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# Designing Computerized Decision Support That Works for Clinicians and Families

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Evidence-based decision-making is central to the practice of pediatrics. Clinical trials and other biomedical research provide a foundation for this process, and practice guidelines, drawing from their results, inform the optimal management of an increasing number of childhood health problems. However, many clinicians fail to adhere to guidelines. Clinical decision support delivered using health information technology, often in the form of electronic health records, provides a tool to deliver evidence-based information to the point of care and has the potential to overcome barriers to evidence-based practice. An increasing literature now informs how these systems should be designed and implemented to most effectively improve outcomes in pediatrics. Through the examples of computerized physician order entry, as well as the impact of alerts at the point of care on immunization rates, the delivery

of evidence-based asthma care, and the follow-up of children with attention deficit hyperactivity disorder, the following review addresses strategies for success in using these tools. The following review argues that, as decision support evolves, the clinician should no longer be the sole target of information and alerts. Through the Internet and other technologies, families are increasingly seeking health information and gathering input to guide health decisions. By enlisting clinical decision support systems to deliver evidence-based information to both clinicians and families, help families express their preferences and goals, and connect families to the medical home, clinical decision support may ultimately be most effective in improving outcomes.

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**I**mproving the safety and quality of health care has become a priority for our health system.<sup>1,2</sup> In this context, health information technology (HIT) is often cited as a necessary foundation for improving health care delivery.<sup>2</sup> This prioritization has recently had a dramatic effect on public policy. As a key element of efforts to improve the health system, the American Recovery and Reinvestment Act (ARRA) of 2009 provided \$19bn to promote the

adoption of electronic health records (EHRs).<sup>3,4</sup> These ARRA funds are targeted to increase the use of EHRs by pediatric primary care practices from current rates of nearly 20% and expand opportunities to use HIT to improve medical decision-making.<sup>5,6</sup> With the growth of HIT, clinical decision support systems (CDSS), tools to deliver intelligently filtered, appropriately timed, and actionable information to patients or clinicians, have become a centerpiece of efforts to use HIT to improve health care and outcomes.<sup>7,8</sup>

By reviewing the details of systems functioning in distinct contexts, the goal of this review is to provide an understanding of the role of HIT in pediatric decision-making with a focus on the primary care setting. Reviews of HIT-based CDSS have documented that effective decision support must be carefully designed to fit within clinical workflows,<sup>9,10</sup> and these workflows depend on how clinicians and families approach decision-making and how they choose to interact. Given this complexity, considering CDSS in a narrow context may limit the examination of unintended consequences and not fully capture the impact of HIT-based CDSS on the decision-making pro-

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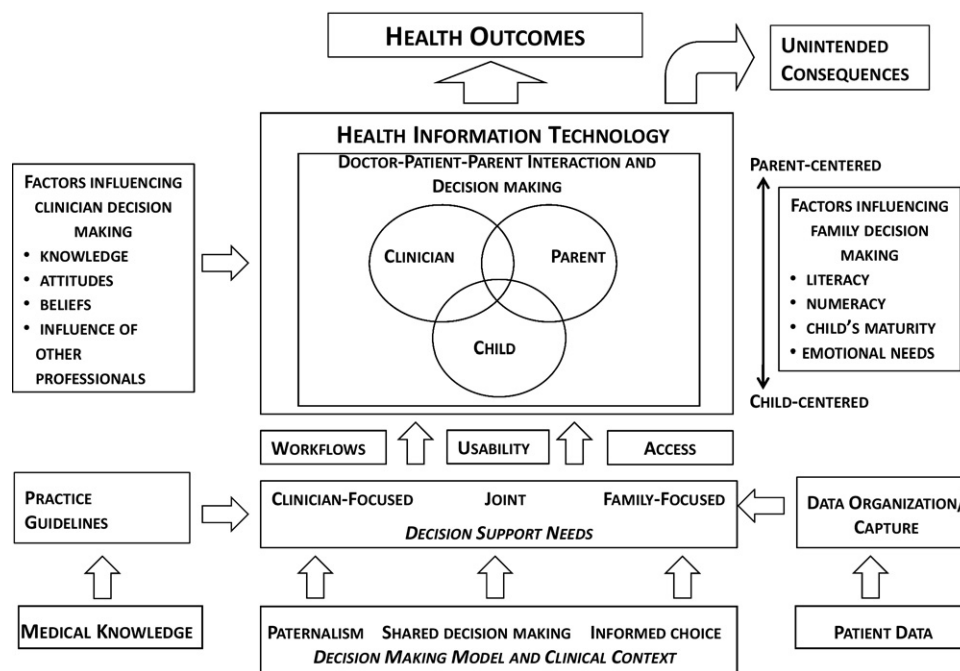
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**FIG 1.** Framework for how decision-making interactions and decision support impact health outcomes. This figure highlights how the doctor–patient–parent interaction as well as decision support may impact health outcomes. Medical knowledge, organized into practice guidelines, and patient data, gathered from the family and past history and captured and organized within electronic health record (EHR) systems, are needed to guide decision support. Decision support systems also need to be designed to match the decision-making model and the clinical context. Workflows, the usability of these systems, and the ability of clinicians and families to access the systems all must be considered. Multiple factors influence how both clinicians and families participate in decision making and are highlighted in the model.

cess.<sup>11</sup> Therefore, we consider the role of HIT broadly in the setting of different patterns of decision-making. Specifically, we consider 3 prototypes for decision-making in medicine identified through prior research: (1) paternalistic models in which practitioners make treatment decisions and communicate them to families; (2) informed patient-models in which patients reach their own healthcare decisions with information from clinicians or other sources; and (3) models of shared decision-making (SDM), which depend on the exchange of both medical and personal information between clinicians and families as they arrive at a decision.<sup>12,13</sup> As these descriptions illustrate, the flow and content of information that needs to be presented to or captured from clinicians, patients, and their families differ in each model.

This review considers the requirements for and potential benefits of CDSS in the context of these 3 distinct styles of decision-making. A conceptual model outlining the relationship between styles of decision-making, decision support, and health outcomes is shown in Figure 1 and discussed in more

detail in the following section. We use this framework to guide our discussion. By drawing examples from work in computerized physician order entry (CPOE), childhood immunization, asthma, and attention deficit hyperactivity disorder (ADHD), we highlight promising approaches for using HIT to support decision-making as well as future directions for research. This review addresses the importance of practice guidelines and discrete clinical data to drive decision support algorithms, explores barriers to gathering these data, considers issues in health system design, including workflows, usability, and access to CDSS, and then explores how the clinical context may shape the effectiveness as well as unintended consequences of a decision support intervention. Throughout, we suggest that clinical decision support may be most likely to improve outcomes if it is matched to the model of decision-making favored by clinicians and families in a particular situation. Developing a growing understanding of these models in distinct pediatric conditions and their implications for CDSS will be an important focus of future research.

## A Framework for Thinking About the Role of HIT in Supporting Decision-Making in Pediatrics

Through family, professional contacts, peers, and the mass media, we are frequently exposed to a wide range of new technologies. While it is tempting to focus on these individual tools and their potential roles in specific clinical settings, the framework for this article instead focuses on the decision-making process as a whole. Prior reviews of clinical decision support systems in the office or hospital setting and their impact have widely discussed the importance of workflows.<sup>9,10</sup> For decision-making in the primary care setting, the workflow is shaped by the extent and timing of involvement of the clinician, parent, and child.<sup>14</sup> For these reasons, in the framework presented, the clinical decision-making model, whether paternalistic, informed, or shared, is the foundation for the HIT supported decision-making process (Fig 1). Based on the decision-making model adopted in a particular clinical context, decision support needs differ. Information may need to be directed at the clinician, parent, child, or all the above. Distinct types of tools have been developed in varied settings to meet these needs and are addressed later in this review. Regardless of the type of HIT tools used, integrating the system into clinician workflows, ensuring the usability of the system for clinicians and families, and, especially for families, guaranteeing access to the system are critical to the success of the intervention.

For clinical decision support systems to be effective, they depend on both patient information and clinical guidelines.<sup>15</sup> Therefore, practice guidelines that follow a logic that can be adapted for computers as well as patient data that are organized into retrievable databases are both fundamental for functioning CDSS. Challenges inherent in both of these processes are reviewed in sections that follow.

As reflected in Fig 1, the core of any decision-making process in pediatrics is the interaction of the clinician, parent, and child. Given this multiparty process, challenges for CDSS can include raising awareness of the need for a test or procedure, delivering adequate information to address decision-making needs (eg, information on options and their risks and benefits), effectively sharing knowledge, or helping all involved identify and communicate their treatment preferences and goals. To meet these needs, HIT in this framework is presented as surrounding the

interaction between the doctor, patient, and parent, capable of supporting any of these decision-making needs and reaching the clinician, parent, or child (Fig 1).

Prior research has shown that the doctor, patient, parent interaction is not static, but varies across health conditions, decisions, and contexts.<sup>16</sup> Doctors may take and parents may delegate control over decision-making to the physician in certain situations while retaining it in others. In addition, patterns of decision-making often vary among clinicians, parents, or children/adolescents for a particular decision.<sup>16</sup> As a result, the health condition and context are highlighted in Fig 1 as an important input to the decision-making process. Similarly, parents vary in the extent that they delegate decision-making authority to children, and children vary with age and maturity in the extent to which they participate.<sup>17,18</sup> Of note, the Committee of Bioethics of the American Academy of Pediatrics has advised that, whenever possible, decision-making related to the treatment of older children and adolescents in routine practice should include the assent of the child in addition to parental permission.<sup>19</sup> These dynamics influence whether decision support may be best directed at parents, clinicians, or both.

For families and clinicians, the literature has demonstrated many factors that influence decision-making. For clinicians, knowledge, attitudes, and beliefs as well as the influence of other professionals shape how particular decisions are approached. Similarly, for families, the influence of their own social networks, levels of health and general literacy and numeracy (the understanding of quantitative concepts), emotional needs related to having a child with a medical concern, and the child's maturity level help to shape medical decision-making.

Finally, the framework illustrated emphasizes improving health outcomes as the goal of CDSS. By citing findings from our work and the published literature, we highlight examples of how decision support may succeed or fail in different contexts. As we discuss outcomes, we will also focus on potential unintended consequences of HIT based interventions. Throughout our review of the impact of these systems on outcomes in pediatrics, we highlight the need for additional study to better define how these systems can be implemented to improve children's health and health care. Historically, the emphasis of decision support systems has often been on health care processes as opposed to health outcomes.

	PATERNALISTIC	SDM	INFORMED
INFORMATION EXCHANGE	ONE WAY (CLINICIAN → FAMILY)	TWO WAY (CLINICIAN ↔ FAMILY)	ONE WAY (CLINICIAN → FAMILY)
PARTICIPANTS IN DELIBERATION	CLINICIAN ALONE, OR WITH OTHER CLINICIANS	CLINICIAN AND FAMILY TOGETHER, PLUS OTHERS IF DESIRED	FAMILY ALONE, PLUS OTHERS IF DESIRED
DECISION MAKER	CLINICIAN	CLINICIAN AND FAMILY	FAMILY

**FIG 2.** Patterns of information exchange, participants in deliberation and decision-makers in paternalistic, shared, and informed models of decision-making.

## Models of Decision-Making in Pediatrics

Knowing how best to use HIT to improve decisions depends on understanding patterns of decision-making. Patterns of decision-making in pediatrics fall along a spectrum based on the extent to which decision-making authority is centered with the clinician, parent/family, or both (Fig 2). In the “paternalistic model,” clinicians retain control and communicate the plan to patients. Traditionally, paternalistic approaches have been favored when the medical evidence indicates the clear superiority of 1 option over another.<sup>20</sup> For example, bacterial meningitis requires prompt antibiotic treatment. Lengthy discussion in that setting increases morbidity and mortality. Another setting where paternalistic models may be preferable is when patients or families prefer a passive role. While many patients prefer to be actively engaged in decision-making and the literature has increasingly focused on promoting patient-centered care,<sup>21</sup> a range of studies indicates that, for some, active participation may be unwelcome or have negative consequences. Although the issue is not well studied in pediatrics, breast cancer studies in the adult setting suggest that, for some, the prospect of participating in decision-making may increase distress and anxiety.<sup>22,23</sup>

In contrast to the paternalistic model, the “informed” model of decision-making places the patient/family in charge of selecting the preferred treatment. The growth of this approach has paralleled the broader trend toward “consumerism” and the increasing availability of electronic resources empowering pa-

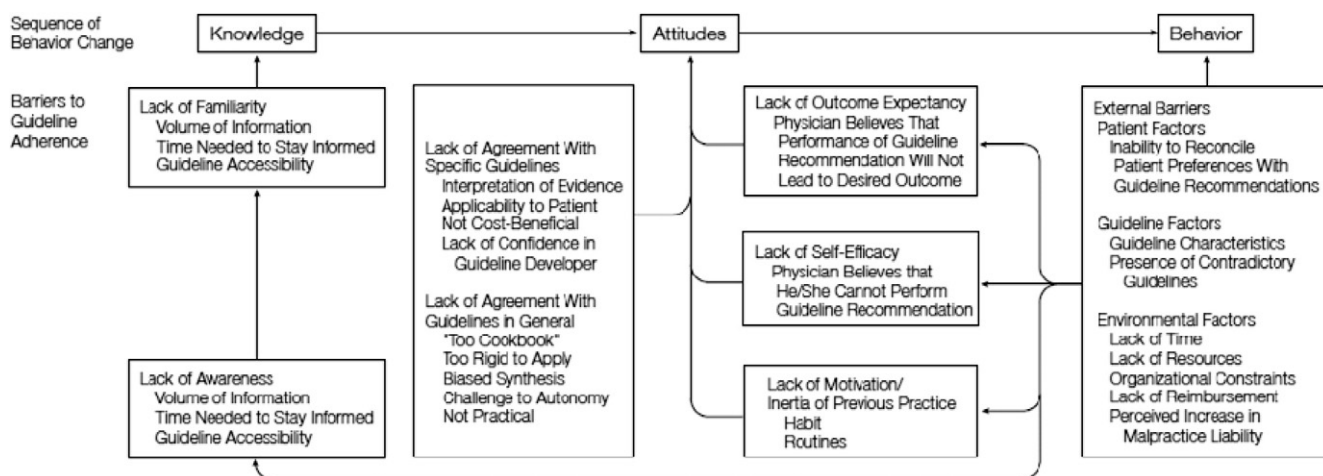
### COMPONENTS OF SHARED DECISION MAKING

- **PARENTS ARE INVOLVED WITH THE CLINICIAN IN THE TREATMENT DECISION-MAKING PROCESS.**
- **PARENTS AND CLINICIANS SHARE INFORMATION.**
- **PARENTS AND CLINICIANS EXPRESS TREATMENT PREFERENCES.**
- **A TREATMENT DECISION IS MADE THAT IS AGREEABLE TO BOTH PARTIES.**

**FIG 3.** Components of shared decision-making. (Adapted from Charles et al.<sup>12</sup>)

tients/families to take ownership over decisions.<sup>24</sup> Those favoring this approach argue that a patient and his or her family may be most invested in exploring all options and may be best positioned to understand how available options coincide with their values. However, this approach has pitfalls since the medical expertise of the clinician may no longer act as a filter to separate evidence-based from ill-founded information.<sup>15</sup> A variety of cognitive errors may also impair judgment and lead families to make choices that are inconsistent with their values or not in the best interest of their child. For example, testimonials from other patients or families, even if they do not match the medical evidence, may guide decisions.<sup>25</sup> In pediatrics, the potential harms of consumerism and “informed” decision-making are reflected in the growing number of families adopting alternative vaccine schedules that





**FIG 4.** Barriers to physician adherence to practice guidelines in relation to behavior change. (Reproduced with permission from Cabana et al.<sup>41</sup> Copyright 1999 by the American Medical Association.)

delay timely immunization receipt.<sup>26</sup> Although they have vocal supporters, decisions to delay or withhold vaccination frequently contradict medical evidence with potentially life-threatening consequences.

Unlike the paternalistic and informed models, SDM brings clinicians' medical expertise as well as parents' knowledge of a child's specific situation and the families' values to the decision-making process (Fig 3).<sup>27</sup> As a result, both the medical evidence and the personal information are prioritized and exchanged.<sup>12</sup> As most commonly defined, SDM involves both families and clinicians actively participating in the decision-making process, the sharing of information, each party expressing decision-making preferences, and the family and clinician jointly arriving at a treatment decision.

While research on SDM in pediatrics has been limited, results do suggest potential benefits. A study of otitis media presented parents with vignettes that featured either paternalistic or shared approaches to decision-making.<sup>28</sup> Parents in the SDM group were less likely to use antibiotics in these hypothetical scenarios and more likely to report being satisfied with the care they received. In the behavioral health setting, interventions to help clinicians improve communication with families around behavioral health improved outcomes, especially for minority families.<sup>29</sup> Based on these results in pediatrics and the results of trials largely in the adult setting, SDM has increasingly become a favored model of decision-making.<sup>13,30</sup>

## Health Information Technology and Decision-Making

### *Translating Research into Practice: The Argument for Health Information Technology-Based Decision Support Systems*

Regardless of the decision-making model used, the process of integrating research findings into daily medical practice represents an ongoing challenge. Even under ideal circumstances, the literature on innovation suggests that it may take 5-10 years or more for research findings to be disseminated.<sup>31,32</sup> Fortunately, pediatricians have been leaders in the development of guidelines to support care. Although clinical trials continue to bolster the evidence base, as of 2005, pediatricians had 215 available practice guidelines.<sup>33</sup> In addition, after reviewing a subset using the Appraisal of Guidelines for Research and Evaluation instrument, researchers showed that pediatric guidelines, especially those published or endorsed by the American Academy of Pediatrics (AAP) or registered in the National Guideline Clearinghouse, were of a higher quality than those in other fields.<sup>33</sup> Within this group, guidelines for asthma, acute otitis media,<sup>34</sup> otitis media with effusion,<sup>35</sup> ADHD,<sup>36,37</sup> febrile seizures,<sup>38</sup> and obstructive sleep apnea<sup>39</sup> are among the most prominent in primary care. Overall, guideline development in pediatrics has been facilitated by policies from the AAP Steering Committee on Quality Improvement and Management that provide standards for this process.<sup>40</sup>

However, obstacles to disseminating research findings in clinical practice are reflected in the literature on guideline implementation and have implications for the design and implementation of CDSS. In their 1999 review, Cabana and coworkers evaluated barriers to guideline adoption in the context of physician behavior change and found that barriers exist in terms of clinician knowledge, attitudes, and behavior<sup>41</sup> (Fig 4). The volume of new information, limited clinician time to assimilate new information, and a potential lack of access to or awareness of guidelines present knowledge barriers. Among clinicians, attitudinal barriers to following guidelines include a lack of agreement with guidelines in general, lack of agreement with specific guidelines, a sense that following guidelines will not lead to desired outcomes, a lack of confidence that it will be possible to follow guidelines in practice, and comfort with the status quo. When implementing guidelines, clinicians can be challenged by patient preferences that do not correspond to guidelines, difficulties in applying guidelines to a particular situation, and practical barriers, such as the time and resources needed to implement the guideline.

Given these barriers, the rates of guideline adoption in pediatrics, as in other fields, are low. Findings suggest that many pediatricians do not view guidelines as helpful and may not even be aware of many preventive guidelines and that fewer than 40% change their behavior based on guidelines.<sup>42</sup> A national survey found that a maximum of 27% of pediatric clinicians use any given guideline.<sup>43</sup> Those that were simple and flexible were most likely to be used. Results such as these have prompted calls for improved strategies to help clinicians adopt guidelines.<sup>44,45</sup> Clinical decision support systems are among the most prominent and well-studied approaches for achieving this goal.

## Clinician-Focused Decision Support

Clinician-focused decision support systems are well matched to situations when decision-making is pater-

nalistic or it is technically most feasible to deliver information to the clinician (as opposed to the family) at the point of care. Although additional research is needed in this area, CDSS may also be helpful when decisions are shared if they prompt clinicians to engage families in discussion or motivate families to be active participants. If carefully implemented, clinician-focused systems have been shown to overcome many of the barriers to guideline adoption. For example, the team that develops the system and times information delivery to the clinician removes the

burden of guideline awareness and detailed knowledge of a particular guideline from the physician. With a well-designed CDSS, the information simply appears at the appropriate time. If the local implementation of the CDSS is planned with respected clinical experts and administrative leaders, doubts about the quality of the recommendations may be mitigated. Also, if the system provides tools to facilitate implementation of the recommendations, such as patient instructions, clinician concerns about families' ability to follow-through on recommendations may also be reduced.

### *Strategies for Implementing Effective Clinical Decision Support Systems*

While CDSS have many potential benefits, clinicians may resist the implementation of these systems for many of the same reasons they resist practice guidelines. Several reviews have highlighted

effective strategies for implementing decision support systems that overcome common barriers and effectively change clinician behavior. These strategies, as described by Bates and colleagues in 2003 based on their experience with multiple decision support systems (Fig 5),<sup>9</sup> include (1) Ensuring that reminders appear without delays that slow workflows. Studies suggest that clinician users prioritize speed more than the ability of a system to improve quality or reduce costs; (2) Anticipating the needs of clinician users and

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delivering information without requiring the clinician to search for it. System designers should recognize that these needs may be “latent” or not yet consciously realized; (3) Fitting decision support into users’ workflows; (4) Prioritizing usability. Experience has demonstrated that seemingly small changes in how information is delivered can dramatically alter how clinicians respond; (5) Avoiding interventions that require clinicians to stop. For example, if canceling an order is recommended, suggest an alternative; (6) Encouraging clinicians to change direction instead of stopping is more effective. This type of approach may be particularly useful when a given drug should be ordered at a different dose or frequency; (7) Emphasizing simplicity. If the presentation of a guideline or alert is complex, it is more likely to be overlooked; (8) Whenever possible, avoid asking for additional information. Experience suggests that the more data elements that are required from the clinician, the lower the likelihood that the decision support will succeed; (9) Monitoring impact, getting feedback, and responding. This approach is especially important immediately following the implementation of a decision support system to ensure that problems are recognized and addressed before clinicians bypass the system; (10) Managing and maintaining the system. Although this aspect of decision support implementation is often overlooked, ongoing maintenance is critical to ensure that a decision support system functions as intended. For example, decision support rules often need to be revised when updates to guidelines are released.

In 2005, Kawamoto and colleagues conducted a systematic review of 70 research studies to further define optimal approaches for CDSS implementation.<sup>10</sup> Their work confirmed findings from Bates and distilled 4 rules for successful decision support. They found that decision support was most effective when recommendations were automatically provided within the context of the workflow, recommendations were provided instead of just assessments, decision support was provided at the time and location of decision-

making, and when decision support was computer vs paper-based. The importance of automated prompts was confirmed in a second systematic review conducted at the same time.<sup>46</sup>

### *Creating Effective Implementation Teams*

Teamwork between different technical, administrative, and clinical experts is needed to effectively implement CDSS and should also be prioritized in the development process (Fig 6).<sup>7</sup> Input from practicing clinicians is necessary to understand needs, integrate CDSS into workflows, understand subtle points that may increase the effectiveness of the system, and, overall, to ensure that the implementation is consistent with style of practice used in a given setting. These needs likely explain why CDSS evaluated by clinician experts who were also involved in their implementation have proven more effective.<sup>46</sup> Depending on the type of system under development, involvement of medical assistants, nurses, nurse practitioners, or physicians may also be needed. Furthermore, inclusivity early in the process may limit resistance to adoption once the intervention is developed.

Administrative expertise further contributes to the success of CDSS. Administrators can help developers best align a given intervention with health system priorities, with which they are often most familiar. In this context, administrators can help frame CDSS

as a vehicle to achieve a clearly recognized goal as opposed to a burden or threat to clinician autonomy. For example, EHR alerts improved billing for pulse oximetry performed in a primary care setting.<sup>47</sup> The billing problem had been identified by administrators but was relevant to clinicians as well. In addition, although clinical guidelines may endorse a range of approaches in a given situation, the development of simple and effective CDSS often depends on the ability to suggest a single recommendation. Based on their distinct training and perspective, administrators, especially if they also have clinical expertise, may be particularly helpful in building consensus among

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1. SPEED IS EVERYTHING.
2. ANTICIPATE NEEDS AND DELIVER IN REAL TIME.
3. FIT INTO THE USER'S WORKFLOW.
4. LITTLE THINGS CAN MAKE A BIG DIFFERENCE.
5. RECOGNIZE THAT PHYSICIANS WILL STRONGLY RESIST STOPPING.
6. CHANGING DIRECTION IS EASIER THAN STOPPING.
7. SIMPLE INTERVENTIONS WORK BEST.
8. ASK FOR ADDITIONAL INFORMATION ONLY WHEN YOU REALLY NEED IT.
9. MONITOR IMPACT, GET FEEDBACK, AND RESPOND.
10. MANAGE AND MAINTAIN YOUR KNOWLEDGE-BASED SYSTEMS.

**FIG 5.** Ten commandments for effective clinical decision support. The 10 commandments refer to evidence-based approaches for effectively implementing clinical decision support. (Data from Bates et al.<sup>9</sup>)

stakeholders in these situations. Finally, as the example above illustrates, the implementation of a CDSS often has either explicit or implicit economic consequences. Being mindful of these implications during the planning stage may help ensure the long-term sustainability of a project.

Many of the tenets for the effective development of CDSS depend on technical expertise. Questions of speed, developing strategies to integrate alerts into workflows, programming the system so that decision support can be followed without stopping clinicians, simplifying content delivery, monitoring the success of the intervention, and maintaining the system all require technical skill. Increasingly, universities are developing departments of medical informatics, a field that integrates information science, computer science, and health care. Compared with computer science, this field emphasizes the application of technology to health problems as opposed to focusing exclusively on computers or other pieces of hardware.<sup>48</sup> Experts in medical informatics, who are often clinicians themselves, are valuable partners in achieving these technical goals.

### *Building Clinician-Focused Decision Support Systems: Where to Begin?*

Clinicians, administrators, and medical informatics experts considering implementing decision support systems often identify target conditions to address from a list of competing priorities. In their text, “Improving Outcomes with Clinical Decision Support: An Implementer’s Guide,” Osheroff and colleagues present an approach for clarifying this decision<sup>7</sup> (Fig 7).

Specifically, they measure the value of a project based on patient impact, organizational impact, clinician impact, the number of patients positively affected, the gap between ideal and actual behavior pertinent to the intervention, the difficulty associated with addressing the objective, and the cost involved in meeting the goal. If 1 of these elements has an overwhelming impact, the authors argue that it should be weighed more heavily. In addition, the relative importance of each of these elements may differ if the goal is research, quality improvement, or achieving a business objective. In any context, reviewing each of these elements should help project teams more systematically determine the likely benefit from creating and implementing a particular decision support system.

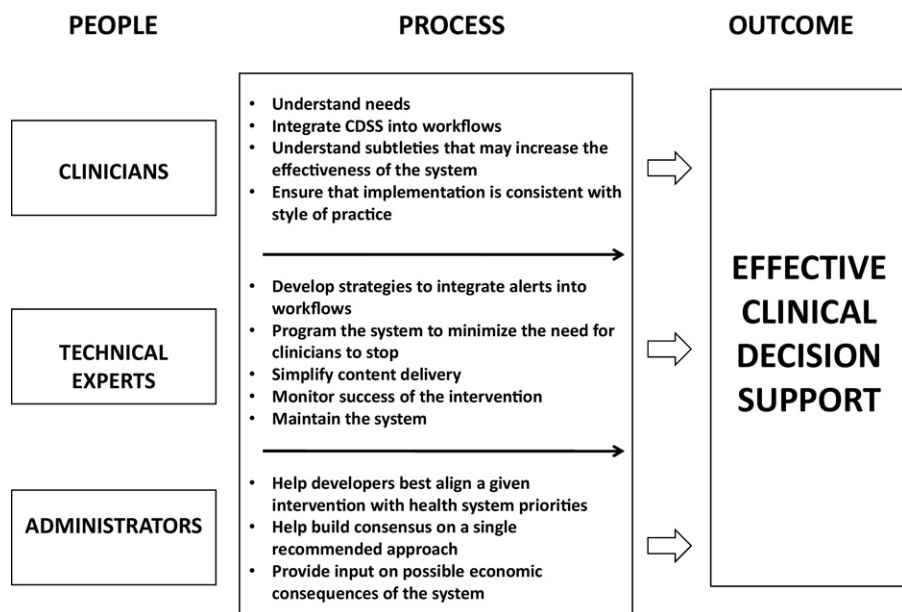
### *Prerequisites for Health Information Technology-Based Decision Support: Accessible, Organized Patient Data and Logically Structured Practice Guidelines*

In addition to an understanding of how decision-making unfolds in a particular clinical situation and the creation of an effective implementation team, the success of HIT-based decision support depends on accessible and actionable patient data as well as guidelines that summarize medical evidence in a manner that can guide programmable logic (Fig 8). Guidelines provide the evidence-based rules to specify how care should be delivered and define the patient information needed to determine a recommended action. Complexities in both the structure of guidelines and the organization of patient data present challenges to HIT-based decision support. These complexities as well as strategies to address them are highlighted in the paragraphs below.

### *The Organization of Patient Information*

We begin with a discussion of the organization and capture of patient data in electronic systems and focus first on data within EHRs, a frequent source of patient information to inform CDSS. The special requirements for data within pediatric EHRs were highlighted in a 2007 publication from the AAP Council on Clinical Information Technology.<sup>49</sup> These include the ability to record and manage immunization data, the ability to track growth, the support of pediatric weight-based medication dosing, the inclusion of pediatric data norms, and the protection of private information for special populations, such as adolescents. In advo-





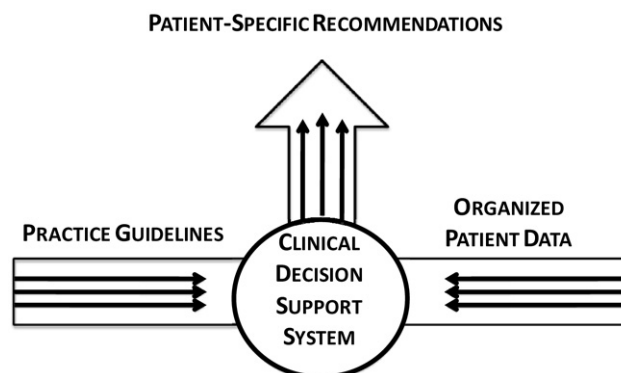
**FIG 6.** Teamwork necessary to effectively implement clinical decision support systems.

1. Patient impact (individual/population) (positive, e.g., quality, safe, cost-effective care; improved morbidity and mortality, of interest to patients)
2. Organizational impact (positive, e.g., regulatory or audit compliance, appropriate resource use, liability)
3. Clinician impact (favorable, e.g., enhanced workflow; consistent with consensus, local standards, feasible to address, of interest to clinicians)
4. Number of patients positively affected
5. Gap between ideal and actual behavior pertinent to the intervention
6. Difficulty associated with addressing the objective
7. Cost of addressing the objective

**FIG 7.** Factors affecting the desirability of implementing a particular clinical decision support intervention. These are factors that should be considered by an organization or research team when considering 1 or multiple possible contexts for implementing a clinical decision support system. (Adapted from Osheroff et al.<sup>7</sup>)

cating for these requirements for any pediatric EHR system, the group highlighted the additional benefit of these features for many nonpediatric populations. These functions also provide a foundation for creating a standard data set to support decision-making for many pediatric conditions.

Despite this guidance and a widespread recognition of the benefits of standardization in the capture of patient data, the use of EHRs has generated some concern among physicians who feel that the computer may compromise doctor–patient–family communica-



**FIG 8.** Inputs for effective clinical decision support. Both useful practice guidelines and organized patient data are needed for a clinical decision support system to effectively function in providing clinically useful, patient-specific recommendations.

tion. The historical context is useful in understanding this perspective. The present day problem-oriented medical record (POMR) has its roots in efforts to organize patient information in a way that facilitates patient care, research, and education.<sup>50</sup> Prior to the development of the POMR, medical data were entered in charts with a focus on the visit and little attention to tracking problems over time. Before the eventual widespread recognition of its value, the POMR was initially met with skepticism by many clinicians who were reluctant to adopt a new approach to organizing medical information.

The implementation of the EHR within practices represents another major transition in how patient information is captured and retrieved. In the EHR, the POMR in many ways has been translated into electronic form as tools often exist to review chronic problems, laboratory results, or diagnoses that span many encounters. However, although many praise the ability of these systems to capture discrete data that can be used to measure and improve the quality of care, critics argue that the ability to enter an unstructured narrative in the note can be crucial to adequately conveying a patient's condition.<sup>51</sup>

As this tension highlights, a balance is needed between structured and unstructured data. In the EHR, clinical data may be unstructured and entered as free text, entered as text in response to open-ended prompts, entered using a series of multiple-choice options, or hard-coded "discrete data" entered from a finite list of options and then transferred from the note into a database. Because of this variability, a fundamental step in the design of any CDSS is reviewing how the data needed to provide decision support for a particular problem are structured within the EHR. Unfortunately, for developers of CDSS and clinicians or researchers seeking to improve the quality of care, the capture of information often varies across institutions and clinicians who may develop their own styles of EHR use, even if they use the same EHR system. In the ideal scenario, the data fields needed to address a particular problem would be captured as discrete data in mandatory fields. As the required data become less and less structured, "text mining," a process of searching the narrative for key phrases, becomes much more important.<sup>52</sup> When data are not captured reliably or in a fashion that can be extracted, fields may need to be custom built for a project to proceed. As will be discussed in more detail later, personal health records (PHRs), patient portals, office-based kiosks, or forms within the EHR to facilitate data capture may be particularly helpful tools in settings where EHR data are inadequate to inform CDSS.

### *Data Quality*

Any discussion of data quality and capture warrants consideration of common data errors that can undermine CDSS. Inaccuracies in the EHR arise through a variety of mechanisms. Human error is a common cause of mistakes. For example, a clinician might indicate a normal cardiac examination in the physical examination section of a patient's chart, but elaborate

on a murmur in the assessment and plan. Defaults of "normal" in the EHR can facilitate this type of mistake. Limitations in the range of choices available in the EHR may also contribute to poor data quality. For example, a clinician may want to code "left acute otitis media" as a diagnosis, but the International Classification of Diseases, 9th Edition, does not permit the designation of laterality.<sup>53</sup> While alternative systems for entering more specific diagnoses, such as Intelligent Medical Objects (Northbrook, IL), are available, transitions between coding systems may also introduce data inconsistencies that complicate the development of CDSS. Finally, health systems themselves may merge, delete, or update medical record numbers. CDSS systems need to be responsive to these updates to effectively support decision-making in "real-time."

### *Synthesizing the Medical Evidence: Clinical Practice Guidelines*

Inaccurate, disorganized, or inaccessible patient data compromise any effort to effectively support decision-making using HIT. Similarly, medical evidence must be available and organized to effectively trigger any decision support system. Clinical practice guidelines outline the path to follow in a given clinical situation and therefore function as the roadmap for logic embedded in any CDSS. As stated above, a substantial number of guidelines already exist in pediatric practice. However, many guidelines have not been written with the logical framework needed to inform computer-based algorithms.

For example, in the case of the AAP acute otitis media practice guideline, the first recommendation reads: "To diagnose acute otitis media the clinician should confirm a history of acute onset, identify signs of middle-ear effusion, and evaluate for the presence of signs and symptoms of middle-ear inflammation."<sup>34</sup> To develop a rule based on this recommendation, definitions are needed for such terms as "acute," "middle-ear effusion," and "middle-ear inflammation." While these rules must be understood by clinicians, the logic must also be programmable for HIT-based decision support to be implemented. Only once these definitions are established and rules outlined can a computer system use patient data to determine if criteria for a given condition or treatment are met.

To address the gap between the language in guidelines and the requirements of computer-based rules,

experts in CDSS now participate in many committees generating clinical guidelines. In addition, scholars have created frameworks for adapting guidelines for computer-based decision support. Among the most prominent is the Guideline Elements Model developed by Karras and coworkers and Shiffman and coworkers.<sup>54,55</sup> In this system, a hierarchical template is used that includes markers for the different elements needed to operationalize the guideline. This system draws heavily on the original text of the guideline. Elements considered include the target clinical user, the intended patient population, and the required knowledge elements. Once these are outlined, the required data elements, conditions, and actions, effectively a series of “if . . . then” statements, are specified. Through this process, the practice guideline is decoded into logical elements in preparation for programming. Of note, clinical expertise is needed as these steps proceed to ensure that the result of this process is consistent with standards of care and the final product remains clinically relevant.

### *Computerized Physician Order Entry: A Prototype Proving the Effectiveness of Clinician-Focused Decision Support*

The emphasis on clinician-focused decision support systems is warranted since HIT-based CDSS have already improved clinical practice. Early work demonstrating the value of clinician-focused decision support systems evaluated CPOE, the process of entering orders for medication or procedures into an EHR equipped with logic to identify potential errors. CPOE was and remains a prime target for clinician-focused decision support since, although both families and clinicians may be involved in choosing a preferred course of treatment, clinicians are responsible for ordering medications. In addition, medication errors are common, potentially fatal, and preventable.<sup>1</sup>

Given how well the clinical context in CPOE is matched to clinician-focused decision support, the success of CDSS in this area is not surprising.

Reviews of studies of CPOE indicate significant rates of error reductions with these systems, with a reduction of >50% in serious medication errors in inpatient settings.<sup>56,57</sup> In the adult primary care setting, researchers found that advanced prescribing systems could prevent 95% of adverse drug events.<sup>58</sup> While the overall literature on decision support emphasizes simplicity, researchers in this setting found

that more basic systems that only suggested certain standard doses and required completion of mandatory fields, such as drug, dose, quantity, and duration, were not effective. Rather, more complex systems with dose and frequency checking were needed to improve outcomes. Additional work in the field has also demonstrated that computerized prescribing advice can increase the initial medication dose, increase serum concentrations of medications, reduce times to therapeutic stabilization, reduce the risk of toxic drug levels, and reduce the length of hospital stay.<sup>59</sup> Of note, the benefit of CPOE in pediatrics has also been demonstrated. Studies suggest that 93% of pediatric hospital adverse drug events could be prevented through CPOE.<sup>60</sup> However, the impact of these systems may be reduced in pediatrics if systems are not customized to address the unique challenges in selecting and dosing medications for children.<sup>61</sup>

## **Clinician-Focused Decision Support in Pediatric Primary Care**

As the example of CPOE illustrates, clinician-focused decision support systems can transform the delivery of pediatric care in high-risk inpatient settings. However, most pediatric care is delivered in the primary care setting. For pediatricians in primary care practice, CDSS has the potential to improve everyday procedures, such as immunization delivery as well as the management of chronic illness. In the following paragraphs, we review work in the fields of immunization, asthma care, and ADHD as examples of the strengths and limitations of outpatient pediatric CDSS. In this discussion, the data elements needed to inform these systems, the challenges in developing systems likely to change behavior, as well as the impact of using this technology on health outcomes are highlighted.

### *Pediatric Immunization Delivery*

Like CPOE, pediatric immunization delivery is an ideal setting to examine clinician-focused decision support. These systems provide decision support in the form of clinical alerts, which notify the clinician when vaccines are due. Many aspects of immunization delivery argue for the use of technology to enhance care. Both the facilitators and the barriers to implementing immunization decision support are highlighted in Fig 9. First, thanks to the efforts of the AAP's Council on Clinical Information Technology,

## FACILITATORS

- Immunization information is captured as discrete data within the EHR
- Clinicians prioritize documenting immunization data
- Local, regional, or state-wide immunization information systems (previously known as registries) are available in many areas and can help fill gaps in vaccine records
- Annual publication of a standard vaccination schedule provides rules to guide the implementation of immunization decision support
- Vaccines are delivered in the office setting so providing decision support to clinicians can directly change clinician practice and improve outcomes



## BARRIERS

- Even with a nationally standardized vaccine schedule, local implementation of the schedule often varies
- To determine the age to begin to alert for a given vaccine and the range of combination products to consider, a local consensus is needed
- Vaccine shortages may emerge quickly with little notice

**FIG 9.** A case study: facilitators and barriers to implementing immunization decision support. (Color version of figure is available online.)

immunization information is generally captured as discrete data within the EHR.<sup>49</sup> When vaccines are ordered within the EHR, they automatically populate the system's database. In addition, clinicians prioritize documenting immunization data because it is viewed as 1 of the most important functions of primary care. As a result, pediatric offices routinely develop systems to enter data on immunizations administered in other settings, for example, in the case of influenza vaccines administered at schools or when children move to a new practice, into the EHR. Furthermore, thanks to the efforts of pediatricians and others, local, regional, or statewide immunization information systems (previously known as registries) are available in many areas and can help fill gaps in vaccine records.<sup>62</sup> The annual publication of a standard vaccination schedule also provides rules to guide the implementation of immunization decision support so the adaptation of immunization rules for CDSS is simplified. Finally, vaccines are delivered in the office setting, making it possible for clinician-focused decision support to directly change practice and improve outcomes.

Challenges to effectively implementing clinical alerts, even in the setting of an ideal prototype for clinician-focused decision support, such as immunization, highlight the complexity of delivering effective decision support in primary care. For example, even with a nationally standardized vaccine schedule, the local implementation of the schedule often varies. The 2010 schedule specified that the diphtheria, tetanus,

and pertussis vaccine is recommended between 15 and 18 months of age and may be given as early as 12 months of age.<sup>63</sup> However, within this range, individual practices and even particular clinicians may choose different ages to begin administering the vaccines. In addition, individual practices may use distinct combination vaccine products. As mentioned above, the most effective decision support systems recommend 1 particular course of action. However, to determine the age to begin to alert for a given vaccine and the range of combination products to consider, a local consensus is needed. Ideally, this discussion should take place early in the development of the system and should combine clinical, administrative, and technical experts. This teamwork is especially important in the setting of pediatric vaccination since the vaccine schedule is updated at least annually and sometimes more frequently and shortages may arise, prompting temporary updates to national recommendations. The follow paragraphs describe results from the evaluation of 2 immunization decision support systems developed by our team.

### *Vaccine Alerts for Routine Immunizations in Young Children in the Urban Setting*

Of all vaccines, those for infants and toddlers are generally most highly prioritized by pediatricians as a means to prevent life-threatening illness. Despite this focus, the National Immunization Survey continues to report rates of coverage for all due vaccines at less





**FIG 10.** Clinical alert in the EHR. Specific recommendations are provided. Combination products available at a given site are recommended when indicated. The system is also designed to facilitate order entry by providing links that direct the clinician to the order entry screen. Links to guidelines and to information for families also help clinicians to more effectively deliver vaccines. (Color version of figure is available online.)

than 70% at 2 years of age.<sup>63</sup> Low rates prompted Healthy People 2010 to designate immunization as 1 of the 10 leading health indicators for the nation.<sup>64</sup> The problem of improving rates in impoverished, urban settings is especially challenging for multiple reasons, including frequently missed appointments that result in vaccine delays for young children.<sup>65</sup>

Beginning in September 2004, our group focused on addressing this problem by designing a system that would alert nurses or clinicians when any vaccine delayed child under 24 months of age arrived in the office and prompt a specific recommendation regarding due vaccines. In response to high rates of missed well-child visits, we worked with clinicians, administrators, and our technical team to develop a system that would alert at the earliest possible opportunity. Alerts appeared prominently at the top of the screen whenever a chart was opened in the EHR (Fig 10). In addition, the alert system was designed to notify the user of invalid doses, such as vaccines given at too young an age or too close to the preceding dose (Fig 11). This approach was meant to minimize the risk that the system would confuse clinicians, leading to distrust in the system.

The project impacted care on a large-scale and resulted in a clinically meaningful increase in vaccination rates. Two urban practices were randomized to a control group and received usual care through the EHR. Two practices received the alerts. At the 2 intervention practices, alerts appeared at 15,928 visits over a 1-year period.<sup>66</sup> Rates of captured immunization opportunities, defined as at least 1 vaccine given if vaccines were due at a visit, increased from 78.2% to 90.3% at well visits and nearly tripled from 11.3% to 32.0% at sick visits (Fig 12). Overall up-to-date vaccination rates for children in the population in-

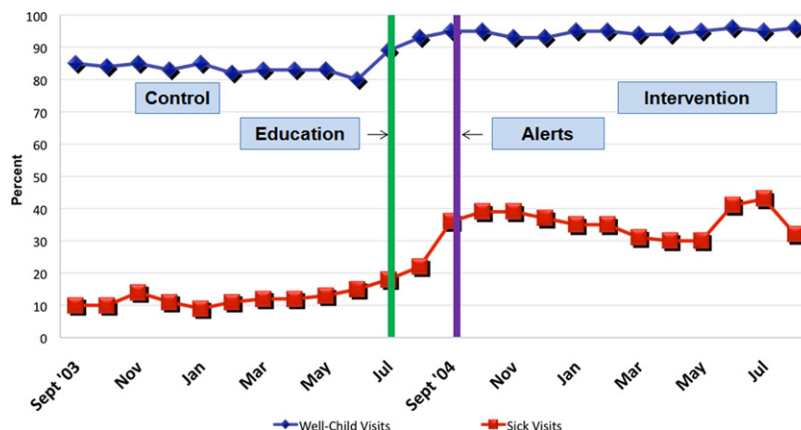
<b>IMMUNIZATIONS ARE DUE</b>
- Hepatitis B
- Pneumococcal Conjugate
<b>INVALID IMMUNIZATIONS</b>
- Hepatitis B: 07/08/2004
- Pneumococcal Conjugate: 04/10/2004

**FIG 11.** Vaccine alert systems can provide detailed information on prior invalid doses that were given too early or too close together. Invalid doses are listed to minimize confusion regarding recommendations that may prompt clinicians to doubt the validity of recommendations. This level of transparency may be especially helpful early in the implementation process for a clinical decision support system. (Color version of figure is available online.)

creased from 81.7% to 90.1% from the control to intervention period. In addition, children in the intervention group became up-to-date on all vaccines due before 2 years of age earlier than those in the control group. The success of the intervention prompted us to explore the impact of the alerts in other populations and for other conditions.

### *Vaccine Alerts for Influenza Vaccine Among Children with Asthma*

In 2006-2007, the Centers for Disease Control and Prevention encouraged the medical and public health communities to develop plans to improve influenza vaccine delivery.<sup>67</sup> Concurrently, the AAP highlighted the importance of improving vaccination rates among children with high-risk conditions.<sup>68</sup> In response to this guidance, we conducted a clinical trial to improve vaccination rates for children with asthma in a multi-state primary care practice-based research network.<sup>69</sup> At that time, universal vaccination with influenza vaccine had been recommended for children <60 months of age, but



**FIG 12.** Percent of immunization opportunities captured for routine childhood vaccines. Results of a trial of immunization decision support for children under 2 years of age. A control period was followed by education then activation of the decision support. The intervention was associated with significant increases in captured vaccination opportunities at both sick and well visits. (Reproduced with permission from Fiks et al.<sup>66</sup> Copyright 2007 by the American Academy of Pediatrics.) (Color version of figure is available online.)

not among older children or adolescents. Although influenza vaccine was recommended for all high-risk children, we focused on those with asthma because they were readily identified on the basis of ICD-9 codes within the local EHR. Given the success of vaccine alerts among infants and toddlers, the prioritization of influenza vaccination in high-risk populations nationally, and recognition of the need to vaccinate children with asthma against influenza, we hypothesized that alerts would improve rates and lead to increased protection. Still, we recognized that in a different clinical context (influenza vs early childhood vaccination), the impact of vaccine alerts might differ.

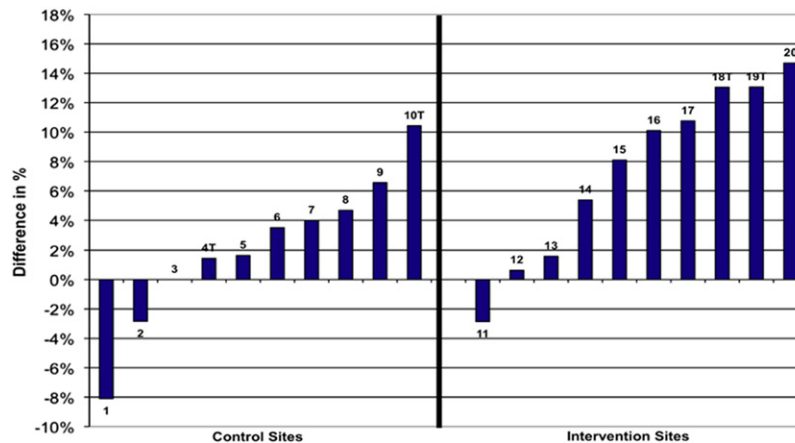
Ultimately, the study found that influenza alerts in this population had only a minimal impact on vaccination rates.<sup>69</sup> Since influenza vaccination rates were known to vary across practices and seasons, we used a pre-post design in which the performance of each practice was compared with the performance of the same practice during the prior year. The study involved a population of nearly 12,000 children in the intervention year and included over 20,000 visits by children or adolescents with asthma who were eligible to be vaccinated. Rates of captured immunization opportunities increased from 14.4% to 18.6% at intervention sites and from 12.7% to 16.3% at control sites, a 0.6% greater improvement that was not statistically significant. Overall, influenza vaccination rates standardized for the characteristics of the population improved only 3.4% more at intervention than control sites, again a nonstatistically significant difference. The change in rates for each of the 20

involved practices between the baseline (control) and intervention year is shown in Fig 13. Of note and again highlighting the importance of context, the system did have a significant but modest effect when the effect of the intervention among only the urban practices was evaluated.

A published commentary on the study considered the results in the context of best practices for decision support implementation.<sup>70</sup> The authors of the commentary argued that substantially improving outcomes may take more than reminders alone. In broad terms, they highlighted the importance of communicating the purpose of the intervention to stakeholders, ensuring that the intervention is acceptable, ensuring that the optimal intervention technique is used, and monitoring the progress of the intervention to ensure success (Fig 14). Of note, they emphasized the importance to the success of a CDSS implementation of ensuring the acceptability of the intervention for patients and families. In the case of the influenza vaccine study, a lack of acceptance of the vaccine among families likely minimized the impact of the intervention. Strategies to better engage families in decision-making and encourage them to accept recommended interventions are addressed later in our discussion of clinical decision support for SDM.

### ADHD Decision Support

ADHD is the most common neurodevelopmental disorder in children and adolescents with prevalence



**FIG 13.** Difference between the study and baseline years in the percentage of patients up-to-date for influenza vaccine, by site. Practices are divided into intervention and control sites. Each bar represents a different site. Sites labeled with "T" are the resident teaching practices, all located in urban settings. (Reproduced with permission from Fiks et al.<sup>69</sup> Copyright 2009 by the American Academy of Pediatrics.) (Color version of figure is available online.)

#### COMMUNICATION AND ACCEPTANCE

1. Has the clinical rule or concept that will be promoted by the intervention been well communicated to the medical staff in advance?
2. Does the intervention, if accepted, change the overall plan of care, or is it intended to cause a limited, corrective action (such as preventing an allergic reaction to a drug)?
3. Are the data used to trigger the alert likely to be accurate and reliable, and are they a reliable indicator for the condition you are trying to change?
4. What is the likelihood that the person receiving the alert will actually change his or her patient management as a result of the alert?
5. Is the patient likely to agree that the recommended actions are beneficial?

#### INTERVENTION TECHNIQUE

1. Is an alert the right type of intervention for the clinical objective, and is it presented at the right time?
2. Is the intervention presented to the right person?
3. Is the alert presented clearly, and with enough supporting information, so that the clinician feels confident in taking the recommended action immediately?
4. Does the intervention slow down the workflow?
5. Is the overall alert burden excessive ("alert fatigue")? Were the study providers receiving other types of alerts at the same time?
6. Is the clinical information system, including the use of CDS (eg, the alerts), well-liked and supported by clinicians in general?

#### MONITORING

1. Is there a way to monitor the response to the alert on an ongoing basis?

**FIG 14.** Questions to consider before the implementation of a real-time, point-of-care clinical decision support system in a particular medical context. (Adapted from Sittig et al.<sup>70</sup>)

estimates between 3% and 16% depending on the sample and measurement techniques used.<sup>36,71</sup> According to the National Survey of Children's Health conducted by the Centers for Disease Control, nearly 4.5 million US children between 4 and 17 years of age had ever been diagnosed with the condition as of 2003.<sup>72</sup> Children with ADHD rate significantly lower in health-related quality of life in all psychosocial areas. Those with comorbidities, such as oppositional defiant conduct, internalizing, and learning disorders,

have even greater deficits.<sup>73</sup> In addition to its impact on the daily lives of children, ADHD impacts the health and functioning of families, schools, and the community. Primary care pediatricians have assumed a growing role in the treatment and management of ADHD, in line with national guidelines disseminated by the AAP. Nevertheless, training in managing children with ADHD has historically been limited and many clinicians remain uncomfortable with managing ADHD.

While ADHD is an ideal prototype for studying decision support, especially in instances when SDM is the preferred model of decision-making and both families and clinicians use the system, published studies to date have only evaluated ADHD decision support focused on the clinician. In this context, the goal was to improve clinician management of ADHD, not decision-making between the clinician and family. A 2010 study in the journal *Pediatrics* reported results from a cluster randomized trial of a system that included (1) on-screen clinician reminders to assess ADHD symptoms every 3-6 months and (2) an ADHD note template with structured fields for symptoms, treatment effectiveness, and adverse medication effects.<sup>74</sup> Using this approach, the intervention sought to improve (1) the quality of documentation of the assessments of children with ADHD in the medical record and (2) the proportion of children with visits during a 6-month period in which the status of child's ADHD was assessed. As reflected in the choice of outcomes, the focus of the study was on process measures, not patient outcomes.

The study did show significant improvements in the care delivered to children with ADHD at the study sites. During the study period, 70.9% of children with ADHD at intervention sites had an ADHD-focused visit as opposed to 53.9% at control sites. ADHD symptoms and treatment were documented more often during well visits for patients in the intervention than control group (78 vs 63%), but this difference was not statistically significant. Of note, only 33% of eligible physicians ever used the ADHD template developed by the research team.

The researchers combined their quantitative evaluation with focus groups that addressed barriers to decision support adoption, an approach that is often needed to better understand the reasons for the success or failure of an intervention. They found that clinicians often forgot the templates were available, preferred to use templates they created for themselves, and found the use of documentation templates to be cumbersome and inefficient. These findings underscore the importance of involving clinicians in the design of a decision support intervention, of minimally interfering with existing workflows, and of only trying to gather additional information from clinicians that is essential to the success of a CDSS intervention.

## *Asthma Decision Support*

HIT-based, clinician-focused decision support has also been explored in asthma. Asthma is the most common chronic physical condition in childhood and affects the health of more than 6 million US children. National guidelines exist to inform care and guide decision support.<sup>75</sup> Nevertheless, despite these guidelines, epidemiologists have highlighted the problems of rising asthma prevalence, hospitalization, and cost.<sup>76</sup> Since office-based procedures for asthma as well as asthma medications are ordered by clinicians, clinician-directed decision support is a reasonable approach to improve adherence to asthma guidelines and the quality of primary care for asthma. The following paragraphs describe 2 examples of pediatric clinician-focused asthma decision support.

In 1 study, handheld computers were used to deliver guideline-based decision support to office-based pediatricians.<sup>77</sup> The intervention was delivered using a Newton Message Pad (Apple Computer, Cupertino, CA) and, similar to the ADHD study, provided a structured documentation template. In addition, the system dynamically generated recommendations based on 1994 guidelines from the AAP, provided assistance with the calculation of the predicted peak expiratory flow rate and medication doses, and printed encounter summaries and prescriptions. As with the immunization and ADHD interventions, clinicians were free to accept or decline recommendations from the decision support system. However, unlike the ADHD study, both process measures and patient outcomes were considered. To prepare subjects, the study team provided on-site training to clinicians in the intervention.

The study was conducted as a "before-after trial," sometimes called a pre-post design. The researchers found that the intervention resulted in more frequent measurements of peak expiratory flow and oxygen saturation, and a greater likelihood that inhaled steroids would be administered. However, clinicians found that the system too often recommended that patients receive supplemental oxygen and ignored those recommendations 90% of the time. Results also demonstrated that the length of visits increased with the intervention and that the fees associated with visits increased from \$103.11 to \$145.61. Patient outcomes, recorded through follow-up phone calls, were assessed 7 days following asthma office visits. No differences were noted in the proportion of children requiring an



Emergency Department visit or hospitalization. In addition, no differences were observed in missed school days or caretaker missed work associated with the asthma exacerbations. Overall, then, adherence to process measures improved, but measured patient outcomes were not affected during the assessment period. The increased costs of care in the absence of improved patient outcomes illustrate the importance of considering both intended and unintended consequences of CDSS interventions, an area considered later in this review.

In contrast to the handheld computer-based study, a 2010 study of asthma decision support from our group focused on improving asthma care using EHR-based decision support guided by family-reported symptoms.<sup>78</sup> For asthma, detailed knowledge of daily symptoms is needed to classify severity.<sup>75</sup> With knowledge of severity, EHR-based CDSS can then be programmed to provide recommendations for specific classes of medication treatment, especially inhaled steroids. Multiple strategies have been used in different settings for gathering patient-entered data, including the use of kiosks<sup>79</sup> or hand-held computers,<sup>80</sup> paper-based forms that can be scanned into the EHR,<sup>81,82</sup> patient portals, or personal health records. Often, the desired approach is guided by practical considerations, especially the availability of these different systems. For our study, a 12-practice cluster randomized trial, our team created and implemented an asthma control assessment tool within the EHR based on a previously published instrument (Fig 15).<sup>83</sup>

Given the potential for an increase in demands on clinical staff to undermine a CDSS intervention, the research team used multiple approaches to promote the integration of this tool into office workflows. First, practices were encouraged to have the tool completed in whatever way minimally disrupted care. In some, nurses completed the tool while in others clinicians preferred to complete the instrument while taking the history. To prevent the duplication of effort, once the form was completed, a clinician could use a simple shortcut to bring a summary of the information captured using the asthma control tool into the visit note. Practices also received a small financial incentive for surpassing a benchmark rate of completion of the tool. Finally, intervention practices received onscreen reminders based on evidence-based guidelines, the information in the asthma control tool, and a child's prior history of medication use. With this approach, rates of completion of the tool at both intervention and

**Asthma Control Tool**

How often does your child have asthma flares?  
 - An asthma flare is an increase in signs of asthma for more than a day  
 - Your child may need more albuterol or other quick relief medicines

Think about the past 3 months:

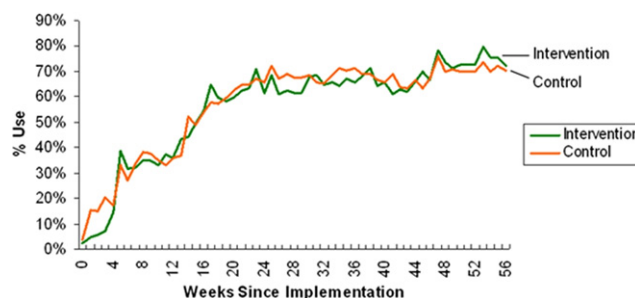
	0	1	2	3	4	5 or more
1. How many asthma flares did your child have?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How many times did your child start on a steroid medicine by mouth for asthma such as prednisone (Prelone, PediaPred or Orapred)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How many times did your child make an emergency visit for asthma?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How many times did your child stay overnight in the hospital for asthma?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How is your child IN BETWEEN asthma flares?  
 Think about the past 3 months:  
 - How often did these things happen when your child was feeling his or her best and NOT having an asthma flare? (check one)

	Never	1 or 2 times per month	1 or 2 times per week	Every other day	Every day	More than once a day
1. Asthma symptoms with running or sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Asthma symptoms while asleep at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. He or she needed to take albuterol or another quick-relief medicine for asthma symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Cancel Accept

**FIG 15.** Asthma control tool. The asthma control tool provides a standardized way to record the recent asthma history with a series of discrete, evidence-based questions. (Color version of figure is available online.)



**FIG 16.** Asthma control tool adoption by clinicians at visits by patients with chronic asthma. Intervention refers to practices that had the benefit of decision support. Control practices received the tool to assist with documentation, but received no decision support on the basis of using the tool. With a small economic incentive, both intervention and control practices adopted the tool and achieved rates of 70% for tool use at eligible visits. (Color version of figure is available online.)

control practices approached 70% at visits by patients with chronic asthma (Fig 16). As Fig 16 shows, 6 months were required to achieve high levels of adoption. This timeline should be considered by those implementing decision support systems, especially those that require adaptations of existing workflows and that address complex clinical issues or processes.

The goal of the intervention, which began with an educational presentation to all involved sites, was to increase the proportion of children with persistent

asthma who had at least 1 prescription for a controller medication, an up-to-date asthma care plan, and a completed office-based spirometry to measure lung function. Once again indicative of the importance of context for any decision support intervention, the impact of the CDSS was different at urban practices serving a largely Medicaid-insured population vs suburban practices that cared for a largely privately insured group of families. Results showed that the intervention significantly increased the number of prescriptions for controller medications over time by 6% more at intervention vs control practices in the urban setting. At the suburban practices, baseline rates of controller medication use were lower and they increased at both intervention and control practices. In the suburban setting, the filing of an up-to-date asthma care plan improved 14% and spirometry improved 6%, both significant changes. Urban practices, with higher baseline rates of asthma control tool completion, had little room to improve.

### *Summary: Clinician-Focused Decision Support*

The preceding paragraphs highlight successes and challenges in projects targeting clinicians to improve guideline-based care. Our work in immunization demonstrates the importance of aligning decision support with the goals of both clinicians and families. The system worked well for young children in the urban setting whose parents readily accepted vaccines, but was less effective in the setting of influenza, a vaccine less widely accepted by families. Studies in ADHD and asthma illustrate the potential of using CDSS to improve the care of children with chronic illness. Using clinician-focused decision support, these studies focused primarily on process measures that are responsive to the actions of pediatricians in the office setting. These examples also illustrate the limitations of data captured as part of routine care as inputs into decision support systems. The asthma control tool was created so that recommendations could be based on assessed symptoms which were not captured in a standard format in the EHR. As a result, before the decision support could be effectively implemented, clinical and financial incentives were used to promote adoption of the tool. These examples illustrate the complexity of delivering decision support to clinicians in primary care pediatrics. An overlapping, but in many cases distinct, set of challenges exists in engaging families at home or in the office in decision-making using family-directed decision support.

## **The Promise of Decision Support That Integrates Families**

This review thus far has focused primarily on decision support directed at clinicians. However, while the decision support systems we have previously reviewed address decisions reached or actions implemented primarily by clinicians, supporting families is especially important in the setting of informed and shared models of decision-making in which families take more responsibility for choices regarding their health. The importance of using HIT to help structure care around patient preferences in addition to practice guidelines, a goal of SDM, has also been emphasized.<sup>84</sup> Even when the responsibility for the decision is primarily the clinician's, families still provide input, including medical and personal information about their specific child. The following discussion briefly summarizes the potential benefits of SDM, reviews barriers to implementing CDSS for SDM, and explores the potential role of HIT in engaging families as more active participants in decisions related to their child's health.

Based on findings primarily from adult health care, the attention of researchers and policymakers, including the Institute of Medicine and the World Health Organization, has increasingly focused on SDM, an approach to engage families as active partners in their health care.<sup>85,86</sup> As mentioned earlier, SDM is supported by studies that demonstrate that improving provider-patient communication is directly linked to satisfaction, adherence, and health outcomes.<sup>87</sup> In addition, since sociocultural differences between clinicians and patients may impair communication and decision-making if not addressed,<sup>88-91</sup> explicitly discussing values in the context of medical decisions is also likely to improve care for minorities underrepresented in the health professions. Of importance, although there are ethical reasons to involve families in a wide range of health decisions, SDM is meant for conditions and circumstances in which families specifically must choose between multiple evidence-based choices.

Despite these potential benefits, many barriers exist to implementing SDM in pediatric practice. Prior research has documented that families often play a passive role in pediatric encounters.<sup>92</sup> In addition, although their families may benefit most from participation, we found that families of US children with ADHD and asthma with high levels of impairment in either their general or behavioral health were less likely than those of unimpaired children to report a high level of participation in

SDM.<sup>93</sup> Low health literacy and quantitative skills in the general population, highlighted in Fig 1, also hinder SDM since facility in these areas is needed to understanding concepts of risk, benefit, and outcomes. This is especially concerning since research on adult literacy indicates that 90 million US adults have basic or below-basic literacy skills and that 110 million have basic or poor quantitative skills.<sup>94</sup> Participation in SDM may also increase stress for some families already confronting the challenges of caring for a child with special health care needs. In that setting, emotional support in addition to medical information may be needed and desired to help families effectively participate in decision-making.<sup>95</sup> Finally, regular access to their health providers for families caring for a child with a chronic illness may bolster SDM. Specifically, we found that families of children with ADHD and asthma who had difficulty reaching their clinician by phone were at least 26% less likely to report a high level of SDM.<sup>93</sup>

### *What Families Need to Effectively Participate in Health Decisions*

The most comprehensive discussion of the decision support needs of families making child health decisions comes from a 2008 systematic review that considered results from studies across such varied areas as prenatal genetic screening, immunization, cancer care, and a variety of surgical decisions.<sup>96</sup> The review identified 3 key needs: (1) information (including suggestions about its content, delivery, source, and timing); (2) talking to others (including concerns about pressure from others); and (3) feeling a sense of control over the process, which could be influenced by emotionally charged decisions, the consultation process, and structural or service barriers. Of importance, information alone was generally inadequate to meet the needs of families who also needed emotional support and to take a role in how the decision-making process unfolded. These needs transcended specific health conditions and were generally poorly met by clinicians.

### *Decision Aids: Tools to Support Families' Decision-Making Needs*

While decision support for clinicians has increasingly been linked to EHRs, the evolution of decision support for patients and families has centered on the development of decision aids. Decision aids include a wide range of tools developed using a standard methodology that help families reach informed choices

consistent with their values.<sup>30,96-98</sup> They include paper-based forms, educational videos, and sometimes interactive computer-based programs. Demonstrating the validity of this approach, meta-analyses of randomized trials of decision aids have shown that these tools improve the quality of health care decisions and reduce the use of options that patients do not value.<sup>30,99</sup> Specifically, the use of patient decision aids results in greater knowledge, lower uncertainty, increased participation in decision-making, and fewer people who remain undecided.<sup>30</sup> Also, those completing decision aids were less likely to elect invasive surgery. In general, more complex decision aids have more impact than simpler ones. However, less is known regarding decision aids for pediatrics since the vast majority of trials of decision aids have been in the adult setting. In the most recent Cochrane review of decision aids, only 2 included trials focused on pediatric decisions: 1 for circumcision<sup>100</sup> and 1 for infant vaccination.<sup>101</sup> The lack of pediatric trials underscores the need for additional research in this area.

Although few randomized trials have been conducted of decision aids in pediatric healthcare, decision aids are increasingly available for pediatric conditions. Pediatric clinicians and families may benefit from decision aids that address such topics as ADHD, birth control, depression, diabetes, enuresis, headaches, smoking cessation, thyroid disease, tonsillitis, warts, and weight control.<sup>102</sup> In addition, certain decision aids provide a format that can be adopted for a variety of health conditions. An example of a paper-based, family-focused decision aid, the Ottawa Family Decision Guide developed by Margaret Lawson and others at the Children's Hospital of Eastern Ontario, Canada, is shown in Appendix A. As this example shows, decision aids generally address the specific needs of families participating in health decisions: information is provided, personal values impacting the decision are elicited, supports or pressures from others that could potentially bias decision-making are assessed, and an individual's or family's readiness to reach a decision is documented.

Through the use of decision aids, many of the barriers to SDM in practice can be addressed. Decision aids often include information on risks and benefits in a fashion that can be readily understood, thus at least partially mitigating the effect of low health literacy and numeracy on participation. For example, research has demonstrated that frequencies (3 of 10 people on this medication experience a side effect) are generally

more meaningful than percentages (there is a 30% chance of a side effect),<sup>103</sup> and decision aids generally present risks and benefits in terms of frequencies. In addition, decision aids provide tools to help families prepare for medical office visits, a strategy likely to increase participation. In addition, decision aids may help families identify needs for emotional supports that may or may not already be acknowledged. Once aware of these needs, clinicians can help families connect with counselors or family support groups who can help them manage stress and move forward with the decision-making process.

### *Health Information Technology and Decision Support for Shared Decision-Making*

Despite their many benefits, decision aids have certain limitations that may potentially be overcome by embedding them within a HIT-based decision support system. Although decision aids have been found to improve decision-making, meta-analyses have not demonstrated a consistent benefit in terms of patient outcomes.<sup>30</sup> One reason is that decision aids are generally used when any 1 of 2 or more options have comparable outcomes. In that context, the goal is often to improve the decision-making, not health outcomes.<sup>30</sup> However, as the authors of the Cochrane review aptly note,<sup>30</sup> an important question is whether the use of decision aids can help individuals or families achieve outcomes they most highly value. Given the passive role of families in many encounters and work from our own group in ADHD that suggests that families' goals are often not assessed,<sup>27</sup> HIT-based systems may help to more systematically capture and track progress toward families' goals, a process that may increase the likelihood that these goals are actually achieved. For example, preferences and goals may be elicited from families through surveys as part of routine care.

HIT-based systems may have additional benefits. As with clinical practice guidelines, clinicians are often reluctant to adopt decision aids and families sometimes access these tools through the Internet without clinician involvement. By implementing decision aids within a HIT-based framework that engages both the family and the clinician, family access to these tools

should be increased and, if the system is implemented following the principles described for clinician-focused decision support, clinician acceptance may also become more widespread. With this approach, a HIT-based system to promote SDM may support both clinicians and families so that they are both better prepared to participate.

In addition, many decision aids have been developed and evaluated for 1-time decisions, such as circumcision. However, pediatric clinicians are increasingly treating chronic conditions, such as ADHD or asthma that involve revisiting treatment decisions over time.<sup>104</sup> For families of children taking daily medications, decisions are revisited constantly. In this setting, keeping families engaged may be even more important to treatment adherence and outcomes than with so-called "one and done" decisions. HIT provides a tool to deliver decision support to families at home as they

negotiate the care of chronically ill children each day. Systems could provide recommendations to families that reinforce the continuation of guideline-based care. Finally, in many settings, it is difficult for families to communicate with their clinicians on a regular basis or for clinicians to know when families modify the treatment plan on their own.<sup>104</sup> As a result, HIT may play an important role in alerting clinicians when families are not adhering to the treatment or follow-up

plan. Overall then, HIT may provide a means to deliver evidence-based recommendations for treatment and follow-up to both clinicians and families to achieve goals that are most salient for families. As a result, the approach of using HIT to engage clinicians and families, share information, facilitate ongoing decision-making, and improve chronic disease management has been heralded as a goal for the next generation of decision support.<sup>105</sup> Despite this promise, little work has been done to date to use HIT to engage families in SDM.

### *Technical Strategies for Delivering Decision Support to Families Using Health Information Technology*

The medical literature is increasingly filled with discussions of how different technologies may be

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***Decisions aids have certain limitations that may potentially be overcome by embedding them within a HIT-based decision support system.***

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implemented to enhance health care.<sup>106</sup> This focus is warranted since many use HIT to play a more active role in their health care. For example, the Pew Internet and American Life project found that 60% of adults and 80% of Internet users have looked online for health information.<sup>107</sup> These approaches are not meant to replace verbal communication, patient handouts, print media, or even audio or videotapes, but to complement their strengths. While the quality of Internet-based information remains a concern, this information does allow families to increasingly reach informed choices.

To be most effective, the technology implemented must be well-matched to the target population and situation. Fortunately, research from Pew has shown that Internet use continues to climb among all age groups and that 93% of adolescents and young adults are now online.<sup>107</sup> However, a lack of familiarity with the Internet does not necessarily prevent patients and families from using HIT in the health care setting. In adult diabetes, Internet-naïve patients were willing to use IT tools if they felt that it would help enhance communication and management of their condition.<sup>108</sup>

For those with access to the Internet, e-mail is among the most widely studied and used of HIT approaches to support family-clinician interaction. A 2002 study found that parents were interested in using e-mail to schedule visits, get information related to test results, or discuss specific health concerns.<sup>109</sup> In that study, clinicians were less enthusiastic than families about e-mail use, citing worries regarding confidentiality.<sup>109</sup> Gerstle and the AAP Task Force on Medical Informatics then provided guidelines for the “appropriate” use of e-mail in the office setting.<sup>110</sup> They prioritize the need for well-established policies that are understood by both clinical and nonclinical office staff and families to ensure confidentiality. In addition, data from a pediatric rheumatology clinic indicated that e-mail communication can save time compared with telephone care and improved access. Despite these positive findings, the potential impact of e-mail com-

munication on the decision-making process and outcomes for children with chronic illness remains incompletely understood.

PHRs, defined as computerized applications to store a person’s health information, have similarly generated considerable interest. They have the potential to pool information from different settings to inform key decision-makers and, in some cases, to help families manage chronic illness. Reflecting these strengths, 87% of respondents to a national survey felt that using a PHR would improve their ability to keep doctors informed of their health status and 81% felt that these could help them get treatments tailored to their health

status.<sup>111</sup> Still, only about 3% of the population is using personal health records. As with e-mail, concerns regarding privacy and confidentiality were the most commonly cited reasons individuals were not using PHRs.<sup>111</sup>

The American Medical Informatics Association’s College of Medical Informatics has prioritized using PHRs to promote patient self-management of illnesses and the linkage of PHRs with EHRs to improve their impact.<sup>112</sup> Patient portals are tools that integrate PHRs with EHRs, allowing families to view portions of their child’s health record and communicate with the medical office.<sup>112</sup> Patient portals also provide a route for families to provide information not routinely captured in EHRs, for example, the level of symptoms a child is experiencing at

home or a family’s preferences for treatment. Portals have been successfully implemented in both the subspecialty and the primary care setting and have, in certain settings, been accompanied by tools to manage chronic disease.<sup>113-115</sup> However, as with all tools designed to provide families with health information and elicit information from them, careful system design is needed to ensure usability. A recent study in a pediatric setting found that even previously tested portals present difficulties to users in navigating, understanding medical language, and recovering from system errors.<sup>116</sup> Ongoing research to improve the usability of these systems is warranted.

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***The approach of using HIT to engage clinicians and families, share information, facilitate ongoing decision-making, and improve chronic disease management has been heralded as a goal for the next generation of decision support. Despite this promise, little work has been done to date to use HIT to engage families in SDM.***

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Social media have also become an increasingly prominent forum for the exchange of information.<sup>107</sup> Sites, including “Patients Like Me” (<http://www.patientslikeme.com>), help individuals or families connect to others in search of support or information. Such tools have potential benefits in both informed and shared models of decision-making. However, well-publicized security breaches and a lack of oversight to ensure that information is evidence-based have raised concerns about the use of social media as part of health care delivery.<sup>117</sup> For example, a 2009 study found limited useful clinical information and substantial incorrect advice on an asthma MySpace site targeting adolescents.<sup>118</sup>

Additional approaches for using HIT to foster the involvement of patients and families should also be considered. Automated phone systems, often using interactive voice response, have been used for some time to remind families of upcoming visits and can provide or gather health information. These tools facilitate large-scale communication between families and the medical home. An application of this technology to support SDM is discussed below. From within medical offices, paper-based questionnaires may be administered to families and scanned into the EHR as a starting point to SDM. Such systems have proven able to accurately provide information to clinicians<sup>81</sup> and have been used to tailor care to families based on risk factors identified through their responses.<sup>82</sup> Office-based kiosks may also be particularly helpful for reaching families with tailored health information or in gathering information on preferences, goals, or health status from families as they seek care. Such systems have been implemented in emergency room settings to gather data on symptoms, medication use, and the unmet needs of children with asthma.<sup>119</sup> Kiosks designed to promote child health have also been successfully placed in community settings, such as McDonald’s, and have prompted families to discuss health concerns in more detail with their clinicians.<sup>120</sup>

### *An Electronic Health Record-Linked Telephone System to Support Shared Decision-Making for Asthma*

Although the potential impact of CDSS on health in many contexts may be greater with systems that support SDM as opposed to targeting clinicians or families alone, far less research has explored this area. In addition, the systems that have been developed and

evaluated in pediatrics have often targeted individual aspects of SDM without addressing the entire process. Still, although no decision aid was implemented, the system highlighted in the following paragraphs reveals how HIT-based tools may be developed to support SDM in pediatric primary care.

Asthma has been the focus of work in pediatrics to use HIT to integrate families into decision-making. Among systems that have been developed, the 1 that most directly addresses SDM between families at home and clinicians in the primary care office is “TLC-Asthma,” a system designed by Adams and colleagues at Boston University Medical Center.<sup>121</sup> TLC stands for telephone-linked communications and this system uses completely automated telephone calls, an example of interactive voice response, to monitor, educate, and counsel families with chronic health conditions. The system communicates with children or their parents using digitized human speech and they respond using the telephone keypad or by speaking into the receiver. Of note, calls into the system may be initiated by the clinician or family. Results of the calls are stored and then used to provide decision support to clinicians. The system was designed to maintain weekly contact with families and usability testing demonstrated its feasibility.<sup>122</sup>

Using this approach, the TLC system provides comprehensive and ongoing symptom monitoring, asthma education, and knowledge assessment and reinforces self-management.<sup>121</sup> All of these features have the potential to enhance decision-making. Specifically, the monitoring components include assessment of the correspondence between treatment and symptom severity, peak flow measures, and knowledge of and adherence to the prescribed medication regimen. Educational features consist of information related to symptom recognition, especially regarding flares, identification and mitigation of potential asthma triggers, the management of exacerbations, medication use, and appropriate use of the health system for routine and urgent care. Knowledge of asthma is tracked through a series of yes/no questions asked each week. Based on responses, additional educational material is provided. The system also summarizes important points, provides positive reinforcement and reassurance, and reminds the child/family to call next week. TLC-Asthma is designed for child participants between 5 and 16 years of age and their parents.

While focused on the child and family and supporting self-management in the home, the system also

alerts clinicians to potential problems that may require medical intervention.<sup>121</sup> For example, if a child reports reduced peak flow readings that are unresponsive to beta-agonist treatment, the system sends a message that prompts an immediate call to the clinician. For less emergent issues, such as medication refills, the system sends a message to a nurse who acts as a care coordinator and addresses the concern. Of importance, early data suggest that the system is feasible to use in practice and that alerts derived from the system can be used to guide targeted follow-up.<sup>121</sup> Results from the full evaluation of the system, including system use, changes in adherence to asthma therapy, and patient-centered outcomes have not yet been published. As this example illustrates, additional research is needed in asthma as well as other health conditions to determine how HIT may most effectively improve SDM, adherence, and outcomes. Of note, the TLC system is also being evaluated in the management of obesity.

## Unintended Consequences of Clinician-Focused Decision Support in Pediatrics

As we have highlighted in multiple areas in this article, the implementation of clinician-focused decision support has sometimes been associated with unintended negative consequences. In the outpatient setting, our group found that decision support to increase vaccination at sick visits contributed to decreased rates of subsequent preventive care.<sup>65</sup> Families who received vaccines were less likely to return for well visits. In the pediatric intensive care unit, the implementation of a CPOE system was associated with increased mortality at 1 site.<sup>11</sup> However, mortality was decreased across all inpatient settings at a second pediatric academic medical center.<sup>123</sup> As these examples illustrate, in both the inpatient and the outpatient settings, those implementing CDSS will benefit from carefully considering the many different behavior patterns that a new system impacts.<sup>124</sup> As the example of immunization at sick visits illustrates for pediatric outpatients, impacts on the behavior of the family, not simply the clinician, must be weighed.

## Conclusions

As payers and credentialing boards increasingly require clinicians and health systems to demonstrate that they

provide high-quality and safe care, practitioners will increasingly rely on tools to support evidence-based practice. In this context, the historically prolonged process of translating research into practice will need to accelerate. Given the \$19bn investment in promoting EHRs included in the ARRA, HIT is likely to have a central role in this process.

This review was designed to provide an understanding of the potential benefit of HIT to decision-making in pediatrics, especially in the primary care setting. For this process to be successful, the implementation team should consider how to apply relevant guidelines to the question of interest and whether existing data are sufficient to inform computer-based recommendations. Teamwork between clinicians, administrators, and IT professionals who can assess workflows, design usable systems, and ensure that systems are aligned with broader goals will promote success. Even in relatively simple clinical contexts such as immunization, the team should be prepared to both proactively address many concerns that will arise from invested groups as well as promptly confront problems internal or external to the system that develop following implementation.

To maximize the benefits of CDSS, clinicians, administrators, and IT professionals will also benefit from considering these tools within the broader context of the literature on medical decision-making and health communication. Delivering the right information to clinicians in the correct format and at the right time and place is sufficient in certain clinical contexts. However, particularly in the outpatient setting, treatment success often depends on engaging the family to ensure that a prescribed treatment is acceptable and that families will adhere to the recommendation. Decision aids have proven to be effective in improving many aspects of decision-making. Using HIT-based CDSS to support families as well as clinicians in the decision-making process, we will likely be able to build on the successes of both clinician-focused decision support and decision aids, 2 sets of tools to promote quality health care that have historically not been integrated. Scholarship is needed to help us understand how best to realize this goal by testing a new set of approaches for improving outcomes.

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# Appendix A. Ottawa Family Decision Guide

## Ottawa Family Decision Guide For Families Facing Tough Health or Social Decisions

You will be guided through four steps: ① ② ③ ④

### ① Clarify the decision.

What decision do you face?

What is your reason for making this decision?

When do you need to make a choice?

How far along are you with your decision?

Are you leaning toward a specific option?

### ② Explore your decision.



#### Knowledge

Below, list the options and main benefits and harms you already know. Underline the benefits and harms that you think are most likely to happen.



#### Values

Use stars (★) to show how much each benefit and harm matters to you. 5 stars means that it matters "a lot". No stars means "not at all".



#### Certainty

Circle the option with the benefits that matter most to you and are most likely to happen.

	☺ <b>BENEFITS</b> Reasons to choose this option	How much it matters Add ★s!	☹ <b>HARMS</b> Reasons to avoid this option	How much it matters Add ★s!
Option #1				
Option #2				
Option #3				

Which option do you prefer? ☐ #1 ☐ #2 ☐ #3 ☐ unsure



#### Support

What role do you prefer in making this choice?





- ☐ I prefer to share the decision with \_\_\_\_\_  
☐ I prefer to decide myself after hearing the views of \_\_\_\_\_  
☐ I prefer that someone else decides. Who? \_\_\_\_\_

Who else is involved? (name and relationship)	Which option does this person prefer?				How can this person help?
	#1	#2	#3	unsure	
Child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	





### 3 Identify your decision making needs.

	<b>Knowledge</b>	Do you know the benefits and harms of each option?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<b>Values</b>	Are you clear about which benefits and harms matter most to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<b>Support</b>	Do you have enough support and advice from others to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<b>Certainty</b>	Do you feel sure about the best choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

People who answer "No" to one or more of these questions have decision making needs. They are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

### 4 Plan the next steps based on your needs.

Decision making needs	Things you would like to try...
<b>Knowledge</b> If you feel you do NOT have enough facts	<input type="checkbox"/> Find out more about the options and the chances of benefits and harms. <input type="checkbox"/> List your questions and note where to find the answers (e.g. library, health professionals, counsellors):
<b>Values</b> If you are NOT sure which benefits and harms matter most to you	<input type="checkbox"/> Review the stars in the balance scale to see what matters most to you. <input type="checkbox"/> Find people who know what it's like to experience the benefits and harms. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Read stories of what mattered most to others. <input type="checkbox"/> Discuss with others what matters most to you.
<b>Support</b> If you feel you do NOT have enough support	<input type="checkbox"/> Discuss your options with a trusted person (e.g. health professional, family, friends). <input type="checkbox"/> Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	<input type="checkbox"/> Focus on the opinions of others who matter most. <input type="checkbox"/> Share your guide with others. <input type="checkbox"/> Ask another person involved to complete this guide. Find areas of agreement. When you disagree on facts, agree to get more information. When you disagree on what matters most, respect the person's opinion. Take turns to listen to what the other person says matters most to them. <input type="checkbox"/> Find a neutral person to help you and others involved in the decision.
Other factors making the decision DIFFICULT	List anything else you need:

CHEO Decision Services © 2009 Lawson, Saarikaki, Kryworuchko, Barnes, Children's Hospital of Eastern Ontario, Canada.

Web site: [www.cheo.on.ca/en/DecisionServices](http://www.cheo.on.ca/en/DecisionServices)

Adapted from Ottawa Personal Decision Guide © 2006 O'Connor, Jacobsen, Stacey, University of Ottawa, Ottawa Hospital Research Institute, Canada.

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