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Spotlight on Kids: Beacon Community Efforts to Improve Pediatric Prevention, Care, and Outcomes

Issue Brief

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Introduction

"We shape our tools….and thereafter, they shape us." Father John Culkin

We all know that health IT is a means to an end. At its best, the end goal for health IT is meeting patient, family and population needs in an effective, efficient and deeply humane manner. Each Beacon Community profiled here reflects an example of leveraging health IT to connect teams of people around a shared commitment to improving health for children, youth, families and communities. Taken together, the health IT approaches profiled demonstrate promise for connecting schools, public health and health systems together in an orchestrated effort to improve health outcomes for children. Each illustrates a different way health IT can help both establish shared goals for care and give everyone involved in reaching these goals access to the best information at the right time and right place. When everyone embraces common goals for care and has access to the best information then everyone becomes a leader. And when it comes to the health of the nation's children and families, we need everyone to lead.

Yet, allowing everyone to be a leader in promoting health and shaping health care is innately disruptive. To use health IT to empower the range of people in a position to facilitate effective and efficient care for children as is to begin to meaningfully advance a model of collaboration and engagement that blurs rather than accentuates lines of authority, expertise and accountability. This can be threatening and complicated. Tending carefully to the cultural shifts required to make health IT work for us then becomes essential. Here we can take tips from root cause analysis of health care safety errors. Over and over reviews of safety errors suggest that no matter the method to improve health, quality or efficiency—including health IT--person to person communication, learning mindsets and the ability to manage complexity, share power and collaborate are key drivers for success. No health IT tool can do this for us. Only we can. In this way, while unspoken, the Beacon Community stories here are as much about success in "human technology" as health IT technology.

Inevitably, engaging families and patients directly will be a next big leap for health IT in children's health. Doing so is propelled by logic, the era of "big data" as well as by upcoming Stage 3 Meaningful Use (MU) standards. These standards compel health care providers to focus on population health and to anchor care in the stated health goals of patients and families. Meeting these needs for children will require connecting not only health care providers, but also public health departments, schools, social workers, and others that bear responsibility for the care and well-being of pediatric patients. As these and similar ACA driven standards and ACO/global budget models of care are implemented, getting the patient voice into the electronic health record and using tools to enable families and patients to be leaders in their own health and health care will be essential. Engaging families and patients in this way is required to answer the call these policies make to shape "beyond diagnosis" models of health care. These models require us to move upstream to promote well-being and to place at the center of care the patient's and family's unique (and ever changing) health goals, strengths and risks. A crosscutting goal is to build family, patient and provider capacity to recognize and address the many environmental, psychosocial and health behavioral factors we know explain much of the variation in clinical outcomes (even among children with the same diagnoses) and that are critical to promoting individual and population health and reducing health care costs.

Obtaining valid information on these continuously changing factors requires engaging families and patients on a regular basis and ideally integrating the information they share with the other clinical data already existing in many EHRs. Early efforts to get the patient voice into the EHR using health IT tools such as REACH Challenge recognized Well Visit Planner affirm that doing so is fundamentally disruptive in a way that catches off guard even those who would otherwise claim that they are highly supportive of such engagement. Once again the cultural factors trump the technical challenges involved.

Over and over health IT will lead to disruption and require traversing the landscape between the already shifting but still dominant culture of medicine to the emerging culture of team based care, population health and patient engagement. The Beacon communities charged head first into this disruption, engaging traditional health care providers and connecting with schools, public health, and others in their quest to support children's health. This is a disruption we should all look forward to and one that will make sure our health IT tools are continuously reshaped to work for us and not the other way around.

"Technology is good, people are better." Ken Ginsberg

//signed//

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What's the issue?

Childhood is a critical period of development, and early life experiences exert persistent influence on health behaviors and outcomes throughout the lifespan.[i] Therefore, children are a major target of preventive public health measures such as immunizations, as well as general efforts to promote healthy development.

As children spend most of their time at home or at school, these locations are increasingly being engaged as major hubs of wellness and prevention activities. Likewise, exacerbations of chronic diseases common to pediatric populations (especially asthma) often occur in these settings, and therefore must be addressed by engaging children as well as their parents, teachers, and pediatricians. However, children's homes and schools are not traditionally connected to primary systems of care delivery, making coordination and communication amongst these parties difficult and inconsistent.

The widespread growth of health information technology (health IT) offers several opportunities to help address these issues and enhance pediatric public health and health care. For instance, children's hospitals have made significant gains in electronic health record (EHR) adoption in the past few years compared to adult hospitals. However, pediatricians in general lag in EHR adoption compared to other provider specialties, and as most currently available EHRs are designed for adult populations, they lack specific functions essential to pediatric care, such as growth charts, immunization tracking, and prescription support for weight-based dosing.[ii]

Recent federal policies such as the Health Information Technology for Economic and Clinical Health (HITECH) Act, the Children's Health Insurance Program Reauthorization Act (CHIPRA), and the Patient Protection and Affordable Care Act include many provisions with implications for pediatric care delivery, health IT, and quality improvement (Table 1).

Table 1. Federal Policies and Programs with Implications for Pediatric Health Care and Health IT

Policy Initiative / Program	Provisions with implications for pediatric health, health care, and health IT
Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009[iii]	• Established Pediatric Quality Measures Program (PQMP) of grants and contracts. • Required identification of core set of children's health care quality measures, to be updated annually. • Authorized development of Children's EHR Format. • Designated Health IT as 1 of 5 categories of project areas.
Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009[iv]	• The EHR Incentive Program provides incentive payments to providers treating Medicaid and CHIP patients (including pediatricians) who demonstrate Meaningful Use of electronic health records. • Stage 2 Meaningful Use criteria include pediatric-specific clinical quality measures (e.g., weight assessment; nutrition / physical activity counseling; immunization status; evidence-based asthma care; STI screening; ADHD follow-up care). • Stage 3 will include an expanded set of measures that reflect pediatric needs and align with National Quality Strategy domains of patient safety and public health.
Patient Protection and Affordable Care Act of 2010[v]	• Increases Medicaid payment to Medicare rates for evaluation and management codes for pediatricians. • Covers Bright Futures services for children with no cost-sharing. • Expands health insurance to cover nearly thirty-two million more children, parents, and other individuals. • Funds Children's Health Insurance Program through 2015 and increases federal funding commitment to states through 2019. • Bans pre-existing condition exclusions for children, and in 2014, prevents children from losing coverage if they become sick. • Eliminates annual caps and bans lifetime limits on health insurance coverage. • Allows young adults to stay on parents' insurance up to age 26. In 2014, extends Medicaid coverage up to age 26 for foster children aging out of foster care system.

What can be learned from the Beacon Communities' Experiences?

To address these unique challenges related to pediatric care and public health, several communities receiving federal funding from the Office of the National Coordinator for Health IT (ONC) through the

Beacon Community Cooperative Agreement Program have developed innovative health IT-enabled strategies, partnerships, and tools to improve care quality and outcomes for children. This issue brief describes several strategies aimed at improving pediatric immunization rates, asthma management, public health surveillance, and health education. These efforts make use of health IT tools and functions including health information exchange (HIE), school portals for shared care plans, immunization and asthma registries, and patient-facing mobile health (mHealth) programs (Table 2). These efforts allow providers to plan and deliver higher-quality and coordinated care to individual patients, enable more effective population health management, and engage parents and schools more actively in promoting their children's health.

Table 2: Using Technology to Engage Community around Children's Health

Technology (Beacon Community)	Tool /Strategy	Partner(s)
Asthma		
School Portal (Southeast Minnesota Beacon Community)	Asthma care plans	Schools, parents, pediatricians
Emergency Department / Admission Alerts; Asthma Registry (Greater Cincinnati Beacon Collaboration)	Asthma care coordination and follow-up	Pediatricians, hospital-based providers, care managers, social workers
Public Health: Immunizations and Surveillance		
San Diego Immunization Registry; SMS Immunization Reminder Pilot (San Diego Beacon Community)	Immunization reminders	Parents, community clinics, public health
Public School Daily Disease Registry (Southern Piedmont Beacon Community)	Infectious disease surveillance	Schools, public health
Health Promotion and Education		
Bright Futures EHR Module(Southern Piedmont Beacon Community)	Pediatric electronic health records	Pediatricians
Anna Automated Health Educator (Southern Piedmont Beacon Community)	Health education	Families, social workers

Asthma

Southeast Minnesota: School Portals for Asthma Action Plans

Asthma is one of the most prevalent pediatric chronic diseases, affecting 1 in 11 American children, or about 7 million children nationwide.[vi] Self-management of asthma is important to improve quality of life, reduce morbidity, and prevent emergency departments (ED) visits and hospital admissions. The Centers for Disease Control and Prevention (CDC) recommend that every asthma patient has an asthma action plan (AAP), based on national clinical guidelines that emphasize preventive care, patient education, and diagnosis and monitoring of asthma symptoms using spirometry (a test of pulmonary function). Emerging evidence suggests that health IT tools, including clinical decision support (CDS), can increase provider adherence to pediatric asthma guidelines, including the development of AAPs and provision of influenza

vaccinations.[vii,viii,ix] Adhering to these plans requires coordination among children and their parents, pediatricians, and schools; such coordination is challenging, however, and leading to inconsistent adherence, poorly controlled symptoms, and preventable asthma-related hospitalizations and ED visits.[x]

Based on input from the community, the Southeast Minnesota (SE MN) Beacon Community is working to ensure that all children with asthma have documented AAPs by improving coordination among children's clinics, homes, and schools. Informed by a multi-stakeholder workgroup, the SE MN Beacon Community developed system specifications and user requirements for a school portal that provides school nurses in 47 school districts with real-time access to their students' AAPs.

On October 15, 2012, 6 schools in 4 districts went "live" on the portal. As of June 2013, 1504 consented electronic AAPs were available through the portal to more than 90 schools, with 55 school nurses accessing. Three of the four participating health systems are using AAPs that include the daily dosages for the child's current controller and rescue medications; this information is accessible to the school and the child's parents. Furthermore, the AAPs include fields specifying how school nurses should administer rescue medications for asthma exacerbations.

School nurses surveyed across 47 schools districts agree or strongly agree that the AAP helps them determine students' medication needs (90%) supports emergency clinical care decisions (88%), improves asthma care management (87%), and improves their confidence in caring for students with asthma (92%), educating other staff about students' asthma (94%), teaching individual students about their asthma (80%), determining when to refer to the ED for asthma exacerbations (91%), and deciding when to contact parents (84%) and providers (80%). One nurse commented: "My hope is that all students, when they are seen by their primary care provider, would have a current [AAP] and that the clinic, parent and school nurse would all be on the same page."

Cincinnati: ED/Admission Alerts, Care Coordination, and Disease Registry

HealthBridge, the regional health information exchange and lead grantee of the Greater Cincinnati Beacon Collaboration (GCBC), collaborated with Cincinnati Children's Hospital Medical Center's (CCHMC) General Pediatric clinics (Gen Peds), the Physician-Hospital Organization (PHO), and other partners to improve care and reduce preventable ED visits and admissions for children with asthma. Their multi-faceted approach includes:

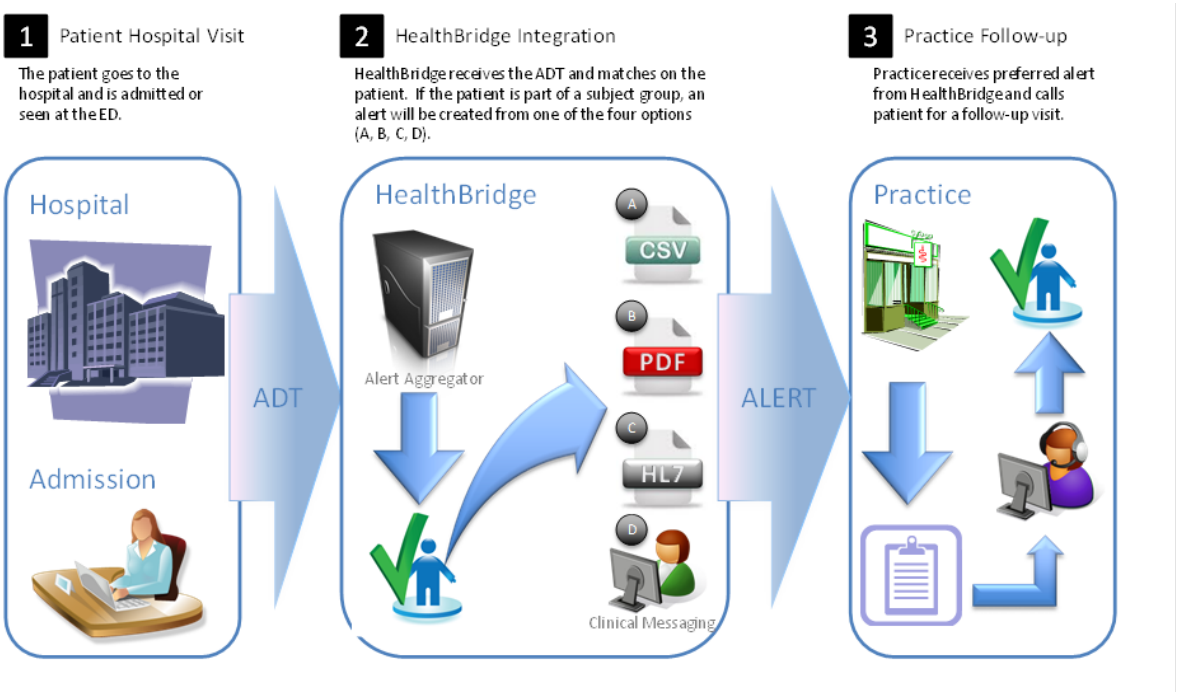
- ED/Admission Alerts to primary care providers for pediatric asthma patients,
- A new asthma registry for Gen Peds (the PHO continued using a pre-existing asthma registry), and
- Quality improvement (QI) efforts to promote evidence-based care and care coordination.

This work builds on long-standing efforts to improve outcomes for children with asthma, with the PHO and Gen Peds having initiated asthma QI collaboratives in 2003 and 2007, respectively.

To help reduce asthma-related ED, hospital, and urgent care visits, HealthBridge and GCBC partners launched the real-time ED/Admission Alert System in April 2012 (see Figure 1). Both the PHO and General Pediatric practices had pre-existing alert systems for only CCHMC-based ED visits and admissions. The new

technology leveraged daily admission, discharge, and transfer (ADT) data feeds to alert practices when their patients experienced an asthma-related ED visit or admission at any hospital across the region. Through timely exchange of health information from regional hospitals, the alert system allows GCBC providers to identify additional children eligible for care coordination by virtue of hospital utilization occurring beyond CCHMC, and helps assure timely patient follow-up. This not only improves patient outcomes and experience of care, but also helps prevent future exacerbations and hospital utilization.

Figure 1: HealthBridge ED/Admission Alert Architecture



As of August 2013, 87 Beacon adult and pediatric practices and two post-acute providers are live on the ED/Admission Alert System, with more than 27,000 alerts sourced from 21 hospitals transmitted across the community.

The alerts triggered the following interventions:

- Scheduling timely follow-up appointments,
- Segmenting patients based on readmission risk, and
- Informing patients of extended office hours, 24-hour nurse help lines and open access appointments.

High-risk Gen Peds patients (those with one or more admissions and/or two or more ED visits in the past year) are referred for intensive care coordination that includes the following intervention bundle: risk assessment, self-management assessment, asthma control test, and multi-user shared AAP. Children "graduate" from the program after having no admissions or ED visits for asthma in a year. As of June 30, 2013, 390 children had ever been enrolled in the program, and 131 children had graduated. This approach demonstrates that implementing health IT is only the first step; when combined with related QI

interventions, these health IT tools have facilitated the provision of evidence-based care, and reduced asthma-related ED/urgent care visits, admissions, and acute office visits.

HealthBridge also collaborated with a health IT vendor and the CCHMC IT team to develop a customized pediatric asthma registry. In addition to asthma care summaries, the registry also includes information on social risks, barriers to care, asthma control assessments, self-management, and care management.

Public Health: Immunizations

San Diego: Using a Registry and SMS to Increase Pediatric Immunization Rates

Childhood immunization rates are important indicators for assessing pediatric health care quality.[xi] While childhood immunization schedules are standardized nationwide, immunization rates in many areas remain below target rates of 90% for young children. The US National Immunization Survey found that while rates are high up to age 1, by age 2 only 67 percent of toddlers received all 14 recommended vaccinations; rates improve by kindergarten, rising to about 98 percent due to immunization requirements for school admission.[xii] Public health agencies and health care providers continue to test innovative strategies to improve vaccination rates through improved access to care and education. Electronic immunization registries have become important tools for improving the accuracy of vaccine documentation and facilitating outreach to parents (e.g., appointment reminders).

One of the core goals of the San Diego Beacon Community was to improve population health by optimizing reporting methods for both the immunization registry and public health surveillance. The San Diego Beacon Community established the San Diego Regional Health Information Exchange (SD-RHIE) between ambulatory clinics and major health systems. Using the HIE, the clinics and health systems reported public health surveillance data—including laboratory and immunization data—to the county public health registry and to the San Diego Immunization Registry (SDIR), which also allowed them to meet the public health reporting criteria for the Meaningful Use incentive program.

The San Diego Beacon also conducted a randomized controlled trial to assess the use of text messaging to engage parents in ensuring their young children have up-to-date immunizations. Using the SDIR to identify potential participants, the Beacon team enrolled parents of children aged 9-13 months seen at participating clinics with low overall immunization rates (<70%) in the trial. Using a text messaging platform called SanText, they sent targeted, tailored text messages to encourage parents to complete their child's 15- to 18-month immunizations before the child's second birthday. The parents received between four and six messages per month in English or Spanish, depending on their primary language.

Those in the intervention group received messages regarding their child's immunization status (based on data in the SDIR), immunization-related educational messages, and reminders to schedule and keep clinic appointments; subsequent messages were tailored based on the parent's responses. Participants in the control group received general messages related child health and development milestones. Initial survey results of 143 parents enrolled in the trial found that 89% and 98% of them thought the messages helped them remember to schedule and keep appointments, respectively. Edward Castillo, PhD, MPH, a researcher at the UC San Diego Department of Emergency Medicine and the evaluation lead for the San Diego Beacon

Project, emphasized that "the project is really a pilot to see what the impact could be for texting services, and how that could improve not only immunization status, but also appointment adherence in community clinics." While the results of the trial are still being analyzed, initial findings suggest that it is feasible and cost-effective strategy to help communities improve childhood immunization rates.

Public Health Surveillance; Health Promotion and Health Education

Southern Piedmont: Daily Disease Reports, Bright Futures EHR Module, and an Automated Health Educator

The Southern Piedmont Beacon Community in North Carolina partnered with local health departments to further public health goals for children in the community. These efforts include a Daily Disease Registry, an automated health educator, and a pediatric EHR module.

Like the Southeast Minnesota Beacon Community, the Southern Piedmont Beacon Community is engaging local schools in improving the health of children in the community. The Cabarrus Health Alliance, one of the three county health departments involved with the Beacon effort, collaborated with the University of North Carolina Gillings School of Public Health to develop and implement a Web-based Daily Disease Registry (DDR) in the public school system. Public school nurses collect and enter counts of student symptoms at their schools each day, and transmit the data via the DDR to the local health departments for monitoring. Pilot testing of the DDR began in June 2012 and implementation was completed in August 2012. Using the DDR enables nurses to fulfill their reporting requirements for ten communicable diseases and conditions, in line with state guidelines. Initially, approximately 40 reports a day were distributed to all primary care and pediatric provider sites and communicable disease nurses during the school year. Following feedback from the user community regarding data overload, the distribution mechanism for the DDR was modified to send out alerts only when certain parameters are triggered. These alerts are sent as emails with links to the DDR site, where providers can view trends and draw comparisons in daily and weekly symptom counts.

The Cabarrus Health Alliance also led development and implementation of a customized pediatric EHR module based on Bright Futures, a national child health and wellness program adopted by the state of North Carolina.[xiii] Though this module, providers are proactively directed to follow the evidence-based practice guidelines that address the content and frequency of routine physical examinations, appropriate child screening activities, timely administration of immunizations, and anticipatory guidance for caregivers. The module was completed in August 2011 and is now available to any health department that uses the Bright Futures program.

Given the emphasis on health promotion and disease prevention during early childhood, health education is a major component of pediatric public health and health care. As health education typically requires significant staff time, the Southern Piedmont Beacon sought to test whether health IT could help to mitigate staff resource constraints and boost productivity. To this end, health departments within the Southern Piedmont Beacon contracted a health care technology company to help develop an evidence-based automated health educator called "Anna" (See Figure 2). Based on the virtual discharge advocate

"Louise" developed in Boston in 2007 as part of Project RED (Re-Engineered Discharge),[xiv] Anna is currently serving to educate families about the Women, Infants, and Children (WIC) program and how to use WIC instruments to purchase food. Anna communicates in both English and Spanish based on the user's preference, and additional modules have been added to Anna that inform users regarding family planning and breast-feeding.

Figure 2: Screenshot of "Anna" Avatar

Following deployment in the three local health departments, Anna was assessed for user acceptance, system usability, and effectiveness of communication. Anna scored high in all categories among both English and Spanish speakers. In addition, a majority of users preferred working with Anna as opposed to interacting with a human being to obtain the same information. While initially the kiosk-based Anna resource was only available in the health department, it was so well received that it was expanded to a more widely accessible Web-based resource. As a next step, a prototype of Anna has been created for use by smart phones.

Next Steps / Policy Implications

The Beacon Communities' efforts provide early insights into how providers and vendors may further develop health IT tools and functionalities to support pediatric care and wellness across different settings. Hopefully, the examples noted above are likely just the first iteration of tools that will support pediatric health care, public health and prevention, and patient education for children and families. For instance, the Agency for Healthcare Research and Quality and Centers for Medicare and Medicaid Services developed a Children's EHR Format that includes a minimum data set and data standards to capture essential information for prenatal, newborn, and pediatric care, [xv] and the advanced EHR functionalities and clinical quality measures have been proposed for Meaningful Use Stage 3.

Vendors and providers should continue to collaborate to implement these and other pediatric EHR functionalities that are just beginning to become available, such as electronic growth charts, growth monitoring, weight based dosing, and additional clinical decision support functions that can be integrated

into the unique workflow of pediatric care.[xvi] Furthermore, just as the disease registries, immunization registries, school portals, and alert systems facilitated care coordination among children's providers, parents, and schools in the Beacon Communities, increasing interoperability among pediatric and adult health IT systems will ensure continuity of care throughout childhood and into adulthood.

Perhaps most importantly, these advanced functionalities and emerging tools must also support the engagement of children and families in their care. This includes mechanisms for broader access to health information, such as through web-portals or other tools, and mechanisms to allow pediatric patients and/or their caregivers to contribute information to their health record, such as age appropriate pain scale measures or information on patient preferences. These activities and functions will help to create more comprehensive and patient-centered medical records to support pediatric care, and will promote health literacy and patient engagement to support wellness across the lifespan.

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