey, giving a mean result of 84.3 (95% CI 80.2-88.4), which places it in the 96th percentile for usability with this standardized survey.[24,25]

Conclusions

Our new design platform provides a means of crowdsourcing electronic health record design from multiple users remotely and asynchronously. The versatility of the interactive canvas means that interface designers can use this process at multiple steps throughout the design cycle as the product moves from rough sketches to high fidelity prototypes and ultimately to a fully functional release candidate. An initial canvas may have little more than plain text or hand drawings, while a design in its later stages may be a fully functional SMART on FHIR application that draws data from a live EHR.

Involving stakeholders at the start of the design process has been shown to improve end user satisfaction and efficiency by matching the final product to the user’s workflow. While not a replacement for user-centered design methods like workflow observation, in-depth interviews, and participatory design sessions, this new design platform adds another low-cost tool that can be used to involve multiple users throughout the design process.

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CHAPTER V

NICU Handoff Information Needs

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Abstract

Background
In inpatient settings, implementing a printed handoff document that interfaces with the electronic medical record has been shown to improve consistency and accuracy of information. The Newborn Intensive Care Unit (NICU) is a complex environment and due to the needs of tiny NICU patients has specific data needs (such as fluids in mL per weight or Apgar scores) not shared by other care areas. Yet, the NICU-specific elements, their display and formatting required to provide an effective NICU patient handoff between providers have not previously been enumerated.

Methods
Neonatal attendings, fellows, and advanced practice clinicians were surveyed to provide input into the design of a NICU handoff document. Six clinicians were invited to complete a participatory design session, while the remaining were invited to use a novel web-based user interface design crowdsourcing platform.

Results
Thirty-five clinicians provided input using the two participatory design methods. The data indicate strong preferences for including identifying information, a “to do” list, ventilation settings, age and weight settings, and a medication list. Compared with supervising physicians, frontline clinicians appeared willing to spend more time updating a handoff document and also requested detailed information on more of their patients. Through the new online design platform, users were able to indicate data formatting preferences.

Conclusions
This study enumerates the patient data elements that neonatal clinicians consider important to include in a handoff tool. The variety of data acquired illustrates the power of using the two user-centered design methods, which complement each other and provide an example for further electronic health record software development.

Background

Individuals vary in their ability to communicate effective handoff information and may exclude pertinent information or add extraneous data that tend to obfuscate valuable information.[26,27] Communication breakdown is a top root cause of sentinel events; an estimated 80 percent of
serious medical errors involve miscommunication between providers during patient handoffs.[28,29] More restricted duty hours for trainees have increased the number of transitions in care and the potential associated communication failures.[30] In a prospective survey of pediatric residents following a call night, nearly one third felt unprepared to handle a situation during call, and in 80% of these cases, the resident reported that potentially helpful information was omitted during their sign-out.[31]

Implementing standardized handoff bundles significantly reduces overall medical error rates.[32] In addition, incorporation of a printed handoff document that is automatically populated with data from an electronic health record (EHR) has improved consistency and accuracy of information transferred during handoffs.[32,33] Incorporating a physician handoff tool into the EHR further facilitates communication among non-physician providers.[34]

Similar to other specialized inpatient care areas, the neonatal intensive care unit is a unique environment with specific data needs.[35,36] Despite the recognition that an effective handoff is necessary for patient safety, the specific elements necessary to provide an effective handoff in neonatology have not been identified.[37] We propose that identifying required data elements, optimal display, and formatting for handoffs will enable development of an optimized tool that can standardize handoffs and improve efficiency, consistency, and quality.

Involvement of the clinician end user is critical for the design of a successful neonatal handoff tool that integrates with the electronic health record. User-centered design employs the three key principles of (1) an early focus on users and tasks, (2) empirical measurement and testing with users, and (3) an iterative cycle of design to address problems and innovations discovered during testing.[38] In a randomized trial, we compared the utility of a novel web-based user-centered design platform to the traditional pencil and paper approach.

**Methods**

We collected user input on the design of a neonatal patient handoff tool from neonatology clinicians, including attending physicians, fellows, and frontline clinicians including hospitalists and nurse practitioners, in order to obtain representative views from each group and to help identify contrasting preferences in the way information is presented. We used two types of cooperative design methods in collecting input: (1) a new web-based user interface design platform we developed called Vanderbilt Active Interface Design (VandAID) and (2) one-on-one participatory design (PD) sessions, a standard method of user-centered design, whereby a prospective end-user creates a low fidelity prototype using tools like paper, pens, scissors, and sticky notes with the help and guidance of a user interface design expert.[39,40]

We invited all eligible clinicians to provide feedback for the design of a handoff tool. Of those who expressed initial interest, two from each professional group were randomly selected, using R software,[41] to participate in one-on-one PD sessions. Prior to each PD session or use of VandAID, a small amount of demographic information was collected, including preferences regarding included patients and level of detail as well as time each participant was willing to spend.
updating a handoff tool. Each PD session was video recorded and then transcribed for further evaluation. All artifacts created were collected by the design team at the conclusion of the session. All remaining interested clinicians were invited via email invitations sent with REDCap to use the new VandAID platform, accessible at https://vandaid.azurewebsites.net.[21,22] This new platform allows users to make design decisions through the use of simple survey-style inputs, that are immediately reflected on the screen’s dynamic canvas. To build a neonatal handoff tool, the users first select which items they want to appear on the page, and then format those items according to their preferences, such as by indicating if out-of-range lab values should appear in bold type. Users are also able to provide textual feedback for options or preferences that were not pre-specified options in VandAID. Once the user is satisfied with the handoff tool design and presses the submit button, her selections and comments are automatically sent to the design team for evaluation.

The design team can evaluate user selections in two ways: (1) stored as a REDCap data entry, and (2) through an evaluation interface built into the design platform to view the output created by each participant. This combined approach allows a variety of ethnographic analysis techniques, including both visualization as well as statistical data analysis, each of which can reveal important user preferences.
This study was approved by the investigational review board of Vanderbilt University Medical Center, study ID 160124.

Results

We invited all eligible neonatology attending physicians (19), fellows (10), and frontline clinicians to participate in the study, and 42 (63%) indicated interest. Of these, 6 were randomly selected for the PD session. The remaining neonatal clinicians were invited to use VandAID to build a neonatal handoff document, and 29 of 36 (80%) of these individuals submitted a design using the online software.

![Figure 3 - Percentage of individuals who desired a particular item on the handoff list, separated by role. PD participants are illustrated with the lighter bars, while the data from the VandAID software is shown with dark bars.](image)

As shown in Figure 3, there were several similarities between the items selected in with VandAID when compared with the PD sessions. All individuals requested a to-do list. The patient name was forced to be included with the VandAID software, although users were allowed to choose how it should appear. Nearly all requested ventilation settings, the patient’s location, age and weight information, and a medication list. No individual requested detailed vital signs, although most requested the patient’s current weight. One item that was omitted from the VandAID item list was an option to select current IV access, although from visualization of the designs produced with VandAID, it appears that one individual used the IV Fluids item with only “route” selected as a surrogate for “access.” Of note, only 63% of individuals selected the medical record number to appear, which could be considered an important safety concern.
When contrasting the PD sessions with the VandAID designs, there are some significant differences in the items included between the two groups. Only one of the PD users included the team name, and only one included a plan by system, both of which were included in over half of the VandAID software designs. PD participants also generally did not comment on item formatting, such as bold or italicized data, although one individual did volunteer that they would like to have resuscitation status bold if not “full code.” Most PD participants also required prompting from the facilitator in order to clarify how laboratory values should appear, whether in a table or in a fishbone diagram.

Several individuals left comments regarding specific items or options not present. Comments were very helpful and addressed specific items not represented by the examples developed.

Several clinicians commented that laboratory values should only be displayed if resulted within a specific time frame, which was a discussion point during several of the PD sessions as well. Another common and expected theme was a focus on automation, that the information in the handoff document should feed directly from the EHR without direct input from the clinician. With automation, there must also be an assumption of a balance between providing general information that would apply to all patients versus specific information key to the care of an individual. For example, some individuals requested a manual checkbox for whether or not to include a specific lab value for a patient, while others were satisfied with an automated process that simply showed the last value if it was within a specific time frame. Adding other items like to-do lists and anticipated problems appeared to be a manual process, although one PD participant pointed out that portions of a to-do list could be automated such as following up on pending or ordered labs or radiographic studies. Attending physicians and fellows, who supervise coverage of a large set of patients, indicated a smaller amount of time that they would be willing to spend preparing a handoff tool than did frontline clinicians (Figure 4).

Figure 4 - Histogram indicating minutes each user would be willing to spend updating a handoff document. A time of zero implies the user would like the entire tool to be created automatically with information pulled from the EHR.

Several clinicians commented that laboratory values should only be displayed if resulted within a specific time frame, which was a discussion point during several of the PD sessions as well. Another common and expected theme was a focus on automation, that the information in the handoff document should feed directly from the EHR without direct input from the clinician. With automation, there must also be an assumption of a balance between providing general information that would apply to all patients versus specific information key to the care of an individual. For example, some individuals requested a manual checkbox for whether or not to include a specific lab value for a patient, while others were satisfied with an automated process that simply showed the last value if it was within a specific time frame. Adding other items like to-do lists and anticipated problems appeared to be a manual process, although one PD participant pointed out that portions of a to-do list could be automated such as following up on pending or ordered labs or radiographic studies. Attending physicians and fellows, who supervise coverage of a large set of patients, indicated a smaller amount of time that they would be willing to spend preparing a handoff tool than did frontline clinicians (Figure 4).
Figure 5 - Histograms from each clinician group indicating user preferences on the types of patients to include on the handoff document and the general amount of detail requested for the patients, with the option to include more detail on relatively critical, sick, or active patients. The least amount of data is represented by the top bars, and the most by the bottom bars.

One of the PD participants and one of the VandAID users indicated specifically that they would like to have a different format for “critical” vs “non-critical” patients. The PD participant indicated there is a certain core set of information that could be included on each patient beyond just demographic information, while the relatively critical, sick, or active patients could have more detail included. This was also captured by asking which patients to include on the printed handoff, where supervising physicians trended toward including details only on relatively sick or critical patients, while frontline clinicians had a stronger tendency to request details on each patient (Figure 5).

The data also show how the VandAID software was able to obtain granular formatting information not easily gained from classical user-centered design techniques such as surveys or PD sessions. Users were given options to italicize new lab values or bold out-of-range values. Each of these options had 52% of individuals who selected it. Users also had the option of adjusting the baseline font size, which potentially allowed for more information to be presented on each page. There did not seem to be a prevailing font size preference.

Mean time spent using the VandAID software was 9.6 minutes per user (median 9, 95% confidence interval 7.4-11.8 minutes), compared with the PD sessions, which lasted a mean of 26.3 minutes (median 27.5, 95% confidence interval 20.3-32.3 minutes).

Discussion

Design of usable electronic health record system requires early involvement of clinicians, as they alone have the “relevant knowledge and understanding of the actions, and the consequences, of their work.”[14] A usable system is one which allows users “to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.”[42] The level of user involvement during the design process can vary from (minimal) user-centered input with surveys and interviews, to (moderate) cooperative design approaches where users and designers work together to design a product, to (maximal) user-driven innovation where users design a product and then present it to a design team for implementation.[17]
This study enumerates the items that neonatal clinicians perceive as important to include in a neonatal handoff tool. It also identifies important differences in information needs according to the clinician’s role. All clinicians emphasized the importance of automation in generating the content for the tool, while frontline clinicians appeared willing to spend more time preparing the content prior to handover; this may be expected since they will likely require more specific information to handle questions throughout overnight shifts. Frontline clinicians also were more likely to request detailed information on every patient as opposed to supervising clinicians, who were more likely to request detailed information on only critically ill patients.

We used two user-centered design methods to obtain input on the content, classical one-on-one PD sessions and a new web-based crowdsourcing platform. Important information was gleaned from both methods, and they proved complementary to each other. Compared to the PD session, the use of the VandAID tool was significantly faster and less onerous to providers and researchers while yielding similar results. Using REDCap functionalities, this tool could be used to incorporate input from much larger groups.

When examining the data on requested items from the VandAID software, it is important to recognize the number of individuals who did not include the patient’s medical record number in their handoff design. While this may seem superfluous to some, it remains an important safety item as a unique identification point. This emphasizes the need for a complete multidisciplinary design team including patient safety experts in the creation of health information technology.

**Role of the Clinical Informatician**

Part of the success of the initial use of VandAID was likely attributable to the fact that the lead designer of the software (KRD) is also a neonatology subject domain expert, which led to user-driven innovation. Identification of items for the toolbox and design of the example items was enhanced by having the expertise of an informatics-trained user. Lacking such a perspective would have required earlier PD sessions or other user-centered techniques.

**Limitations**

The design and options presented in the VandAID prototype were designed by Dr. Dufendach and were thus influenced by his initial vision. Different results may have emerged with an alternate example design. The items and options contained in the Toolbox were limited to what Dr. Dufendach thought were reasonable options to consider. The VandAID software did not collect freeform drawings, although it did collect textual comments as providers felt appropriate. These results represent a single-site study, and they may thus represent a bias to the neonatal information preferences at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

**Next Steps**

Using the information gained from this study, the next steps are to refine the prototype and then send it for further feedback, which can again be done with the VandAID software. For the next version, items and formatting can be preloaded so as to represent the proposed tool. This version could also be sent to multiple sites for additional feedback. In addition, this use case demonstrates the utility of VandAID as a general user interface design tool. This same software and method can additionally be used to create other user interfaces such as patient dashboards or clinical progress notes.
Acknowledgements

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CHAPTER VI

Summary

Effective electronic health record software design requires input from end users of the software through a user-centered design process in order to create usable software that matches the needs and requirements for the end users.[4] This is especially important for clinical software, where the end user often has a unique perspective on the workflow needs and consequences of design decisions.[14] A usable system is one that allows users “to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.”[42]

An EHR used in the care of children requires functionalities specific to the work of child health care providers to assure delivery of quality and safe care.[43] These functionalities relate specifically to the child’s evolving physiology and maturity and conditions related to those.[44] Key areas include vaccination, child development, physiologic medication dosing, pediatric disease management, pediatric norms, and the relationship between pediatric patients and their caregivers, including adolescent privacy. While many of these are not strictly pediatric functionalities, their key role in the care of children means they may get overlooked if an EHR is designed primarily for adult care.[45,46]

As a subset of pediatrics, neonatal care represents an extreme time of human growth and development. Many of the same challenges seen in pediatrics such as physiologic medication dosing, pediatric norms, relationships between neonates and caregivers, and vaccination all apply. All neonates must be screened for a host of diseases, including metabolic disease, congenital heart disease, hearing loss, and hyperbilirubinemia. In addition, those born extremely prematurely share additional risks including severe neurologic, pulmonary, and gastrointestinal disease. Neonates have additional data requirements, including neonatal pain or activity scores.[47,48] The EHR must also support documentation at the extreme range of neonatal physiology, including blood pressures and weights that may be a fraction of those in adults. The EHR must support medication and nutritional orders that are safe for neonates.[49,50] The EHR must also support transitions of care including the very act of being born and must also support transfer appropriate information from the infant’s prenatal history to the postnatal record. In order for the EHR to support the care of these patients, it must be built to support these unique needs and functionalities.

User-centered design seeks to involve end users in all stages of the design process in order to help build software that is more congruent with the work that needs to be accomplished. Current EHR certification requirements from the ONC require EHR vendors to attest to implementing user-centered design principles, but compliance remains low.[3,5] In addition, the actual methods of user-centered design employed by vendors is highly variable. The level of user involvement during the design process can vary from (minimal) user-centered input with surveys and interviews, to (moderate) cooperative design approaches where users and designers work together to design a product, to (maximal) user-driven innovation where users design a product and then present it to a design team for implementation.[17] Unfortunately, while many clinicians have opinions on the usability of medical care software, and vendors also agree that user-centered design is important, very few clinicians actually share their comments with the software design team. Workflow mismatches will often lead to workarounds or potentially medical errors.[4,5,51]

One of the main aims of this research was to create a new method to involve multiple end users in remote user-centered design. This type of input is often obtained using surveys, but these fall short
in truly allowing the user to participate in the design process, as they simply become a list desired items, and the user does not see the consequences of those items. A surveyed user may initially think she wants all information available on a specific patient, but if she were shown a user interface with that information, she may find that including all such information may tend to obfuscate the really important information. This is why we created Vanderbilt Active Interface Design (VandAID), a novel user interface design platform that allows users to make survey-style design decisions and to see the effects of those decisions in real time with a dynamic display that updates in real time, changing based on the selections of the user.

The VandAID platform provides tight integration with REDCap.[21] By using a REDCap API token, VandAID can obtain its question fields directly from a REDCap project. The design team then programs the dynamic canvas to respond to the user’s selections. When the user is satisfied with her design and presses the “Save and Submit” button, her selections are automatically stored as an entry into the REDCap project, where the design team can analyze the results. This tight integration with REDCap also lends this software platform to other potential uses through dynamic surveys with real-time feedback.

VandAID runs entirely in a web browser, which helps to facilitate remote user involvement in cooperative design, as a design team can send invitations via email. The dynamic canvas, which represents the user interface being designed, is written as an HTML-based web page and can incorporate modern web functionality through JavaScript or web services. Although any type of user interface can be represented as a web page, this tight HTML integration makes VandAID an optimal design platform for the creation of new web-based interfaces such as those that use the SMART on FHIR platform.[20,23]

Optimal user-centered design involves end users throughout the design process, from the initial planning stages through all iterative prototyping, and on into deployment and post-deployment review. As the application matures, the VandAID platform can be used to test design decisions with end users, allowing them to give feedback and input into the product. Initial prototypes may contain static images, potentially even scanned drawings. Later versions may allow users to test the full functionality of the software. There is also no reason to limit the platform to using fabricated example patients. By interfacing with SMART on FHIR technology, designers could present live patient data into the VandAID canvas, which would ensure all relevant nuances of an actual patient are represented. In its optimal implementation, the VandAID platform can be used to give end users an unobtrusive means of providing post-deployment feedback on a software product.

In the initial use case, the VandAID software was used to help design a handoff tool for use in the neonatal intensive care unit. Thirty-five neonatal clinicians participated in a randomized controlled trial that compared the cooperative design strategies of classical participatory design (PD) methods with the new VandAID platform. Both methods produced valuable design information. The VandAID platform was able to obtain granular formatting preferences, including font size and styles like bold and italics. Overall, the VandAID platform also involved more users, took less time, and was rated highly in terms of usability.

This platform does not seek to replace other user-centered design methods, but rather to add another tool that can be used to obtain user feedback throughout the design process. The VandAID platform is still limited to displaying feedback on options it can evaluate electronically, which means designers still need to have early input from users on potential options to be included in the
software. This information can be gained from participatory design workshops or from input gained from a clinical informatician.[14]

By integrating an end-user feedback mechanism directly into the design of a medical software user interface, this new tool helps to bridge the gap between the design team and end users. This tool supplies a powerful, yet lightweight user interface design and feedback tool. Its versatility is broad enough that it can be used for multiple types of design projects at multiple steps along the process. By showing end users the immediate effects of their selections, this tool seeks to mitigate the effects of unintended consequences to design decisions. The tool itself also would lend itself well to an adapted Delphi method to designing user interfaces. With varying levels of customization, it can support a wide range of user interface design tasks, from obtaining comments from users to creating completely customized user interfaces. This research seeks to advance scientific approaches to user-centered design of health information technology by creating a means of collecting remote feedback from multiple users.
APPENDIX A

Role of the student in the manuscripts

Core Functionality in Pediatric Electronic Health Records
Dr. Dufendach was lead author on this manuscript and played an important role in the planning, evaluation, and writing processes. He acted as lead for the clinical and informatics trainee group. He responded to all clinical critiques from public comments. He provided substantive editing for the final version of the manuscript.

Topics in Neonatal Informatics: Essential Functionalities of the Neonatal Electronic Health Record
Dr. Dufendach was lead author on this manuscript and wrote a significant portion of the document. He also played a significant role in editing and responding to editor comments.

An Interactive Crowdsourcing Platform to Facilitate User-Centered Design
Dr. Dufendach was lead author on this manuscript and wrote the majority of the document. He was also the inventor and creator of the software platform itself.

NICU Handoff Information Needs
Dr. Dufendach was lead author on this manuscript and wrote the majority of the document. He also facilitated the participatory design sessions and performed the majority of the analysis on the data collected.
APPENDIX B

Core Functionality in Pediatric Electronic Health Records
Core Functionality in Pediatric Electronic Health Records
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.

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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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Core Functionality in Pediatric Electronic Health Records

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 Children’s EHR Format created almost 700 requirements pertaining to pediatric functionality. While the report included multiple desired functions, the large number of requirements as well as the lack of prioritization may have had a paralyzing effect on most 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, child 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 omitted 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 of pediatric-specific functionalities provides further insight into how dissemination and development will be driven in the future.
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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. In particular, they suggest that EHRs used in the care of children may increase patient safety through standardization of care and reducing errors and variability in documentation and communication of patient data. However, adoption has lagged, and lack of pediatric functionality is often cited as a reason for the lower rates of adoption in pediatrics. 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.

Empirical data describing the specific benefits of pediatric EHRs are scarce, and few studies have been conducted in the pediatric setting to assess the potential benefits of pediatric functionalities. Some studies describe improvements in immunization rates, attention-deficit/hyperactivity disorder care, preventive care counseling for children and adolescents, and hepatitis C status followup in infants. Ultimately, available research on outcomes has yielded inconsistent results, potentially due to great variety and variability of systems reviewed.

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. Organizations including the Agency for Healthcare Research and Quality (AHRQ), Health Level 7 (HL7) International, and the AAP 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.

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. 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. 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. It is unclear whether providers 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. Only 31 percent of pediatricians use...
an EHR with basic functionality, and only 14 percent use a fully functional\textsuperscript{a} EHR.\textsuperscript{52} Only 8 percent of pediatricians are using a fully functional EHR with pediatric functionality.\textsuperscript{53}

The Children’s EHR Format included almost 700 requirements pertaining to pediatric functionality.\textsuperscript{46} While the report included desired functions to support care of children, the large number of requirements may have had a paralyzing effect on vendors, who, additionally confronted with Meaningful Use requirements, did not leverage the format to improve their products. Reports from Children’s Health Insurance Reauthorization Act 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. Similarly, the HL7 requirements\textsuperscript{b} 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. Fundamental to pediatric care is supporting the dynamic physiological and developmental changes to assure change is occurring at the right pace and time.\textsuperscript{54}

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).

\textsuperscript{a} 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 followup 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\textsuperscript{49} and Jha et al., 2009\textsuperscript{51}).

\textsuperscript{b} HL7 EHR Child Health Functional Profile (CHFP), Release 1. Available at http://www.hl7.org/implement/standards/product_brief.cfm?product_id=15.
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, 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 functionalities 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 gray 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 (GQ) and have summarized the available literature and Key Informant perspectives. GQ1, GQ2, and GQ4 reflect information found in published and unpublished literature, including opinion pieces and general materials. They also include the perspectives of our Key Informants. GQ3 is limited to a high-level evidence map of empirical studies. Thus, GQ1 and GQ2 lay out the issues that were found to be of highest relevance, while GQ3 identifies the available empirical literature on those issues. GQ4 then addresses challenges and opportunities related to implementation and dissemination.

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 provider 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 (1) vendors; and/or (2) 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 (1) better quality, including safety and cost outcomes for patients; and/or (2) improved workflow or job satisfaction for providers?

GQ3B: Which pediatric-specific functionalities influence (1) patient outcomes (including safety, quality, cost, equity, standardization of care; and/or efficiency); (2) the ability of a pediatric provider to conduct work within the EHR; (3) improvement of workflow and provider satisfaction; and/or (4) 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 10 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 (GQs). Before the call, we provided the participants with a copy of the protocol and GQs. 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.

We conducted discussion calls with nine Key Informants. We were not required to obtain Office of Management and Budget (OMB) clearance for the Key Informant interviews because we included fewer than ten non-government associated participants. 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 GQs; we further evaluated the publications for evaluation studies that met prespecified criteria (Table 1) for GQ3 (Evidence Map).
To identify newly published relevant literature, we updated the literature search during peer review and the posting period for public comments. We incorporated 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 G).

### Table 1. Inclusion and exclusion criteria for evaluation studies

<table>
<thead>
<tr>
<th>Category</th>
<th>Criteria</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Pediatric, outpatient</td>
</tr>
<tr>
<td>Publication languages</td>
<td>English only</td>
</tr>
<tr>
<td>Admissible evidence</td>
<td>Study design</td>
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<tr>
<td></td>
<td>Randomized controlled trials, including wait-list control, cohorts with comparison, pre-post cohort without comparison, stepped wedge designs, and case-control.</td>
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<tr>
<td>Outcomes</td>
<td>• Healthcare quality including safety and cost</td>
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<tr>
<td></td>
<td>• Improved workflow</td>
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<tr>
<td></td>
<td>• Job satisfaction for providers</td>
</tr>
<tr>
<td></td>
<td>• Patient outcomes including safety, quality, cost, equity, standardization, efficiency</td>
</tr>
<tr>
<td></td>
<td>• Patient and family involvement including education and shared decision making</td>
</tr>
<tr>
<td>Other criteria</td>
<td>Original research studies that provide sufficient detail regarding methods and results to enable use and adjustment of the data and results.</td>
</tr>
</tbody>
</table>

### 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 relevant consensus statements in Appendix E. We retrieved records from ClinicalTrials.gov to identify ongoing research (Appendix F).

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 Web site and summarized those by functionality (User Perspective from AAP Review System). The goal was to identify any themes that might emerge in users’ spontaneous reviews of systems, but we should be clear that we did not conduct primary data collection to gather this information. It reflects those issues raised through the AAP.

### 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

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the literature, Key Informant discussions, and gray literature for each theme for GQ1. In GQ2, we address contextual issues including transition of care, health care setting, and implementation considerations from the literature base and the Key Informant input. For GQ3, 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 (GQ3). We highlight the roles of testability and usability in the successful dissemination and future development of pediatric-specific EHRs in GQ4.

Based initially on Key Informant input and with confirmation from the literature, we organize the report around eight categories for the pediatric functionalities: (1) vaccines; (2) routine health care maintenance; (3) family dynamics; (4) privacy; (5) managing pediatric populations; (6) medications; (7) documentation and billing; and (8) pediatric-specific norms and growth charts.

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 make 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.
Findings

In this section, we summarize information from the published and gray literature sources to address Guiding Questions (GQs). 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 child development, family dynamics and privacy challenges, medication ordering, and pediatric growth and child 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 (GQ1). In GQ2, we provide a discussion of transition, care setting, and other contextual issues important to the implementation and adoption of pediatric-specific functionalities described in GQ1. The results presented in GQ3 are the combined summary of existing evidence from the published literature. We present implications and areas for future research in GQ4.

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?

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 consistently. 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. The ability to communicate between the healthcare setting and schools and other settings where children exist was described as essential, as was recognition that providers in children’s healthcare represent a wide range of clinical specialties, all of whom need information and means of communication to provide care.

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 following section will address specific information for: (1) vaccines; (2) routine health care maintenance; (3) family dynamics; (4) privacy; (5) managing pediatric conditions in...
vulnerable populations; (6) medications; (7) documentation and billing; and (8) pediatric-specific norms and growth charts. The functionalities identified and described 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 GQ3.

1. 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. As noted in the Evidence section below, vaccination reminders appearing in a clinician’s workflow have successfully improved vaccination rates in some populations. 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. To assist in documentation of progress in specific vaccine series, combination vaccines should optionally be viewable according to individual components. 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. In one study, immunization reminders did not significantly improve immunization rates at a primary care clinic. However, other empirical studies, further described in GQ3, have shown significant increases in vaccination rates with CDS. 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, 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.

**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, including interstate registries, when available. 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. 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. 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. One recommendation has been that a flow sheet incorporated into the system provide additional information on recent or anticipated immunizations, thus providing additional tracking.

**User Perspective From AAP Review System**

Comments on functionality related to vaccinations were common on the AAP EHR review Web site, 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 (e.g., DTaP-IPV-Hib).
• Ability to enter the combination vaccine and have the system recognize that the vaccine provides adequate immunization to multiple illnesses.

2. Routine Health Care Maintenance (RHCM)

Summary of Recommended Functionalities and Issues Identified by Key Informants

Childhood routine health care maintenance, also known as “well child care,” accounts for nearly half of healthcare visits made by children in the United States. 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 child development, two key elements of a childhood RHCM.

The most widely used pediatric preventive care guidelines are the Bright Futures Guidelines for the Health Supervision of Infants, Children, and Adolescents. These emerged prevalent both in the literature as well as in discussions with Key Informants. These guidelines describe a comprehensive system of care and contain content for the 21 primary care visits recommended by the AAP for children from birth to 21 years of age. Key Informants noted a lack of synchrony between currently available EHRs and Bright Futures.

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. 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.

Summary of Recommended Functionalities and Issues Identified in the Literature

An idealized EHR would use 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 compatible with recommendations such as those in Bright Futures. The results of the questionnaire would serve as the starting point of the visit.

As of 2008, no existing EHRs was completely “Bright Futures compatible.” Since then, several products have implemented portions, but adoption has been slow. Compliance with Bright Futures requires 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. Compliance also requires supplying patients and families with an after-visit summary including current height and weight, anticipatory guidance, immunization forms, school or sports physical forms, and informational handouts. The AAP Task Force on Medical Informatics also recommended 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.60

**User Perspective from AAP Review System**

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

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

**3. 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. By successfully tying family structures together, an electronic health record can help identify and populate shared family history, social environment, and even billing structures. An EHR should support easily sharing related data between family members and linking between individual records. As family structures become more complex and dynamic, this feature is increasingly important to the clinician to understand the influences on a child’s health in order to provide the most appropriate care. Without the functionality for family within an EHR, workflow can become unduly complicated when information needs to be duplicated between family members or privacy and confidentiality policies need to be updated for children who reach a certain age.

**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.21,66 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 from AAP Review System**

We identified few comments on functionality related to family dynamics on the AAP EHR review Web site. 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.

4. 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 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 medical 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. 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. 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. 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.

Part of the difficulty of implementing successful privacy management for adolescents stems from the fact that individual practices have widely varied needs due to unique local laws and clinic policies. Currently, the responsibility for delivering confidential patient care is shared among clinicians, hospital and clinic administrators, patients, families, and EHR vendors. A breach of confidentiality can happen at any point in the process, from scheduling of the appointment to billing for services provided (Table 2). 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 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

<table>
<thead>
<tr>
<th>Step</th>
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<tbody>
<tr>
<td>Scheduling an appointment</td>
</tr>
<tr>
<td>Confirmation of appointment</td>
</tr>
<tr>
<td>Reviewing and reconciling medication or problem lists with a parent present</td>
</tr>
<tr>
<td>Receiving and filling new medication prescriptions</td>
</tr>
<tr>
<td>Releasing sensitive laboratory results</td>
</tr>
<tr>
<td>Automated posting of an explanation of benefits or after visit summary</td>
</tr>
<tr>
<td>Request for summary of care or copies of medical records</td>
</tr>
</tbody>
</table>

Note: Adapted from Table 1 in Anoshiravani et al., 2012 and Gracy et al., 2012

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. 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. 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. 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 nonsensitive data. An optimal EHR designates sensitive information private to unauthorized individuals while allowing access to non-sensitive information. While most elements of the visit should remain confidential, some routine laboratory results and immunizations could be shared with a parent or guardian 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.

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. 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, Lynch Syndrome, 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.70 While EHR designers will undoubtedly develop their own implementations of this functionality, Anoshiravani et al., (2012)70 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.22,70 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.70 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, 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.72 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.48,68 A simple example of control would be to allow age-based differential access that are enforced once a patient reaches
specific milestones such as age 13 and 18, although many other options exist. An adolescent should be able to provide such access in a noncoercive manner in a private setting.

**User Perspective From AAP Review System**

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

5. Managing Pediatric Conditions in Vulnerable Populations

**Summary of Recommended Functionalities and Issues Identified by Key Informants**

Although all pediatric populations can benefit from the use of an EHR, this can be especially useful in managing the care of vulnerable populations. 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; as an objective, regulations include generation of patient lists by condition so that a provider may better care for a clinical subpopulation. Key Informants mention that the ability to easily identify specific lists of patient populations allows practices 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. For example, an EHR might recommend thyroid testing or a cervical spine x-ray for a patient with trisomy 21. Little EHR-specific 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.\textsuperscript{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.\textsuperscript{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 asthma 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.\textsuperscript{76}

\textbf{User Perspective From AAP Review System}

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 United States, such as immunization reconciliation and additional screening requirements.

\section{6. Medications}

\textbf{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.\textsuperscript{77} First, a child’s continuously changing physiology presents an important complicating factor for medication management.\textsuperscript{77,78} 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.\textsuperscript{3,79}

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. The range variability among physical characteristics in children is much wider in pediatric patients than for adults, ranging from a 500-gram premature infant to an obese adolescent weighing greater than 100 kg. In certain cases, a specific dosing strategy may be contraindicated, such as when usual weight-based dosing would result in a calculated dose that is larger than a medication’s maximum dose for an adult-sized pediatric patient. 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.\textsuperscript{80}
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, weight, body surface area, 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 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.”

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. The process is further complicated by a large selection of alternative routes (oral, rectal, intravenous, subcutaneous, intrathecal, intraosseous, via gastric tube) and significant variation 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.

While amoxicillin-clavulanate is typically used in one or two dose forms for adults, thirteen different formulations are routinely used in pediatrics, increasing the chance of a prescribing error. The need for individualized dilution of stock medications and pediatric compounding of medications, with parenteral nutrition being the most complex, places 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. For premature infants, even the patient’s age can variably be referred to as chronological age, which is based on birthdate, or postmenstrual age, which represents time of gestation.

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.

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. 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. 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. In a study of pediatric dose range checking, clinicians overrode under-dosing alerts much more frequently than overdosing alerts.

**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 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. 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. 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; automated dose rounding; age correction and adjustment for infants; and optimized display options for medication orders.

**Table 3. Requirements for CDS to support electronic prescribing**

<table>
<thead>
<tr>
<th>Feature</th>
<th>Specific Details</th>
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</table>
| Weight-based dose calculations and range checks | • 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 exit.  
  • Use pediatric norms with respect to range and alert levels, citing patient weight / age with soft-stops for adult dose. |
| Dose rounding                                 | • 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                 | • System should provide appropriate alerts for age correction for preterm infants, neonates, and small weight patients. |
| Optimized options for medications             | • 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                         | • These options may be considered for more advanced systems  
  • Specialized label printing for ‘School-day’ doses. |

**User Perspective From AAP Review System**

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 popup) for brief description and justification of calculations to permit “Show your work”.

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• 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.

7. 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 from AAP Review System

Reviewers mentioned repeatedly that pediatric EHR systems should have the possibility of customization, often without explaining what to customize. The notion is implied that pediatric office visits typically comprise a limited 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, such as when a provider needs to capture a patient’s response to a specific screening tool or when they need to complete documentation for secondary use of medical data, such as with school or athletic forms.

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 and problem lists in children often tend to be more dynamic than in adults.
The fact that providers 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 provider’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 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.

Finally, it was noted in peer review that, optimally, EHRs will connect with evidence-based recommendations directly.

### 8. 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, 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. For example, 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.60 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 references 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 body mass index (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.”60

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.89 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.89

<table>
<thead>
<tr>
<th>Table 4. Desiderata for management and representation of pediatric growth in an EHR system*</th>
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<tbody>
<tr>
<td><strong>Workflow</strong></td>
</tr>
<tr>
<td>Use routinely gathered growth measurements</td>
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<tr>
<td>Automatically generate growth charts</td>
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<tr>
<td>Growth charts accessible from standard EHR system components</td>
</tr>
<tr>
<td>Growth data and calculations reusable for other tasks (e.g., decision support, documentation)</td>
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<tr>
<td><strong>Growth data</strong></td>
</tr>
<tr>
<td>Capture weight, height or length, head circumference</td>
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<tr>
<td>Calculate body mass index and growth velocity</td>
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<tr>
<td>Calculate percentiles and standard deviations based on population norms</td>
</tr>
<tr>
<td>Capture data using different units of measurement (e.g., grams, kilograms, pounds)</td>
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<tr>
<td>Capture context of measurement (e.g., lying or standing, ventilated, receiving growth hormone)</td>
</tr>
<tr>
<td>Support automated data capture from measurement devices (e.g., digital scales)</td>
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<tr>
<td><strong>Presentation</strong></td>
</tr>
<tr>
<td>Display growth data on standardized charts as the default view</td>
</tr>
<tr>
<td>Display against standard population-based normal curves</td>
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<tr>
<td>Display normal curves based on age, gender, and other demographic characteristics</td>
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<tr>
<td>Display using graphical and tabular formats</td>
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<tr>
<td>Display predictive growth curves or growth targets</td>
</tr>
<tr>
<td>Display time and date of birth for infants</td>
</tr>
<tr>
<td><strong>Functionality</strong></td>
</tr>
<tr>
<td>Calculate mid-parental height by gender-specific parent height percentiles</td>
</tr>
<tr>
<td>Display bone age measurements with actual age measurements</td>
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<tr>
<td>Display development states (e.g. Tanner stages) with actual age measurements</td>
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<tr>
<td>Derive and display and the median age at which a given growth point is achieved</td>
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<tr>
<td>Allow adding, deleting, and editing of growth points</td>
</tr>
<tr>
<td>Enable varying the scale’s level of detail (i.e., zoom in or out)</td>
</tr>
<tr>
<td>Support printing and faxing</td>
</tr>
<tr>
<td>Support user preferences (i.e., connected points, superimposed values, table or graphical chart)</td>
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</table>

EHR = electronic health record
* From Rosenbloom et al., 200689
Subpopulation-Specific Growth Charts

Growth may be altered or impaired in some conditions including prematurity and Down syndrome, Turner’s syndrome and others. 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.90 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.91 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.92 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 From AAP Review System

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 Web site expressed satisfaction with the fact that pediatric growth charts were available to them. However, a few reviewers reported using EHR systems that did 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 for automatic percentile calculations;
- 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; and
- 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 needs 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. As with the description of Bright Futures, 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. States differ in how many conditions are tested during newborn screening, but diseases such as phenylketonuria, hemoglobinopathies, cystic fibrosis and several others are common among all states. In the environmental scan for the Children’s EHR Format, Intermountain Health reported that 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.” Due to the rare nature of the diseases being screened, a primary care provider may never have previously encountered one of these conditions. As such, the EHR must facilitate clear dissemination of results and decision support for immediately required actions as well as readily accessible storage of results for use throughout childhood and even into adulthood.

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.\textsuperscript{21}

The transition from infancy into childhood is 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.\textsuperscript{96}

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.\textsuperscript{22} The American College of Obstetrics and Gynecology 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.\textsuperscript{97} Important age-based transitions that the pediatric EHR should support are summarized in Table 5.
Table 5. Key age-based transitions relevant to EHR development

<table>
<thead>
<tr>
<th>Transition</th>
<th>Challenges</th>
<th>Relevant Functionalities</th>
</tr>
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<tbody>
<tr>
<td>Fetal to Newborn</td>
<td>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.</td>
<td>Documentation (specifically growth tracking and screening tests as well as mother baby link to allow maternal labs to be linked to the infant) Child development</td>
</tr>
<tr>
<td>Newborn to childhood</td>
<td>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.</td>
<td>Vaccines Child development Anticipatory guidance Population Management</td>
</tr>
<tr>
<td>Childhood to adolescence</td>
<td>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.</td>
<td>Child development including risk behaviors Medications Population Management Privacy</td>
</tr>
<tr>
<td>Adolescence to adulthood</td>
<td>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.</td>
<td>Privacy Population Management</td>
</tr>
</tbody>
</table>

Inpatient and Outpatient

Some patients transfer between inpatient and outpatient care multiple times. 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”. 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 (HIE). 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 likewise 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 readmission rates for patients with asthma. Two of the three measures have maintained greater than 95 percent compliance nationwide for the use of relievers and corticosteroids for inpatient admissions. The third measure focuses on self-management by providing a home management

\[d\] As defined by the Healthcare Information and Management Systems Society (HIMSS) Health Information Exchange (HIE) “provides the capability to electronically move clinical information among disparate healthcare information systems, and maintain the meaning of the information being exchanged.”
plan of care or “asthma action plan.” Such plans apply also to school and recreation. 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 use 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 followup. The group anticipates that improved EHR support will increase the level of evidence-based care patients receive.

Similar to asthma action plans, the literature search identified forms known as “emergency information forms” (EIF), also known as an individualized plan of care, as an important function to facilitate transitions of care, especially between the patient centered medical home, specialty services, and acute care. The AAP and American College of Emergency Physicians endorsed the EIF as a minimum data set for use in emergencies. The EIF is optimally created in the patient centered medical home for a child with specific or complex medical conditions 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.

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.” 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.”

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 provider 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 child 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 GQ4 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 pediatric provider 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.103

**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.104 The literature search identified concerns in addressing immunization status accuracy. Both parents’ and provider’s records included errors.105 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.

**Routine Health Care Maintenance**

RHCM tracking is a particularly challenging area of general pediatrics. The AAP has approved nine different developmental screening instruments – all of which vary in format, sensitivity, specificity, and modality. Many of these are licensed products, which may impede incorporation into the EHR.106 *Bright Futures*, the most commonly used reference for RHCM, has proven difficult to incorporate actively into electronic health records due to only a minority of recommendations being computationally decidable and executable.65 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. This applies both to anticipatory guidance and screening recommendations as with RHCM as well as with decision support for appropriate diagnosis and treatment during acute visits. Decision support can be used to prompt a provider to recommend the appropriate vehicle restraint device based on the child's age, height, and weight, but the EHR cannot easily evaluate whether a child has accomplished “learning to manage conflict nonviolently”, “avoiding situations in which drugs and alcohol are
readily available”, and “avoiding risky situations.” Implementing Bright Future guidelines electronically will require discrete recommendations, age-based topics, and completely standardized wording.

**Privacy**

Those who do not care for adolescent patients regularly may consider adolescent privacy as a niche issue. 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.

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.

**Managing Pediatric Conditions in Vulnerable Populations**

An EHR that supports management of clinical subpopulations will support generation of patient lists with a unifying feature as well as decision support to improve care of each individual patient. In order to implement such recommendations, clinical practice guidelines must be both decidable and executable. Generation of such lists must be done in the context of respect for patient privacy in cases of potentially sensitive health information. 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.

Implementation challenges for managing a vulnerable population fall generally into two categories: identifying individuals in the population and providing care tailored to their particular needs. Identifying children in social contexts such as homelessness or foster care can be difficult unless an EHR contains a mechanism for tracking these social constructs. If these individuals are identified properly, a Patient-Centered Medical Home can help ensure the children are receiving necessary social and community support. An EHR can assist in identifying children with complex care needs. For these individuals particularly, the storage of complex and varied data types that can be shared between institutions is critical.

**Medications**

Enhancing an adult-focused ordering system for safe pediatric medication management is an intense and sophisticated task and has limitations. Such efforts require high-level sponsorship, involvement of clinicians, and round-the-clock support. Nevertheless, these efforts are seen as necessary and beneficial in reducing medication errors. 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.

Documentation and Billing

An EHR to support billing and documentation incorporates into a clinician’s workflow. Currently, patient data is often spread across multiple health systems. Health information exchange barriers can hinder assimilation of this data. Users of pediatric EHR systems often requested the ability for customization but without specific indicators on what needs to be customized. In order to provide customization, venders will need to know which areas and options the clinician would like to customize. Pediatric providers also often requested incorporation of specific screening tools and local athletic or immunization forms. For proprietary tools, licensing can be a barrier to implementation. Local forms may require specific customization for inclusion.

Pediatric-Specific Norms and Growth Charts

Both the Centers for Disease Control and the World Health Organization have published validated growth charts for boys and girls, with the distinction of the World Health Organization chart being a growth standard and the Centers for Disease Control chart being a growth reference. Unfortunately, validated charts do not exist for many diseases, despite these being highly desired by pediatric providers. This creates a challenge for EHR venders who must choose either to including non-validated charts in their software, to rely on customers to decide which charts they will support, or not to include alternates at all.89-91

Growth charts are not the only pediatric data without validated norms. Almost every information category from laboratory test reference ranges to medication doses to vital sign measurements contains gaps in pediatric normative data. Venders continue to face this constant challenge of what data to use for pediatric standards.
GQ3. Evidence for Pediatric-Specific Functionalities (Evidence Map)

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)?

The evidence base that we identified for GQ3a and GQ3b consisted of targeted existing systematic reviews, supplemented by original studies published since completion of those reviews. For GQ3a and GQ3b, we were limited our inclusion to empirical literature that provided data on the specific outcomes in these questions.

As this is a technical brief, and not a systematic review, we did 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 GQs. Therefore, we describe the empirical literature that is available in an attempt to provide indirect evidence around these issues. For example, studies did not compare non-pediatric to pediatric EHRs, as would be ideal for GQ1. There were a number of studies describing the de novo implementation of a pediatric EHR using a pre-post approach. Therefore, we combined the answers to these GQs to provide as complete a view of the available literature as possible. We have organized the literature around the functionalities described in GQ1.

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, and one assessed pediatric-focused health information technology.

The amount of empirical literature meeting our questions was limited. Nonetheless, we grouped the information thematically into efforts to improve vaccinations 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 directly compared a pediatric-specific EHR to one developed for an adult population.
Across all clinical topics, we examined 30 studies that evaluated the implementation of an EHR overall or modifications to or additions to an existing EHR. One study reported on outcomes related to workflow, including satisfaction, but most studies reported process 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. 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.
Vaccination-Specific Functionality

As described in GQ1, the availability of vaccine services support in a pediatric EHR is consistently described as a 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. 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 was consistently described in the nonempirical literature and by our Key Informants as essential and the body of literature provided 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

<table>
<thead>
<tr>
<th>Author, Date Study Design Setting</th>
<th>Population</th>
<th>Intervention Target outcomes</th>
<th>Results</th>
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<tbody>
<tr>
<td>Fiks et al., 2013&lt;sup&gt;120&lt;/sup&gt;</td>
<td>All girls ages 11 to 17 years due for at least one HPV vaccine in the study period</td>
<td>Clinician and family directed decision support, using an existing EHR&lt;br&gt;Clinician intervention: EHR-based alerts for all routine adolescent vaccinations; 2) 1 hour presentation and 3) quarterly performance feedback reports&lt;br&gt;Family intervention: automated telephone calls based on an EHR-generated roster.&lt;br&gt;HPV vaccination rates (cumulative incidence) and time to vaccine receipt.</td>
<td>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.</td>
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<tr>
<td>Nelson et al., 2014&lt;sup&gt;19&lt;/sup&gt;</td>
<td>Pediatric systemic lupus erythematosus&lt;br&gt;Pre: 40 charts&lt;br&gt;Post: 20 charts</td>
<td>CDS in existing EHR&lt;br&gt;Rates of compliance with infection and cardiovascular disease preventive care quality indicators</td>
<td>PVX vaccine (%)&lt;br&gt;Pre: 31.3&lt;br&gt;Post: 81.0&lt;br&gt;Influenza vaccine (%)&lt;br&gt;Pre: 33.3&lt;br&gt;Post: 95.0&lt;br&gt;Lipid panel (%)&lt;br&gt;Pre: 25.0&lt;br&gt;Post: 76.0</td>
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Table 6. Selected evaluation and outcomes studies on interventions to increase vaccination rates in pediatric care (continued)

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<thead>
<tr>
<th>Author, Date Study Design Setting</th>
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<tr>
<td>Pollack et al., 2014&lt;sup&gt;479&lt;/sup&gt; Pre-post, retrospective Seattle Children’s Hospital</td>
<td>All children 6 months of age and older hospitalized between 2003 and 2012 Admissions: 20,651</td>
<td>System integrated into EMR to determine flu vaccine eligibility, conduct screening and order appropriate formulation Screening status and vaccination status</td>
<td>Screening rate (%) Pre: 19.8 Post: 77.1 Vaccination rate (%) Pre: 2.1 Post: 8.0</td>
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<tr>
<td>Bundy et al., 2013&lt;sup&gt;8&lt;/sup&gt; Interrupted time series Urban, hospital based pediatric primary care clinic</td>
<td>children seen by pediatric residents and selected from 3 age groups</td>
<td>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</td>
<td>Up-to-date on index birthday No clinically meaningful change Up-to-date within one year of index birthday No clinically meaningful change</td>
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<tr>
<td>Fiks et al., 2009&lt;sup&gt;17&lt;/sup&gt; RCT, cluster 20 Primary care sites (2006-2007)</td>
<td>Children ages 5 to 19 years with asthma Participants (visits) Pre-intervention: 10,667 (21,422) Year 1: 11,919 (23,418)</td>
<td>EHR-based clinical alert for influenza vaccine Captured vaccination opportunities</td>
<td>Change in captured vaccination opportunities (%) Intervention sites: 4.8 Control sites: 3.2 95% CI: −2.4 to 4.9</td>
</tr>
<tr>
<td>Fiks et al., 2007&lt;sup&gt;10&lt;/sup&gt; Pre-post 4 urban primary care centers affiliated with an academic medical center</td>
<td>All children younger than 24 months during a 1 year intervention (2004 to 2005) Visits: 15,928</td>
<td>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</td>
<td>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</td>
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Table 6. Selected evaluation and outcomes studies on interventions to increase vaccination rates in pediatric care (continued)

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<tr>
<td>Stockwell et al., 2014\textsuperscript{136}</td>
<td>Children (predominantly Latino and publicly insured). 8481 unique child visits; 6958 not-up-to-date Median age of 6.5 years</td>
<td>Electronic reminders based on merged data from a regional IIS Vaccination status Documentation for non-administration</td>
<td>Influenza vaccination rate (% of non-up-to-date children vaccinated at visit) Reminder on: 76.2 Reminder off: 73.8 Documentation of non-administration Reminder on: 68.1 Reminder off: 41.5</td>
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CDS = clinical decision support; RCT = randomized controlled trial; her = electronic health record; EMR = electronic medical record; HPV = human papilloma virus; IIS = immunization information service

Medication-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.\textsuperscript{113,114,115} CPOE was typically associated with reductions in medication errors and some improvements in vaccine adherence and timeliness of care.\textsuperscript{16,57,58,120,129} Potential associations between reduction in errors and patient outcomes were not clear, and across reviews, studies assessed heterogeneous implementations.

Studies were often conducted in academic medical centers or in specialized populations (e.g., in the NICU or with children with asthma), thus generalizability to other settings and contexts may be limited. Moreover, technologies were 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\textsuperscript{113} 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).\textsuperscript{113}

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,\textsuperscript{12} mortality risk associated with CPOE was elevated (OR=3.28, 95% CI: 1.94 to 5.55).\textsuperscript{114}
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 study\textsuperscript{12} reported an increase in mortality following implementation of CPOE. The investigators note that systems classed as CPOE likely varied considerably in functionality.\textsuperscript{115}

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.\textsuperscript{87} 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.\textsuperscript{87}

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.

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<tr>
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<tr>
<td>McCrory et al., 2014\textsuperscript{137} Pre-post, retrospective Academic children’s hospital</td>
<td>Patients in a PICU who received manual red blood cell exchange</td>
<td>Introduction of a CPOE system (Eclipsys Sunrise Clinical Manager) Protocol compliance and effectiveness of the manual red blood cell exchange procedure</td>
<td>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</td>
</tr>
<tr>
<td>Bissinger et al., 2013\textsuperscript{18} Pre-post, prospective quality improvement study Academic NICU</td>
<td>All infants who had antibiotics initiated for a suspected healthcare-associated infection Phase I:Baseline Phase II: Implementation of a CPOE</td>
<td>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</td>
<td>Antibiotic timing, mean (SD) Pre: 150 (85.1) Phase I: 113 (70.4) Phase II: 74 (43.4) Phase I vs. Phase II: p&lt;0.001 Administration within 2 hours (%) Pre: 45 Phase I: 66 Phase II: 85 p&lt;0.001</td>
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<td>Maat et al., 2012 interrupted time-series simulation study Academic NICU</td>
<td>All neonates hospitalized for one or more days between 2001 and 2007 with one or more risk factors for hypoglycemia or hyperglycemia (n=2040)</td>
<td>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</td>
<td>No significant pre-post difference on numbers of hypoglycemia or hyperglycemia 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.</td>
</tr>
<tr>
<td>Kazemi et al., 2009 pre-post with three periods Iranian neonatal ward</td>
<td>P1: no CPOE P2: CPOE without decision support P3: CPOE with decision support</td>
<td>CPOE with and without decision support Non-intercepted dosing errors in antibiotics and anticonvulsants</td>
<td>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&lt;0.001) Dose errors were more frequently intercepted than frequency errors. Notably, physicians ignored alerts when they did not understand why they appeared.</td>
</tr>
<tr>
<td>Longhurst et al., 2010 pre-post Academic children’s hospital (quaternary care center)</td>
<td>All non-obstetric inpatients admitted 2001 to 2009 Discharges (n) Pre-intervention: 80,063 Post-intervention: 17,432</td>
<td>CPOE (locally modified functionality within a commercially sold EHR to support CPOE and electronic nursing documentation) Mean monthly adjusted mortality</td>
<td>Change in mortality rate, adjusted mean monthly Post-implementation: 20% reduction (95% CI: 0.8 to 40), p=0.03</td>
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<tr>
<td><strong>Kadmon et al., 2009</strong>&lt;sup&gt;132&lt;/sup&gt; Pre-post with four periods Tertiary care medical center, PICU</td>
<td>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</td>
<td>CPOE with and without decision support that included dosage recommendations and limits on prescriptions Prescription error rates</td>
<td><strong>Total errors (%)</strong> P1: 8.2 P2: 7.8 P3: 4.4 P4: 1.4 p&lt;0.0001 <strong>Potential adverse drug events (%)</strong> P1: 2.5 P2: 2.4 P3: 0.8 P4: 0.7 p=0.82 <strong>MPEs (%)</strong> P1: 5.5 P2: 5.3 P3: 3.8 P4: 0.7 p=0.0001 <strong>RVs</strong> P1: 0.002 P2: 0.001 P3: 0 P4: 0.7 p&lt;1.0 Significant decreases in errors occurred only after the addition of decision support to the CPOE</td>
</tr>
<tr>
<td><strong>Yu et al., 2009</strong>&lt;sup&gt;133&lt;/sup&gt; 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</td>
<td>Cases: 4,625 Controls: 18,040</td>
<td>Presence of a CPOE (hospitals that implemented electronic order entry in all clinical domains)</td>
<td><strong>Adverse drug events</strong> Odds of experiencing an ADE were 42% higher in hospitals without CPOE</td>
</tr>
</tbody>
</table>
Table 7. Selected evaluation and outcomes studies on CPOE and weight-based dosing (continued)

<table>
<thead>
<tr>
<th>Author, Date Study Design Setting</th>
<th>Population/Groups</th>
<th>Intervention Target outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ginzburg et al., 2009&lt;sup&gt;37&lt;/sup&gt;</td>
<td>Children ages 12 and younger receiving either ibuprofen or acetaminophen prescriptions</td>
<td>Automated weight-based dosing calculator within the EHR</td>
<td>Pre- vs. Post-intervention</td>
</tr>
<tr>
<td>Pre-post Multi-famiy medicine clinics</td>
<td>Visits (n) Pre-intervention: 316 Post-intervention: 224</td>
<td>Medication and overdosing errors</td>
<td>Medication errors: p=0.002 Strength overdosing errors: p=0.028</td>
</tr>
</tbody>
</table>

CPOE = computerized physician order entry; her = electronic health records; NICU = neonatal intensive care unit; PICU = pediatric intensive care unit

<sup>a</sup> See: “Improving Antimicrobial Prescribing Practices in the Neonatal Intensive Care Unit” (5R01NR010821)

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.<sup>137</sup> All but one of the newer studies identified 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.<sup>117</sup> 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

<table>
<thead>
<tr>
<th>Author, Date Study Design Setting</th>
<th>Population</th>
<th>Intervention Target outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shaikh et al., 2014&lt;sup&gt;1,2&lt;/sup&gt; Pre-post UC Davis Health System</td>
<td>36 pediatric house staff and 12 attending physicians; 432 overweight/obese children (574 total visits)</td>
<td>An alert for high BMI, a checklist and standardized documentation template Adherence to clinical recommendations for overweight and obesity</td>
<td>Diagnosis of overweight/obesity increased from 40% to 57%. Proportion of children scheduled for followup visits increased from 17% to 27%.</td>
</tr>
<tr>
<td>Bode et al., 2013&lt;sup&gt;3,19&lt;/sup&gt; Pre-post Academic military medical center, adolescent clinic</td>
<td>All adolescent patients, ages 12 to 19 presenting for well-child care</td>
<td>Inclusion of BMI percentile and BMI growth curve by the medical screener</td>
<td>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</td>
</tr>
<tr>
<td>Savinon et al., 2012&lt;sup&gt;4,10&lt;/sup&gt; Pre-post Federally funded, privately owned community health center</td>
<td>All children ages 7 to 18 years presenting for a well-child visit for a total of 74 records (40 written and 34 electronic)</td>
<td>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</td>
<td>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</td>
</tr>
<tr>
<td>Keehbauch et al., 2012&lt;sup&gt;1,24&lt;/sup&gt; Pre-post Two community-based family medicine residency clinics</td>
<td>Family medicine residents, pediatric and family medicine faculty Pediatric patients aged 2 to 18 years</td>
<td>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</td>
<td>Correct documentation of overweight or obese status (%) Site 1: Pre: 29.7 Post: 40.2 Site 2: Pre: 19.4 Post: 27.5</td>
</tr>
<tr>
<td>Ayash et al., 2012&lt;sup&gt;1,17&lt;/sup&gt; Quasi-experimental (natural) experiment Multisite group practices</td>
<td>Children ages 2 to 18 years seen for well-child care between 2006 and 2008 Intervention: 34,908 Comparison: 123,446</td>
<td>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</td>
<td>Predicted probability of an obesity diagnosis increased significantly more in the intervention group than in the control.</td>
</tr>
</tbody>
</table>

BMI = body mass index; her = electronic health record; 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. 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. 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>
<thead>
<tr>
<th>Author, Date</th>
<th>Study Design</th>
<th>Setting</th>
<th>Population</th>
<th>Intervention</th>
<th>Target Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rand et al., 2013</td>
<td>Cross-sectional</td>
<td>Analysis of NAMCS and NHAMCES data (2007 – 2010)</td>
<td>National comparison of practices with and without EHRs</td>
<td>Presence of an EHR</td>
<td>Preventive counseling at child and adolescent well-child visits</td>
<td>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</td>
</tr>
<tr>
<td>White et al., 2013</td>
<td>Pre-post, retrospective review of data</td>
<td>Academic medical center</td>
<td>374 adolescents, median age 19 (range: 14 to 20) years; 71 providers</td>
<td>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</td>
<td>Number of pap smears decreased significantly overall (34%, p&lt;0.0005) by 60% among OB/GYNs (p&lt;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.</td>
<td></td>
</tr>
<tr>
<td>Hacker et al., 2012</td>
<td>Pre-post</td>
<td>Academic pediatric practice</td>
<td>Seven pediatricians, serving 6,000 patients</td>
<td>Implementation of an EHR (transition from paper records) with a questionnaire for entering results from paper forms previously used to screen for mental illness</td>
<td>Rate of behavioral screening increased in the baseline period from 70% to 91%, but decreased in the training period by 28%. Half of eligible youths were screened in the month after implementation and screening did not return to baseline levels until 3 years after implementation.</td>
<td></td>
</tr>
<tr>
<td>Carroll et al., 2011</td>
<td>RCT</td>
<td>General pediatric practice</td>
<td>2239 children</td>
<td>CHICA decision support and EMR system Implementation of screening for iron-deficiency anemia and tuberculosis based on family response to trigger questions</td>
<td>Physicians were more likely to screen in the presence of risk factors in the intervention group. Anemia: 17.5% vs. 3.1%, p&lt;0.001 Tuberculosis: 1.8% vs. 0.8%, p&lt;0.05</td>
<td></td>
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</table>
Table 9. Selected evaluation and outcomes studies of other functionalities (continued)

<table>
<thead>
<tr>
<th>Author, Date</th>
<th>Study Design Setting</th>
<th>Population</th>
<th>Intervention Target Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co et al., 2010</td>
<td>RCT, cluster</td>
<td>General pediatrics; 12 primary care practices</td>
<td>EHR-based decision support, including a) clinician reminders to assess symptoms; and b) and ADHD note template</td>
<td>Patients in the intervention practices were more likely to have had any 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.</td>
</tr>
<tr>
<td>Bell et al., 2010</td>
<td>RCT, cluster</td>
<td>stratified on urbanity</td>
<td>CDS alerts embedded in the EHR to encourage physicians to use available asthma management tools</td>
<td>Urban intervention practices had statistically significant increases in asthma controller medications 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.</td>
</tr>
</tbody>
</table>
Table 9. Selected evaluation and outcomes studies of other functionalities (continued)

<table>
<thead>
<tr>
<th>Author, Date Study Design Setting</th>
<th>Population</th>
<th>Intervention Target Outcomes</th>
<th>Results</th>
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<tbody>
<tr>
<td>Samaan et al., 2009&lt;sup&gt;103&lt;/sup&gt;</td>
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<tr>
<td>Pre-post</td>
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<tr>
<td>Urban pediatric academic practice</td>
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<tr>
<td>20 attending physician and 26 transient physicians; residents and medical students seeing 14,000 patients with 35,000 visits annually</td>
<td>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</td>
<td>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 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.</td>
<td></td>
</tr>
<tr>
<td>Schriger et al., 2000&lt;sup&gt;51&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Interrupted time series with ITT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic emergency medicine department</td>
<td>Febrile children less than 3 years of age presenting to the emergency department</td>
<td>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</td>
<td>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.</td>
</tr>
</tbody>
</table>

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. The Child Health Improvement through Computer Automation (CHICA) system is a decision-support and EHR system for 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 were 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 F. 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?

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

Implementation of health information technology projects has a significant likelihood of failure. 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 pediatric providers 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 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 of 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,\textsuperscript{85} 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 GQ1. 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.⁶

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 recommendations⁶⁵ 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 and implementation of Surescripts® electronic prescribing messaging standards for more than 10 years.” Testing also has been employed in immunization ordering and status checking¹³⁸-¹⁴⁰ and in tools to calculate weight-based dosing of prescription medications.¹⁴¹

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.

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.

**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. This issue applies to the development and implementation of all EHRs, of course, but we describe it here because it is

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⁶ See http://www.cdc.gov/vaccines/programs/iis/interop-proj/cds.html
an essential issue to address. 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 lessoned."

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.\textsuperscript{142} In the adult literature, usability of core functionalities has affected EHR adoption and dissemination. The report recommended additional research to document use patterns and evaluate user interfaces in the pediatric domain.

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 and the Patient-Centered Medical Home**

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, 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 GQ1 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, 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.
Summary and Implications

There is expert consensus in the literature that EHRs used in the care of children require specific pediatric 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. Key areas include vaccination, child 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 child 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 child development and growth as well as screening for abnormalities and anticipatory guidance. The EHR could maximally support child development recommendations by providing tailored longitudinal recommendations for individual patients using clinical decision support, such as those from Bright Futures. 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.

Clinicians often describe EHRs as complex and cumbersome to use. An optimal EHR is created according to user-centered design principles to support workflow and reduce documentation workload. Data is assimilated from multiple sources and is readily available for the pediatric provider. The EHR should be flexible enough to support capture and generation of screening forms and health summaries for secondary use of medical data, such as with school or athletic forms.

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 becomes an 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.67

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.48,60 Yet, if these functionalities are implemented well, the EHR will also undoubtedly better support the care of all patients (Table 10).

A number of challenges were identified in the technical brief. For example, 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. In terms of medication management, enhancing an adult-focused CPOE system for a safe pediatric medication management is an intense and sophisticated task and has limitations.110 Such efforts require high-level sponsorship, involvement of clinicians, and round-the-clock support.111 Routine health care maintenance is a
particularly challenging area of general pediatrics. The AAP has approved nine different
developmental screening instruments – all of which vary in format, sensitivity, specificity, and
modality. *Bright Futures*, the most commonly used reference for routine health care
maintenance, has proven difficult to incorporate actively into electronic health records due to
only a minority of recommendations being computationally decidable and executable. Tracking
growth in children adds yet other challenges. Both the Centers for Disease Control and the World
Health Organization have published validated standard growth charts for boys and girls.
Unfortunately, validated charts do not exist for many diseases, despite these being highly desired
by pediatric providers. This creates a challenge for EHR vendors who must choose either to
including non-validated charts in their software, to rely on customers to decide which charts they
will support, or not to include alternates at all.65-91

Table 10. Summary and Implications

<table>
<thead>
<tr>
<th>Core Functionalities in Pediatric Electronic Health Records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccine forecasting and management</td>
</tr>
<tr>
<td>• Reflects regional requirements</td>
</tr>
<tr>
<td>• Supports documentation, including combination vaccinations</td>
</tr>
<tr>
<td>• Communicates with registries</td>
</tr>
<tr>
<td>Routine Health Care Maintenance</td>
</tr>
<tr>
<td>• Facilitates longitudinal assessment of growth and development</td>
</tr>
<tr>
<td>• Calculates body mass index, growth velocity, percentiles, and standard deviations</td>
</tr>
<tr>
<td>• Allows customized growth charts as approved by clinician</td>
</tr>
<tr>
<td>• Provides tailored longitudinal health and safety recommendations</td>
</tr>
<tr>
<td>Documentation and Billing</td>
</tr>
<tr>
<td>• Integrates into a clinician’s workflow to reduce documentation overload</td>
</tr>
<tr>
<td>• Supports use and creation of customized forms</td>
</tr>
<tr>
<td>• Interfaces with schools and community health organizations</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>• Facilitates medication prescribing by weight, body surface area, and age</td>
</tr>
<tr>
<td>• Incorporates dose rounding tailored to a medication’s safety and efficacy profile</td>
</tr>
<tr>
<td>Management of Vulnerable Populations</td>
</tr>
<tr>
<td>• Generates patient lists based on key clinical diagnoses or risk factors</td>
</tr>
<tr>
<td>• Identifies patients in a clinical subpopulation who are due for preventative services</td>
</tr>
<tr>
<td>• Incorporates clinical practice guidelines into a standard clinical workflow</td>
</tr>
<tr>
<td>Family Structures</td>
</tr>
<tr>
<td>• Links families together for easy navigation and data sharing between family members</td>
</tr>
<tr>
<td>• Supports dynamic privacy controls that support differential access to health data</td>
</tr>
</tbody>
</table>

Our Technical Brief does have limitations. It is not intended to be complete systematic
review; nor were we able to include the viewpoints of a wider range of Key Informants. Only
one vendor is represented, for example. Nonetheless, it does provide an overview of the current
state of the science; it was also available for public comment for 4 weeks and we have responded
to those comments and incorporated additional perspectives in that way.
Next Steps

Through discussion with our Key Informants and review of the literature, we have described functionalities that will support the pediatric clinician in caring for children. This technical brief is intended to provide an overview of current practice and research and to identify areas for improvement.

The brief was commissioned for use as part of a larger project being completed by CMS and AHRQ to prioritize functionalities for pediatric EHRs in order to promote their use and implementation. Clearly, this brief has also identified a number of areas that are in need of rigorous research and we hope that it will encourage researchers and funders to ensure that this empirical work is pursued. Given the small number of empirical studies providing an evidence base for what works in this field, it is clear that research that is more rigorous is needed to inform development and implementation. 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 F. 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. We hope this report encourages all stakeholders to collaborate on this effort to improve electronic health records, ensuring we provide the best possible care for children.


# Appendix A. Literature Search Strategies

## Medline via PubMed

<table>
<thead>
<tr>
<th>Search terms</th>
<th>Search results</th>
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</thead>
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<tr>
<td><strong>#2</strong> (child*[tiab] OR paediatr*[tiab] OR pediatr*[tiab] OR adolescent*[tiab] OR neonat*[tiab] OR infant*[tiab])</td>
<td>1535394</td>
</tr>
<tr>
<td><strong>#3</strong> Search (#1) OR (#2)</td>
<td>323347</td>
</tr>
<tr>
<td><strong>#4</strong> (“Medical records systems, computerized”[mh] OR “decision support systems, clinical”[mh])</td>
<td>28598</td>
</tr>
<tr>
<td><strong>#6</strong> Search (#4) OR (#5)</td>
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</tr>
<tr>
<td><strong>#7</strong> Search (#3) AND (#6)</td>
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</tr>
<tr>
<td><strong>#8</strong> Limit to publication year &gt;1998</td>
<td>3240</td>
</tr>
</tbody>
</table>

**Abbreviations:** mh=Medical Subject Heading; tiab=title/abstract word.

**Notes:** Using “medical order entry system” subject heading instead of “medical records systems, computerized” retrieves 2165 records. Using the broader term, “medical records systems, computerized” which encompasses “medical order entry system” and “electronic health records” retrieves an additional 1105 records- many of which may not be relevant to this topic. Cataloguers use the most specific heading available, however in this case, the broader term “medical records systems, computerized” was introduced in 1991, more than a decade before the more specific headings “medical order entry system” and “electronic health records”. Initial search conducted on 8/5/2014 retrieved 3038 records. On 1/5/2015, an updated search retrieved 202 additional unique records.

## EMBASE

<table>
<thead>
<tr>
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<tr>
<td><strong>#1</strong> (pediatric* or child* or infant* or paediatric* or neonat* or adolescent*).mp</td>
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</tr>
<tr>
<td><strong>#2</strong> (“computerized provider order entry” or “cPOE” or “electronic health” or “EHR” or “clinical decision support” or “CDS” or “CDSS”).mp</td>
<td>18501</td>
</tr>
<tr>
<td><strong>#3</strong> #1 AND #2</td>
<td>1475</td>
</tr>
<tr>
<td><strong>#4</strong> Limits: NOT Medline, Publication Date: 1999-Current</td>
<td>84</td>
</tr>
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</table>

**Notes:** Search executed on 8/05/2014; After duplicates were removed, 75 unique records from were retained.
Appendix B. Key Informant Interviews

The Vanderbilt Evidence-based Practice Center (EPC) Director and the Agency for Healthcare and Quality (AHRQ) Task Order Officer reviewed the completed Disclosure of Interest forms for each Key Informant. We conducted discussion calls with nine Key Informants, one of whom was an employee of the Centers for Disease Control and Prevention. We were not required to obtain Office of Management and Budget (OMB) clearance for the Key Informant interviews because we included fewer than ten non-government associated participants.

We scheduled calls to include two or more Key Informants based upon availability and concordance of perspectives. The EPC Director and a co-investigator from the project team led each of the Key Informant discussion calls. We held three calls, each lasting 60 minutes. We recorded the discussion calls and distributed a summary to the participants. We organized the discussion summaries Guiding Question for analysis by the authors. The report authors identified key themes from multiple perspectives and noted unique perspectives from Key Informants.

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martha Bergren</td>
<td>Community Health Nursing Program</td>
<td>University of Illinois</td>
</tr>
<tr>
<td>Bobbie Byrne</td>
<td>Chief Information Officer</td>
<td>Edwards Health System</td>
</tr>
<tr>
<td>Mark A. Del Beccaro</td>
<td>Department of Pediatrics</td>
<td>University of Washington</td>
</tr>
<tr>
<td>Steve Downs</td>
<td>Department of Pediatrics</td>
<td>Indiana University</td>
</tr>
<tr>
<td>Alex Fiks</td>
<td>Pediatric Research Consortium</td>
<td>Children’s Hospital of Philadelphia</td>
</tr>
<tr>
<td>Chip Hart</td>
<td>Vendor</td>
<td>Physician’s Computer Company</td>
</tr>
<tr>
<td>Hetty Khan</td>
<td>Health Informatics</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>Sue Kressly</td>
<td>Physician</td>
<td>Kressly Pediatrics</td>
</tr>
<tr>
<td>Andrew Spooner</td>
<td>Chief Medical Information Officer</td>
<td>Cincinnati Children’s Hospital</td>
</tr>
</tbody>
</table>
Appendix C. Summary of Key Informant Input

GQ1. Description of EHRs
GQ 1A: 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?
- Family relationships, patient engagement, age of majority.
- Determine family relationship through subject to subject relationship. Insurance status, etc.
- Tracking last well-child visit
- PPI transition policy, EHR support checklist (Got Transition)

GQ2. Description of the context in which EHRs are implemented
GQ 2A: 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?
- Add transition from adolescences to adult to the list of transitions
- Pediatric-specific time units, weight units, weight-based dosing, developmental milestones, growth data, family appropriate education, use of pediatric scales
- Private physician wish list (e.g., immunization logic) is not new or specific to EHR functionality
- Core functionality is difficult
- Lack of standards for clinical circumstance (e.g. there are only two growth charts, but pediatricians want more)

GQ 2B: 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)?
- Language translation
- Food safety, domestic violence,
- Data tied to non-clinical data
- Social service case-management data
- Bright Futures Guidance- not there or not computable. CDSS only 20% compatible (publication by Steve Downs)
- Conformance criteria

GQ2C: What are the challenges to implementing specific functionalities? Are some harder than others to implement by a) vendors; and/or b) pediatric providers?
- Functions align with MU or PCMH and is certification driven
- CQM is vague and broken

GQ3. Description of the existing evidence
GQ 3A: 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?
- Health information chapter
- Electronic Pediatric Research in Office Settings ePros
(http://www2.aap.org/pros/epros/eprosa&m.htm)

GQ 3B: 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)?

- Data of usefulness is mostly unpublished

GQ4. Dissemination and future developments
GQ 4A: How does testability and usability of core functionalities promote or impede dissemination and future development of pediatric EHRs?

- Testing for usability can be difficult
- Real-time contextual support
- Provide specific guidelines, concrete and computable information for translation by vendors
- Decrease burden of reports, order, and care plans.
### Abstract Screening Form

- **If you answer “No” to one or more questions (with the exception of #4) the record is excluded.**
- **If you answer “Yes” or “Cannot Determine” to all questions, the record is promoted for full text screening.**
- **To flag a reference for team review, background, or review of references, check one or more reasons listed at the end of the form.**
- **Use the comments field as needed to enter reference specific notes or questions.**
- **Submit the form to move to the next reference.**

#### Questions

1. Population is children, aged 21 years or younger
   - Yes
   - No
   - Cannot Determine

2. Addresses pediatric-specific functionality or feature for an EHR
   - Yes
   - No
   - Cannot Determine

3. Health care setting (i.e., exclude camp, school, public health, kindergarten settings, etc.)
   - Yes
   - No
   - Cannot Determine

4. Reports original research
   - Yes
   - No
   - Cannot Determine
   - Neutral

5. [If #4 is “Yes”]: Addresses Guiding Question(s) 1, 2, 3 and/or 4
   - Yes
   - No
   - Cannot Determine

5. [If #4 is “No”]: Addresses Guiding Question(s) 1, 2, and/or 4

**Guiding Questions**

- **GQ 1A.** 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?

- **GQ 2A.** 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?

- **GQ 2B.** 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)?

- **GQ 2C.** What are the challenges to implementing specific functionalities? Are these harder than others to implement by a) vendors; or b) pediatric providers?

- **GQ 3A.** 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; or b) improved workflow or job satisfaction for providers?

- **GQ 3B.** Which pediatric-specific functionalities influence: a) patient outcomes (including safety; quality; cost; equity; standardization of care; and efficiency); b) the ability of a pediatric provider to conduct work within the EHR; c) improvement of workflow and provider satisfaction; or d) involvement of patients and families (including their education and shared decision making)?

- **GQ 4A.** How does testability and usability of core functionalities promote or impede dissemination and future development of pediatric EHRs?

**Does not address a guiding question**

**Retain for:**

- Team Review
- Background/Discussion
- Review of References
- Other

**COMMENTS:**

*Note: In Distiller, question #4 uses branching logic to ensure that Guiding Question 3 is addressed by original research. If the answer to #4 is “No” the option for Guiding Question 3 will be hidden.*
# Full Text Screening Form

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<tr>
<th>Senior reviewer decision for study status:</th>
<th>Include</th>
<th>Exclude</th>
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</thead>
<tbody>
<tr>
<td>If excluded, mark reason(s)</td>
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<td></td>
</tr>
<tr>
<td>Not children (i.e. older than 21 years of age)</td>
<td></td>
<td>X-1</td>
</tr>
<tr>
<td>Does not address pediatric-specific functionality or feature of an EHR</td>
<td></td>
<td>X-2</td>
</tr>
<tr>
<td>Not a healthcare setting of interest</td>
<td></td>
<td>X-3</td>
</tr>
<tr>
<td>Not relevant to outpatient setting</td>
<td></td>
<td>X-4</td>
</tr>
<tr>
<td>Does not address a Guiding Question</td>
<td></td>
<td>X-5</td>
</tr>
<tr>
<td>If included, mark Guiding Question(s)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### GQ 1A. 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?  

### GQ 2A. 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?  

### GQ 2B. 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)?  

### GQ 2C. What are the challenges to implementing specific functionalities? Are these harder than others to implement by a) vendors; or b) pediatric providers?  

### GQ 3A. 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; or b) improved workflow or job satisfaction for providers?  

### GQ 3B. Which pediatric-specific functionalities influence: a) patient outcomes (including safety; quality; cost; equity; standardization of care; and efficiency); b) the ability of a pediatric provider to conduct work within the EHR; c) improvement of workflow and provider satisfaction; or d) involvement of patients and families (including their education and shared decision making)?  

### GQ 4A. How does testability and usability of core functionalities promote or impede dissemination and future development of pediatric EHRs?  

### Does not address a guiding question  

**Retain for: ____ Team Review ____ Background/Discussion ____ Review of References ____ Other**

**COMMENTS:** D-2
## Appendix E. Summary of Consensus Statements

<table>
<thead>
<tr>
<th>Citation</th>
<th>Title</th>
<th>Notes</th>
<th>Category</th>
</tr>
</thead>
</table>
| Gray et al., 2014<sup>1</sup> | Recommendations for EHR Use for Delivery of Adolescent Health Care | - Global, excluding China and India, EHR usage in 2010.  
- Adolescent confidentiality protection summarized.  
- Adolescent may forgo healthcare if their privacy is threatened.  
- No incentive for EHR vendors, in current regulatory environment, to incorporate granular privacy controls in their products.                                                                 | Privacy (adolescents)     |
| Patterson et al., 2013<sup>2</sup> | Enhancing EHR Usability in Pediatric Patient Care: A Scenario-Based Approach | - Summary of the NIST 7865 report (see below) Highlights a few selected recommendations for EHR vendors and developers, small-group pediatric practices, and children's hospitals.  
- Special considerations for pediatric patients from clinical experts  
- Relevant concepts for human factors engineering from Human Factors experts                                                                 | Pediatric-specific norms  |
| Blythe et al., 2012<sup>3</sup> | Standards for Health Information Technology to Ensure Adolescent Privacy | - Recommends nine basic principles for 'ideal' EHR  
- Supports the caution that adolescent may forgo healthcare if privacy is threatened  
- States that HIPAA not specific to adolescent privacy issues which may result in deferral to state laws regarding minors                                                                 | Privacy (adolescents)     |
| Lowry et al., 2013<sup>4</sup> | A Human Factors Guide to Enhance EHR Usability of Critical user Interactions when Supporting Pediatric Patient Care. [NIST.IR.7865] | - Highlights the user interactions unique to or salient for pediatric care and  
- Details the unique features of pediatric patient care, in contrast to general adult patient care including patient physiology, complexity of routine tasks, and limited communication abilities.  
- Provides conceptual model of unique user-related risks of EHR systems for pediatric patients.  
- It covers human factors guidance for critical user interactions along 9 themes (patient identification, medications, alerts, growth chart, vaccinations, labs, newborn care, privacy, and radiology  
- Suggests opportunities for innovations to consider for specialized child modules that can be used in conjunction with an established EHR.  
- Appendix covers scenarios citing the potential pitfalls.                                                                 | Pediatric-specific norms  |
| ACOG Committee on Adolescent Health Care 2014<sup>5</sup> | ACOG Committee Opinion # 599: Adolescent confidentiality and electronic health records | - Clarifies that HIPAA privacy rule leaves health care providers with questions about the relationship between HIPAA local applicable laws  
- Standards lacking for state and other laws pertaining to minor consent, provisions for privacy and services governed by federal laws.  
- Details the nature and requirement of the adolescent privacy and confidentiality of services consented by a minor                                                                 | Privacy (adolescents)     |
| Gerstle et al., 2007<sup>6</sup> | Electronic Prescribing Systems in Pediatrics: The Rationale and Functionality Requirements | - Describes the levels and implementation of e-prescribing.  
- Cites pediatric specific advantages of CPOE  
- Suggests and provides guidelines, potential barriers, and cautions against potential pitfalls.  
- Cites benefits of e-prescribing to public health, patient, pharmacists, insurers and providers.                                                                 | Medications / CPOE        |
References


Appendix F. Ongoing Studies

A search of ClinicalTrials.gov retrieved 46 records. The table below summarizes the records that were retained as relevant (n=17).

Search strategy: ((EHR) OR (EMR) OR (electronic AND record)) AND (functionality OR HIT OR CPOE OR "decision support" OR "electronic prescribing" OR "order entry" OR "information technology" OR "quality improvement") | Child

<table>
<thead>
<tr>
<th>Study Name Location</th>
<th>Sponsors and Collaborators</th>
<th>Population Disease/Condition Age</th>
<th>Interventions / Groups</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>An Electronic Decision Support Tool to Improve Outpatient Asthma Care</td>
<td>Agency for Healthcare Research and Quality (AHRQ) Children's Hospital of Philadelphia</td>
<td>Children with a diagnosis of asthma</td>
<td>Behavioral: Computerized decision support</td>
<td>Primary: The proportion of patients on appropriate asthma controller medication at the end of the trial. Secondary: an updated asthma action plan. documentation of spirometry (6 to 18 years) in those with asthma. an updated problem list that reflects an assessment of asthma severity.</td>
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<tr>
<td>Children's Hospital of Philadelphia</td>
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<td>Age 1 to18 years</td>
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<table>
<thead>
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<th>Interventions / Groups</th>
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<tbody>
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<td>Ages 5 to 17 years</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Study Name Location</th>
<th>Sponsors and Collaborators</th>
<th>Population Disease/Condition Age</th>
<th>Interventions / Groups</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Health Improvement Through Computer Automation (CHICA) Highlighting Study</td>
<td>Indiana University</td>
<td>Physicians practicing in one of our four study clinics who use CHICA</td>
<td>Other: Highlight set 1 (two prompts). Other: Highlight Set 2 (two different prompts)</td>
<td>Whether or not prompt was answered.</td>
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<td>IUMG Clinic System</td>
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<th>Population Disease/Condition Age</th>
<th>Interventions / Groups</th>
<th>Outcomes</th>
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<td>Comprehensive Clinical Decision Support (CDS) for the Primary Care of Premature Infants</td>
<td>Children's Hospital of Philadelphia National Library of Medicine (NLM)</td>
<td>Premature infants aged 20 weeks to 35 weeks</td>
<td>Other: Clinical Decision Support Tool</td>
<td>Primary: Evaluate usability of the intervention. Secondary: Evaluate effect on care.</td>
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<td>Children's Hospital of Philadelphia</td>
<td>NCT01478711</td>
<td>Boston Medical Center Agency for Healthcare Research and Quality (AHRQ)</td>
<td>Parents of children will be enrolled in the study if they meet a set of eligibility criteria which includes: • A primary care patient at Boston Medical Center • An English speaking child and parent • Ages 0 to 11 years</td>
<td>Behavioral: Safety Training Behavioral: Personal Health Partner and Counseling</td>
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<td>EHR-Based Clinical Decision Support to Improve BP Management in Adolescents</td>
<td>NCT01760239</td>
<td>HealthPartners Institute for Education and Research National Heart, Lung, and Blood Institute (NHLBI) Recruiting</td>
<td>Pediatric and family medicine providers • Ages 12 to 19 years</td>
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<td>Electronic Health Record (EHR) Decision Support to Improve Outpatient Asthma Care</td>
<td>NCT00918944</td>
<td>Children's Hospital of Philadelphia Agency for Healthcare Research and Quality (AHRQ) Completed</td>
<td>Known patients with asthma</td>
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<td>Evaluation of a Shared Decision Making Portal for Pediatric Asthma</td>
<td>Children's Hospital of Philadelphia</td>
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<td>Parents/legal guardians of children aged 6 to12 years with persistent asthma, currently receiving chronic</td>
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<td>Improving Otitis Media Care With Clinical Decision Support (OMHIT)</td>
<td>Children's Hospital of Philadelphia (CHOP) Agency for Healthcare Research and Quality (AHRQ)</td>
<td>All CHOP primary care and ENT practice sites with patients receiving care for otitis media</td>
<td>Other: 3-Part Intervention (A combination of training, an otitis media episode grouper, and clinical decision support)</td>
<td>Primary: Quality of otitis media care  Secondary: Clinician adoption of intervention and Resource Utilization</td>
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<td>Giving Immunizations Through Vaccine Education</td>
<td>Children's Hospital of Philadelphia Agency for Healthcare Research and Quality (AHRQ)</td>
<td>All clinicians practicing at participating sites  Parents with an eligible adolescent girl  Adolescent girls aged 11 to 17 years  Has a visit at one of the primary care centers within the last 15 months  Has not completed the teen vaccine series</td>
<td>Behavioral: Family Decision Support (informational vaccine reminder telephone calls) Behavioral: Clinician Decision Support (an EHR-based decision support mechanism including reminders, education, audit and feedback on vaccination success) Other: Family Decision Support and Clinician Decision Support Other: Control</td>
<td>Primary: Rate of HPV vaccination among girls actively cared for at participating sites  Secondary: Rates of meningococcal and tetanus, diphtheria, and pertussis vaccines among girls in the study</td>
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<td>Study Name Location Trial Identifier</td>
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<td>NCT01715389</td>
<td></td>
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<td>maintenance therapy, cared for at a study practice, with consistent access to a computer with an internet connection where they feel comfortable accessing MyChart (patient portal) Clinician at study site</td>
<td>• Goal Attainment  • Asthma-Related Quality of Life  • Asthma Control  • Asthma-related Utilization  • Asthma Medication Adherence/Receipt  • Feasibility of Recruitment  • Feasibility of Follow-up  • Feasibility of Portal Use</td>
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<td>Improving Pediatric Safety and Quality With Health Care Information Technology</td>
<td>Massachusetts General Hospital Agency for Healthcare Research and Quality (AHRQ)</td>
<td>• Partners-affiliated pediatric practice providers utilizing Longitudinal Medical Record (LMR), which is an electronic health record system. Also the parents of the patients of the above noted pediatric providers</td>
<td>Other: weight based dosing decision support</td>
<td>• Impact on rates of medication errors</td>
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<td>Improving the Medication Management of Patients With Attention-Deficit Hyperactivity Disorder</td>
<td>American Academy of Pediatrics, University of Colorado, Denver QED Clinical, Inc. Children's Hospital of Philadelphia Enrolling by invitation</td>
<td>• Children aged 5 to 12 years diagnosed with Attention-Deficit Hyperactivity Disorder (ADHD)</td>
<td>Behavioral: Clinical decision support for medication titration</td>
<td>Primary: Improvement in symptoms, as measured by the parent-reported Vanderbilt Assessment Scale Secondary: Side effects as reported on the ADHD Vanderbilt Scale</td>
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<td>Informing Policy to Implement Pediatric Family Engagement in Meaningful Use Stage 3 PROS PeRC</td>
<td>Children's Hospital of Philadelphia Agency for Healthcare Research and Quality (AHRQ) American Academy of Pediatrics DARTNet Institute Recruiting</td>
<td>• Child has a diagnosis of asthma on his/her problem list • Ages 6 to 12 years</td>
<td>Other: MyAsthma Web Portal</td>
<td>Primary: Use of the MyAsthma Portal Survey Secondary: Asthma management</td>
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<tr>
<td>Intervention to Improve Adherence in Teen Kidney Transplant Multiple sites</td>
<td>McGill University Health Center Children's Hospital of Philadelphia Children's Hospital Medical Center, Cincinnati Seattle Children's Hospital Washington University Early Recognition Center British Columbia Children's Hospital The Hospital for Sick Children St. Justine's Hospital Recruiting</td>
<td>• At least 3 months post kidney transplant • Ages 11 to 24 years</td>
<td>Behavioral: Action-focused problem-solving Device: Electronic pillbox monitoring, dosage reminders, and feedback</td>
<td>• Taking adherence • Timing adherence • Clinical outcomes • Healthcare system factors</td>
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<tr>
<td>Study Name and Location</td>
<td>Sponsors and Collaborators</td>
<td>Population Disease/Condition Age</td>
<td>Interventions / Groups</td>
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<td>PECARN, Emergency Care Registry, The Children's Hospital of Colorado, Cincinnati Children's Hospital Medical Center, Children's Hospital of Philadelphia, Data Coordinating Center</td>
<td>Children's Hospital of Philadelphia Agency for Healthcare Research and Quality (AHRQ) Recruiting Start: January 2011 Complete: NR</td>
<td>All patients (0-18) who registered in the ED during 2011 and during a 24 month study period between 2012 and 2015</td>
<td>NR</td>
<td>Improved performance and decreased variability (variation) of care</td>
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| NCT01657344  | Study of Technology to Accelerate Research, Harvard Vanguard Medical Associates  | Harvard Pilgrim Health Care Brigham and Women's Hospital Cambridge Health Alliance Harvard Vanguard Medical Associates Completed Start: December 2010 Complete: September 2013 | Child's BMI exceeds the 95th percentile for age and sex (CDC criteria)  
Parent can respond to interviews and questionnaires in English  
Child has obtained well-child care from HVMA for at least the previous 15 months  
Ages 6 to 12 years | Behavioral: Usual Care Behavioral: Clinician intervention only Behavioral: Clinician intervention plus Direct-to-parent communication | Primary  
Change in screening and assessment of childhood obesity at the point of care, including BMI, blood pressure, and laboratory screening, and provision of nutrition and physical activity counseling  
Secondary  
Change in Body Mass Index  
Change in Health Behaviors  
Costs (including clinician and family time) and cost-effectiveness in terms of children's change in BMI and weight-related behaviors |

F-5
## Appendix G. Reasons for Exclusion

<table>
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<th>Exclusion Code</th>
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<td>X-2</td>
<td>Does not address pediatric-specific functionality or feature of an EHR</td>
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<td>X-3</td>
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<td>X-4</td>
<td>Not specific to outpatient</td>
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<td>X-5</td>
<td>Does not address a guiding question</td>
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<td>X-7</td>
<td>Duplicate</td>
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References with reason(s) for exclusion


17. Ben Said M, Robel L, Vion E, et al. Implementation and experimentation of TEDIS: an information system dedicated to patients with pervasive developmental


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42. Crossno CL, Cartwright JA, Hargrove FR. Using CPOE to improve communication, safety, and policy compliance when ordering pediatric chemotherapy. Hospital Pharmacy 2007 April;42(4):368-73. PMID: 2007199187. X-4


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132. Lykowski G, Mahoney D. Computerized provider order entry improves workflow and outcomes. Nurs Manage 2004 Feb;35(2):40g-h. PMID: 14767222. X-4


195. Sloane EB. Using a decision support system tool for healthcare technology


205. Stuart K. You can't get there from here: misplaced incentives can undermine the goals of health care reform in the NICU setting. J Perinatol 2012 Aug;32(8):570-3. PMID: 22842801. X-5 X-


APPENDIX C

Topics in Neonatal Informatics: Essential Functionalities of the Neonatal Electronic Health Record
Essential Functionalities of the Neonatal Electronic Health Record

Kevin R. Dufendach, MD,*† Christoph U. Lehmann, MD*†

Abstract
Despite the increased use of electronic health records (EHRs), many pediatricians use EHRs that do not contain pediatric functionalities, and no recent attempts to define neonatal functionalities have been made to date. This article describes the fundamental functionalities required in an EHR to provide safe and effective care to neonates, including neonatal data requirements and appropriate display of neonatal data; the need for the mother-infant dyad in the EHR; neonatology-specific scores; and special considerations for medication ordering, nutrition, newborn screening, transitions of care, and documentation. Many EHRs currently lack the functionalities required to provide safe and effective care to neonates. Neonatologists must lobby for better tools to ensure quality and safety for their patients.

Objectives After completing this article, readers should be able to:
1. Analyze electronic health record (EHR) functionality to determine the presence or absence of neonatal functionality.
2. Communicate the principles of neonatal functionalities in EHRs.
3. Describe the importance of neonatal functionalities to safety and quality in neonatal care.
4. Develop enhancement requests to EHR vendors to improve EHR functionalities for care of neonates.

Introduction
A 2012 survey of office-based pediatricians found that only 8% use electronic health records (EHRs) that support pediatric functionalities, such as weight-based dosing, age-specific normal values, or immunization forecasting. (1) Recent efforts by the American Academy of Pediatrics and the Agency for Healthcare Research and Quality have begun to explore the specific needs of pediatricians in inpatient environments (2) and the evidence that supports the inclusion and use of pediatric functionalities in outpatient EHRs. (3) In 2013, the Agency for Healthcare Research and Quality published a set of more than 700 pediatric functionalities for pediatric EHRs. (4) Despite these efforts, no attempts have yet been made to define further the subset of neonatal functionalities.

Neonatal Medicine
Of the approximately 4 million infants born every year in the United States, approximately 440,000 (approximately 11%) are born prematurely and taken care of in neonatal intensive care units (NICUs). (5) Neonatology is a pediatric
subspecialty that defines itself through its work at the extreme of the human growth and developmental spectrum. The neonatal period represents the most narrow age range of all health care specialty groups, yet it also is the period at greatest risk for childhood morbidity and mortality. Despite advances in prevention and treatment, some predict an infant mortality rate of 5.6 per 1,000 live births by 2020. (6) Extreme prematurity is associated with abnormal end-organ functionality, resulting in respiratory failure, weakened immune systems, challenges to eliminate and protect against toxins, nutritional challenges, and inability to manage fluid status and thermoregulation effectively. Furthermore, neonates undergo extremely rapid development, learning to feed orally, establishing thermoregulation, and acquiring skills to communicate basic needs, all while rapidly changing in weight and size. From these extremes come certain functionalities and unique needs to enhance neonatal clinician workflow in EHRs. From a high level, neonatologists must be able to order and document using appropriate ranges and units of measure; document data specific to the neonatal period; measure and monitor rapid growth and development while flagging abnormalities; order and document neonatal-specific diets, medications, interventions, and procedures; and use and document neonatal-specific findings, scores, and plans. To help neonatologists in the EHR selection process and in the creation of enhancement requests to EHR vendors, this article reviews neonatal-specific functionalities needed and recommended for EHRs used in the care of neonates and premature infants.

Neonatal Data Requirements
An EHR built with user-centered design principles will focus on the needs and workflow of neonatal clinicians. EHRs must present data in an easily interpretable fashion. For neonates, this means that age may need to be given initially in hours, subsequently in days, and eventually in months. Alongside chronological age, the EHR should give an infant’s corrected postmenstrual age in completed weeks and days. Other data must be represented in units of measure that are meaningful to infants. Care for neonates may require that variables for infants have attribute choices that are not used in adults. For example, sex may be ambiguous or unknown in the neonate and subsequently updated on further evaluation. Some data elements may need reclassification to fit neonatal care, such as reclassifying a bradycardia as a respiratory or feeding event and redefining the default indication of medications, such as caffeine and sildenafil. Data representation for neonates is critical for any secondary use of captured data, such as creating alerts and reminders, (7) e-prescribing, (8) measuring outcomes, quality and predictive modeling, (9) and research.

Inpatient Monitoring
In the NICU, thousands of data points are measured on each patient every day, from vital signs to imaging to nursing assessments, consultations, and progress notes. Because a neonate cannot describe symptoms, the care team must interpret these data to determine the infant’s clinical status and respond appropriately. An EHR can facilitate this interpretation in the way it models data by prioritizing and presenting the data items neonatal clinicians need to provide clinical care. (10)(11)

Vital sign and laboratory result graphs must adjust to the reference ranges for neonates to allow proper visualization (Fig). (12) Because change is the norm, an EHR should just as easily respond to out-of-range velocities (eg, slowing weight gain) as it does to out-of-range values.

Mother-Infant Dyad
An essential and unique requirement of an effective EHR is to link a mother’s record with that of the infant, supporting ready access to fetal information that affects postnatal care. Prenatal imaging and laboratory values can help guide postnatal cardiac, pulmonary, or other treatment decisions. These prenatal studies often remain hidden in a mother’s record even though they describe the fetal anatomy. The infant’s record should include maternal laboratory results, such as ABO blood typing and infection status. The EHR should have the ability to update the information at any time, such as if there are new laboratory results or confirmed erroneous data. In the EHR, the infant’s medical history section offers a reasonable location for this information.

The EHR should store some birth information data in a structured format that can subsequently be used for decision support or in the creation of patient lists. For example, time and gestational age at birth allow derivation of current chronological and corrected gestational age for use in hyperbilirubinemia risk assessment, retinopathy of prematurity screening, and chronic lung disease screening. Other examples include birth weight to allow calculation of growth and listing on growth charts adjusted to corrected gestational age; Apgar scores; delivery mode; birth order if not a singleton; resuscitation and procedures performed during delivery; maternal information, such as prior pregnancies, blood type, antibody status, and sickle cell status; maternal exposure to medications, toxins, drugs, and tobacco during pregnancy; and maternal infection status, such as rubella, hepatitis, syphilis, gonorrhea, Guillain-Barré syndrome, chlamydia, and human immunodeficiency virus.
The recent US Supreme Court decision on same-sex marriage illustrates the importance that EHRs used in neonatal care can record a multitude of dynamic family scenarios. In the case of a surrogate, an infant may have 3 mothers. Other complex family structures involve foster care, adoption, and child protective services involvement. An EHR must support privacy and infant protection by capturing who is permitted to visit, make medical decisions, and consent to care and also who is responsible for the financial aspects of care.

Transitions of Care
The neonatal period comprises multiple transitions of care, each with its own unique challenges. Even before the infant is born, his/her prenatal care can play a significant role in ensuring a smooth postnatal transition. An EHR must support assigning a unique patient identifier immediately in the delivery room or potentially even before delivery. (13) In the case of prostaglandin drips for prenatally diagnosed cyanotic congenital heart disease, it is imperative that medications be available at delivery. The EHR must also support placing orders before the infant’s birth or arrival to the NICU. The absence of the functionality to order before arrival of a transport has been linked to increased mortality in a pediatric intensive care unit. (14)

Just as hospital visit summaries are important when transitioning from inpatient to outpatient status, an interim or transfer summary is also important for caring for an infant with a long inpatient hospitalization because clinicians change during the hospitalization. An EHR must support ready creation of interim care summaries or snapshots for intramural team changes and extramural patient transfers. A summary is also important to keep parents involved with updates on their infant during an extended hospitalization in the NICU.

Neonatal-Specific Scores
The EHR must support documentation of neonatal-specific scores and data elements. This documentation includes data from the delivery (see the Mother-Infant Dyad section) and a series of scores, such as the Clinical Risk Index for Babies I and II, (15) the Finnegan Score, (16) the Neonatal Pain, Agitation, Sedation Scale, (17) the Score for Neonatal Acute Physiology, (18) Score for Neonatal Acute Physiology II, and Score for Neonatal Acute Physiology Perinatal Extension II, (19) to name a few.

Newborns of all gestation are at risk for developing hyperbilirubinemia that can lead to kernicterus. (20) The EHR should provide clear visualization and decision support for managing neonatal hyperbilirubinemia. Decision support should assist the care of both term and preterm infants.

Newborn Screening
Newborn screening is mandatory in all states in the United States but varies in scope from state to state. EHRs must support recording more than one collection and include the collection date and time of a state screen to no less than the nearest hour. The EHR must also support documentation of hearing screening and critical congenital heart disease screening because both are part of
mandatory newborn screening in most states. Because newborn screening may detect diseases with serious complications if left untreated, results must be readily available along with resources for action, especially because the primary care clinician may have never before encountered many of these diseases. (21) The EHR must document that the findings and conclusions from a state screen have been relayed to the family member responsible for medical decision-making. In some cases, the results must be communicated efficiently across state lines.

**Medication Ordering**

The small sizes of neonates and their extremely dynamic drug metabolism complicate medication ordering in the NICU. (22) Medication doses may easily be 100 times smaller than an equivalent adult dose. This sometimes means a change in units from grams to milligrams to milligrams to micrograms. For clinicians, a dose of 50 µg is easier to process than 0.05 mg. To avoid dosing and administration errors, the unit of measure in an EHR should reflect the least complexity for the clinician. (23) The EHR ordering system must accommodate for these unit changes and make the difference apparent to everyone involved in the ordering, preparation, and administration of medications to avoid catastrophic dosing errors. (24)

Extremely small medication doses can also present complications when delivering intravenous medications because the volume of carrier fluid needed to dilute medications can have adverse effects. The carrier fluid of an infusion may significantly affect total daily fluids for an infant. The EHR should consider this when determining total fluids, calories, and electrolyte infusion rates. In some cases, standard concentrations of drug and carrier fluid must be altered to support a variety of infusion rates to ensure that critical drugs and nutrition get delivered while not overloading patients with fluids. The EHR ordering system must accommodate such specialized fluid and drug orders.

Clinical decision support should take into account drug metabolism and volume of distribution changes that occur as neonates grow and organs develop. Neonatal dosing and dose ranges may change based on chronological age, corrected gestational age, birth weight, or renal or hepatic function. Dosing may be fixed, weight based, or body surface area based. Medication doses also need to be adjusted frequently with growth. Effective medication ordering with clinical decision support will incorporate all these in guiding clinicians.

Immunization recommendations for premature neonates and those with specific exposures differ from those for full-term infants. An EHR should support decision support for appropriately indicated immunizations both in the hospital after discharge from the NICU. This includes postdischarge palivizumab recommendations for those infants at risk.

**Velocity of Change**

At no other time in a person’s life is there such significant velocity of change in physiologic and biometrical parameters as during the newborn period. To provide adequate monitoring, an EHR must appropriately identify vital sign and laboratory reference ranges that change dynamically as an infant develops. Because growth velocity is such a pivotal area of neonatal care, it deserves special attention. Neonatal growth charts are critical to neonatal care to determine adequate nutrition and growth velocity in the neonatal period. An EHR should provide ready access to neonatal-specific growth charts that allow correction for gestational age and monitor for significant change in velocity to ensure that infants are receiving adequate nutritional support.

**Nutrition**

Neonatal nutrition is critical to successful care of the neonate and is rather distinct from nutrition later in life. The mere existence of a nutrition protocol reduces rates of necrotizing enterocolitis. (25)(26) EHRs must allow the ordering, dispensing, and administering of age-specific enteral nutrition. In the neonatal period, this translates to human milk or formula. Therefore, an EHR must have an inventory of available and orderable infant formulas, including special formulas for metabolic diagnoses. EHRs must support the safe and effective ordering of neonatal parenteral nutrition. (27) For both enteral and parenteral nutrition, the EHRs should calculate the daily caloric intake, including the amount of protein, glucose, and fat received. The EHR should also calculate electrolyte content in milliequivalents per kilograms per day from both total parenteral nutrition and other drips. Although weight should be given in grams, weight velocity should be calculated in grams per kilograms per day for premature infants and in grams per day for older infants.

The critical role of human breast milk in neonatal nutrition is associated with a number of challenges. Breast milk is considered a bodily fluid, and great care must be undertaken to avoid exposure of an infant to breast milk that is not from the mother or an accepted donor. The EHR can support systems that manage the storage, expiration dates, and safe administration of human milk, similar to how it supports use of blood and other donor products.

**Documentation**

In its optimal state, the daily patient note represents a concise story that communicates medical history, events, findings, problems, and decision-making.
(28) This note may include selected relevant laboratory results, radiographic findings, and vital signs, but it need not include every new value from the previous 24 hours. Major events could automatically prepopulate the patient note, such as discontinuation of medication use and advanced imaging studies. To support a concise note, especially for neonates whose care is complex and involves many events during a day, the EHR should support re-creating a snapshot of the clinical picture at the time of the documentation, including active medication lists, resulted laboratory values, and vital signs. If the EHR makes this information readily available, it need not be recapitulated in the daily progress note.

Individual plans of care for a neonate may include both acute and chronic care items. To facilitate creating a clear and concise daily progress note, the EHR needs a place to record inactive patient care items (eg, the need for hepatitis B vaccination and a car seat test before discharge). It should support creation of triggered events, such as “alert clinician to consult surgeon when patient weight is greater than 2 kg” or “remind clinician to order head ultrasonography when patient is 30 days old.” By allowing creation of such reminders and a plan of care, the daily clinical note can focus on the immediate plan for the day.

Requirements for third parties should not add clutter to a clinical note. The primary purpose of the clinical note is to support patient care through documentation of medical evaluation and decision-making. Documentation requirements levied by third-party payers or legislative bodies should not require additional information added to the note other than what already exists to support patient care. If these groups require additional information, the EHR should extract the data automatically and include them as metadata or as a supplement.

For research and quality improvement purposes, the data in an EHR must be searchable for neonatal-specific data items. It should be possible, for example, to identify all infants born after opiate exposure during pregnancy or all infants with an Apgar score of less than 5 at 10 minutes after birth.

**Discussion**

Neonatal care focuses on patients with the most narrow age range of any field in medicine, yet the physiologic changes and range of disease covered demand specific features in the EHR tailored to care appropriately for these infants. Use of an EHR without these features will lead to workarounds outside the EHR, which in turn may interfere with the delivery of quality neonatal care and potentially lead to increased errors.

The entire EHR is actually an integrated decision support system with varying levels of support. The EHR decides which pieces of information are provided to the user; organizes that information; possibly highlights specific values; offers alerts, options, and suggestions on placing orders; and organizes and structures documentation and data entry. If this decision support remains designed for adult care and does not accommodate the needs of neonatal clinicians, it will produce results entirely incongruent with the goal of quality neonatal care.

The meaningful use portion of the 2009 American Recovery and Reinvestment Act has been disruptive to health care. Within 5 years, 20% of the US economy has been transformed from managing on paper to EHRs. As a result, many quickly implemented EHRs are not meeting pediatric functionality requirements, and even fewer are able to support the needs of neonatal clinicians. As EHR designers add functionalities to support neonatal care, it is also imperative that they do so with user-centered design principles so the added functionality complements neonatal clinician workflow. (29) Usability focuses on effectiveness, efficiency, and satisfaction of a product. (30) EHR features should serve to simplify the clinician’s work so that clinicians can better focus on the care of patients, spending less time at the computer terminal and more at the patient’s bedside.

Pediatricians have more challenges to participate in meaningful use because of their eligibility through Medicaid, reducing financial incentives for EHR vendors to compete in the pediatric and neonatal market. (31) It is critical that neonatal clinicians lobby for EHRs that support the care of neonates. Future meaningful use certification requirements will be influenced by our efforts and, it is hoped, will support data representation according to neonatal ranges, links between maternal and infant medical records, transitions of care, neonatal-specific data and screening instruments, neonatal-specific medication ordering, nutrition protocols and growth monitoring, and documentation in neonatal care.
References


Parent Resources from the AAP at HealthyChildren.org
• https://www.healthychildren.org/English/family-life/health-management/Pages/Technology-to-Improve-Your-Childs-Medical-Home.aspx
Topics in Neonatal Informatics: Essential Functionalities of the Neonatal Electronic Health Record
Kevin R. Dufendach and Christoph U. Lehmann
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