Pediatric HealthCare IT in PA: Functionality, Flexibility, Funding and Focus for the Future

A Special White Paper Report from the PA eHealth Initiative

Dr. C. Cavanaugh

Jan 2013 – June 2014
Premise: Kids are not just little adults: Why is there a difference between the kids table and the adult table regarding functionality, flexibility, funding, and a focus on the future for Pediatric Health Information Technology in Pennsylvania?
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1.0 INTRODUCTION

The purpose of this report is to provide the membership of PA eHealth Initiative (PAeHI) and other interested parties with a summary of the findings from a series of interviews conducted between January and Dec 2013 of key stakeholders as it relates to Pediatric HealthCare IT across the Commonwealth. The scope of this effort begins to address the key issues involving functionality, flexibility, funding and the focus for the future.

The author wishes to acknowledge the assistance and support from the PAeHI Board of Directors and all the individual interviewees who took time to provide background information, and engaged in dialogues, interviews, and conference call to share their ideas regarding these key issues. The author wishes to express a sincere thanks to the leadership and vision for this project, namely Dr. Sue Kressly, Dr. Don Levick, and Sharon Dorogy who without their design, support, and encouragement provided the necessary framework for this research paper. Their premise was that kids are not just little adults, therefore why is there a difference between the kids table and the adult table regarding functionality, flexibility, funding, and a focus on the future for Pediatric Health Information Technology in Pennsylvania? This paper hopes to share some of the issues and gaps in the current implementation of Pediatric HealthCare IT and to provide some a framework for areas of improvements.

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Executive Director
PAeHI

SPECIAL THANKS!
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6th Annual Mid-Atlantic Healthcare Informatics Symposium
Center for Biomedical Informatics
The Children’s Hospital of Philadelphia
April 26, 2013

Pictured Above (left to right)
Dr. Chris Cavanaugh (Executive Director), Dr. Thompson Boyd, William ‘Buddy’ Gillespie, Sharon Dorogy, Sue Salkowitz, and Dr. Donald Levick.

This information was selected and presented as a poster session during the 6th Annual Mid-Atlantic Healthcare Informatics Symposium at the Center for Biomedical Informatics at The Children’s Hospital of Philadelphia (330 attendees and 28 exhibitors) on Friday April 26, 2013.


A full copy of the poster presentation is included in the Appendix of this report.

A special thanks to the PAeHI Board of Directors for their support and participation in this presentation.
2.0 ABSTRACT

Kids are not just little adults: Why is there a difference between the kids table and the adult table regarding functionality, flexibility, funding, and a focus on the future for Pediatric Health Information Technology in Pennsylvania?

ARE OUR CHILDREN in Pennsylvania getting a failing grade from Pediatric Health Information Technology? This presentation/paper provides what technology savvy pediatricians and clinicians, along with key information specialist stakeholders identify as necessary functionality, flexibility, funding and the direction for the future regarding Pediatric Health Information Technology. While today’s HIT products are primarily designed for BIG adults, how does one scale EHRs to calibrate for a 900 gram neonatal baby, cardiology and asthma for little people or even address the unique needs of pediatric rehab? What about issues regarding adolescent privacy when sharing information of 13 year olds? What would it take to turn this grade to an A that the children in Pennsylvania deserve?

THROUGH EXTENSIVE INTERVIEWS and case studies from across the Commonwealth, this research paper focuses on issues ranging from the diverse perspectives of the pediatricians/clinicians, the chief medical officers, public health officers, children’s rehab and acute care hospitals, and information technologists who are challenged to implement new electronic medical records and connect to health information exchanges that do not quite fit into the specialized world of pediatrics. Key issues and findings included discussions on product development, funding, standards, functionality, support expertise, adolescent privacy, chronic disease registries, immunization registries, implementation, workflow, workforce development and dealing with an environment where interruption is the norm for a pediatrician.

WHILE MOST OF THESE CHALLENGES affect all pediatric practitioners across the country, how does Pennsylvania address this unique population? Specifically addressed include the impact from numerous local programs focused on issues critical to pediatricians. These include Pennsylvania unique projects such as the PA-SIIS (Immunization Registry) program, the PA-CHIPRA grant that developed quality measures that were incorporated into the Meaningful Use Stage 2 Metrics, and how the new DIRECT and Health Information Exchanges are addressing the unique challenges of organizational exchange between regional exchanges. Additionally, identified gaps in pediatric needs as well as strategies to overcome those gaps by sharing successful case studies highlight how pediatric HIT can improve the care of children in the Commonwealth.
3.0 METHODOLOGY

**Interview Questions**

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In establishing the design and approach/methodology for this white paper, the PAeHI Board of Directors established a set of questions to be asked of all participants. Though a series of interviews and case studies from across the Commonwealth, this research paper focused on issues ranging from the diverse perspectives of the pediatricians/clinicians, the chief medical officers, public health officers, children’s rehab and acute care hospitals, and information technologists who are challenged to implement new electronic medical records and connect to health information exchanges that do not quite fit into the specialized world of pediatrics.

Key issues and findings included discussions on product development, funding, standards, functionality, support expertise, adolescent privacy, chronic disease registries, immunization registries, implementation, workflow, workforce development and dealing with an environment where interruption is the norm for a pediatrician. As shown in the chart above, the five functional areas of questions involved (1) the current status, (2) gaps, (3) functionality and flexibility, (4) funding, and (5) focus on the future. A copy of the survey instrument questions can be found in the Appendix A.3. The following section of key findings is organized by these five overarching themes and the responses are consolidated from participants regarding each of these functional areas.
4.0 FINDINGS

The following are the perspectives, suggestions, and comments generated by participants as they responded to the interview questions. To ensure readability as well as confidentiality of responses, these comments and ideas have been edited for grammar, synthesizes and consolidated from all respondents.

Perspectives on the Current Status of Pediatric Health Information Technology

- Pennsylvania is one of two states under the CHIPRA Quality Demonstration Grant (see Appendix A.4 for more information) that are implementing the pediatric EHR model format developed by Westat for CMS/HHS (http://healthit.ahrq.gov/childehrFormat). Five of PA’s grantees are implementing a portion of the model format’s 568 requirements in an effort to build pediatric specific EHRs. The five individual health systems working on this project contracted with five different EHR vendors and it soon became evident that each vendor was at a different level when it came to including pediatric elements in the EHR. Within this group there didn’t appear to be a minimum standard industry level when it came to providing pediatric specific elements in an EHR. On average, 30% of the 568 model format requirements were not functionally available in the standard EHR. It is important to note that these numbers were self-reported and may be underestimated.

- My perspective is generic about pediatric HIT. The basis of a foundation is to develop records to share using a technology. More comes from an adult perspective when we are building tweaking and redesign to meet our pediatric world. We need to be thinking neonatal to 18 plus beyond. Immunization schedules and how they continuously changed and currently updated.

- Demographics indicate that there are in Pennsylvania approximately 2,200 Pediatricians, residents, specialists. There is great complexity as pediatricians provide care especially when 17%-18% of the cases are complex medical issues. As for the volume, adult physician family medicine and internal medicine may see 1-3 patients per hour typically where pediatricians will see 3-6 patients per hour. In terms of family care, this is unique to pediatricians as they provide more Family Centered Care – “While parents aren’t the patients they are part of the influence of care.”

- There are location issues in which to provide and connect care in multiple locations. Children will often seek care in multiple places not connected to the physician’s office. This includes the pediatric school nurse where there is currently NO connection between education and health care continuum.
EHR Incentive Program – 1443 Pediatrician payments have been issued (268 for Meaningful Use (MU) – 27% of total MU payments as of 4/15/2013).

CHIPRA Quality Demonstration Grant -- Pennsylvania is one of two states implementing the pediatric EHR model format developed by Westat for CMS/HHS. Five of PA’s grantees are implementing a portion of the model format’s 568 requirements in an effort to build pediatric specific EHRs. Pennsylvania’s CHIPRA grantees are able to electronically extract and report 14 of the CMS core pediatric quality measures directly from the EHR.

The Children’s Electronic Health Record (EHR) Format was developed to bridge the gap between the functionality present in most EHRs currently available and the functionality that would more optimally support the care of children. Specifically, the Format provides information to EHR system developers and others about critical functionality, data elements, and other requirements that need to be present in an EHR system to address health care needs specific to the care of children, especially those enrolled in Medicaid or the Children’s Health Insurance Program (CHIP). To address these needs, the Format includes a minimum set of data elements and applicable data standards that can be used as a starting point or checklist for EHR developers seeking to create a product that can capture the types of health care components most relevant for children. The child-specific data elements and functionality recommendations are sorted into various topic areas, including —

- Prenatal and newborn screening tests
- Immunizations
- Growth data Information for children with special health care needs
- Well child/preventive care

The Format allows for interoperable exchange of data, including data collected in school-based, primary, and inpatient care settings; is compatible with other EHR standards; and facilitates quality measurement and improvement through collection of clinical quality data. The Format was authorized by the 2009 Children’s Health Insurance Program Reauthorization Act (CHIPRA) and developed by the Agency for Healthcare Research and Quality (AHRQ) in close collaboration with the Centers for Medicare & Medicaid Services (CMS). For more information, regarding the Children’s Electronic Health Record Format, AHRQ has a detailed information at: http://healthit.ahrq.gov/childehrFormat.

Like all HIT, this is an evolving picture. Some of the special requirements pediatrics brings to the table is more challenging. Such as community practice and the volume of
practice are greater than other specialties. Electronic medical records aren’t built for that type of efficiencies and are more focused on the ambulatory side.

- I echo what others have been saying and that the challenges are in the amount of customization done at the pediatric level. Design as adults as primary capacity. You HAVE to do customization, especially the pediatric view. And there are no standards and adjustments to suit the needs. Contain data in different forms and different ways. Adult system or pediatric within a health system. Some exceptions (outpatient/neonatal places on long period of time carve outs to meet those needs. Specifically designed from Neonatal. But not about pediatric patients (birth to 18 and beyond).

- Agree with the assessment of shortcomings already listed. Practices connected with a Children’s Hospital, e.g. CHOP, have access to an EPIC system which has been enhanced by CHOP Informaticians, but most commercial products are not optimized like that.

- Pediatric systems need to have the capability to link children to family to facilitate the simultaneous scheduling of a family for well child, immunizations e.g. templates for well child and or electronic problem-solving treatment (EPST).

- Greater attention might be given to providing parent access, since for children, parents are surrogates for the patients. These features would allow for remote monitoring, such as for asthma, the maintenance of food diaries and the like, to be entered by the parent. For older children/adolescents, the patient might be engaged in this activity. This function would also allow the parent to access and print an up to date immunization record for school and camp, etc.

- Need to match the workflow with easy navigation.
Gaps with Pediatric Health Information Technology

Where are the gaps in the current Pediatric HealthCare IT offerings?

Interviewees indicated there were many gaps for pediatricians in the current electronic medical records systems over and above those for adults. Specific issues involved weights and measures especially small dosing for neonatal medications, connections to other systems such as immunization registries, ease of use or less clicks to input due to high volume of patients, lack of electronic screening tools and embedded decision support tools that use pediatric protocols and standards. Below are some of the various perspectives presented when identifying gaps with pediatric healthcare IT offerings.

- **Products**: there are very few pediatric-focused EHRs in the marketplace. Many pediatricians do not have a choice over what product they chose (sponsored by a healthcare system or multi-specialty group) and are forced to work with a product that was built to support adult medicine. Even some of the vendors who say the ‘support pediatrics’, have < 10% of their users as pediatrician. This often leads to ongoing development efforts focused on features other than those that address pediatric needs. There are a few pediatric-specific vendors who do a good job of giving pediatricians what they need, but recently some of their development efforts have focused on MU certification, some of which has no applicability to pediatric care. Some of them are also cost-prohibitive to independent practices.

- **Funding**: in PA, 50% of pediatricians get ZERO incentive dollars or assistance to adopt EHR technology because they don’t meet the Medicaid thresholds. While multiple stakeholders benefit from EHR adoption, the financial burden lies entirely on the pediatrician which is already among the lowest paid physician groups and does not have the resources to support this.
- Lack of standards: HL7 standards development has been focused on adult technology. Many things that are integral to pediatric care still lack standards. These include but are not limited to developmental testing and assessment, vaccine refusals/reactions, adolescent privacy, newborn care (neonatal hearing and newborn metabolic screening) and others.

- Functionality: the recent AAP article describes many of these, but by and large most vendors do a poor job of clinical decision support for vaccine administration, vaccine inventory maintenance (including unique reporting needs for Vaccines For Children), weight based liquid dose medication support, appropriate well visit templates for different ages/stages of development, support for integration of developmental surveillance and screening, growth charts (including unique needs of prematurity, Down syndrome, Turner’s syndrome), pediatric problem-specific templates (chest pain in a 3 year old has a whole different differential than in a 50 year old), age specific exam documentation (red reflex in infants, Tanner maturity staging, etc.), recalls for well visits according to Bright Futures Periodicity schedules, transmission of vaccine information to state registries, etc.

- Lack of Support Expertise: many of the RECs have vast experience on assisting adult medicine practices choose, adopt and implement EHRs. However, workflows including the high percentage of same day visits, need to address parents and children/adolescents are unique to pediatrics and expertise in the existing workflow does not meet the demands of pediatric practices.

- Adolescent Privacy: huge issue with respect to how/who has access to patient portals or medical records. Most entities have “punted” on this issue and just exclude patient information for adolescents. In addition, even the Quality Measures for chlamydia testing in sexually active teens do not address the need to keep this testing confidential if a teen chooses to do so; the current method threatens the confidential physician-patient relationship.

- Adult focus on chronic disease registries: this is not relevant to most of pediatrics. Instead pediatricians need thoughtfully implemented solutions to supporting medically fragile children/children with special needs, children in foster care, and ability to connect to tertiary care networks where complex children are often cared for by multiple specialists but still need support in their community medical home.

- Additional costs for connections to laboratories: many labs are waiving implementation fees for adult practices to connect electronically to their labs because the practice volume of lab makes it a good ROI for the lab. On the other hand, pediatricians in
general don’t order a lot of labs and the ones we often do order, are not expensive. Pediatricians have often had to pay additional monies to hook to their most frequently used labs. This burden is unique to the pediatric community and an unfair burden.

- Ergonomics of the EHR are not there. Systems are built in a silo or modules and not to accommodate the provider work flow. Providers feel stress due to all of the clicking to bridge the gaps between their flow and the rigidity in code of the EMR. Build is so concrete in code that it is unable to be modified. Need to find to help get it done faster and with less clicks.

- From the clinician standpoint EMRs are focused on adults, lots of thoughts for adults built in and these can hinder workflow. Delivery of care is in the ability of having pediatric information and recommendations right out of the box.

- Chronic disease registries, genetic, congenital heart disease, follow ups on special situations (i.e. Down syndrome) requires specific maintenance and observations.

- At two years old, certain testing is known, recommendation for years but no clinical practice guidelines or workflow to help aid that prompts as a reminder, normal welfare and maintenance.

- Immunizations, this is a huge sticking points as the majority of the immunization which is huge occurs with first few months to few years. Polio is vaccinated routinely and done. But no decision support system prompts and administer and has been recommended by the AAP but there is no incorporation into the technology. This is a HUGE GAP. What we are expected to do?

- Regarding registry immunization, we use Cerner but do not turn on because it could prompts the immunization but not flexible so if child has an illness, the schedule can be changed to accommodate which causes delays but the current system won’t do that. Scheduled at the wrong time. While they were trying, but not flexible enough.

- Issues with e-Prescribing such as weight, write complex prescriptions, and a pharmacist knowing that a complex prescriptions steroids needs to be written for different dozes.

- Workflow has had great benefits for patient safety, readily available to many people, physician can access the information in different locations for consultations...the computer really with efficiency with workflow...example...chart on paper...is faster...find a way to have the efficiencies seeing a patient 20-30 minutes...the system has to work quickly and quick clicks...not slow down but speed it up.
Volume is also an issue. Seeing inpatients and outpatients with specialty needs presents issues as they are usually not coming for a well childhood.

Gaps – immunizations, building the interfaces for registries and interfacing with EMRs. On the inpatient side, so much is weight based such as fluid rates, medications does and transfusions and these systems are just now being built for appropriate dosage. Same for ambulatory side, but most clinicians do it in their head yet much more need for ambulatory side (as it is not as precise) but inpatient side when dealing with more complex medications, those calculations are more important for neonatal.

Children will often seek care in multiple places that are not connected. Injured at work, occupational medicine site is connected and mechanism to the PCP. However in school, a pediatric school nurse has NO connection between education and health care continuum.

I don’t see anything for behavioral health. Many of the children are medicated and the maintenance of this information and selective sharing is important. PA’s law which allows opt out for behavioral would cause the entire record not to be shared. Not good.

Children with special health care needs. These are patients for which care coordination and the wraparound of non-medical supportive services, educational services etc. are really important.

Dental health another area that should be integrated.

Also, allergy information and intervention is a big deal for children in school. FERPA prevents a lot of important health information to be shared, as well as even immunizations. An HIE which includes schools might be a consideration as well as a DIRECT communication for this discrete information.

In the CHIPRA grant’s pediatric model format, the 568 requirements are broken down into 21 topic sets with each topic set having a varied number of requirements. The topic sets address items such as birth information, quality measures, registry linkages, etc. Across the CHIPRA institutions only 18% of the 35 Specialized Scales and Scoring requirements were fully functional in the EHR; 21% of the 16 Registry Linkage requirements were fully functional; and 24% of the Quality Measure requirements were fully functional. It should be noted that some requirements were created for future use within the PEHR and current health information technology infrastructure cannot support those items. Those items were excluded from these comments.
In addition to the results of the gap analyses, the following gaps were identified as grantees began attempting to electronically report CHIPRA quality measure data directly from the EHRs. Please note not all information below was used for quality reporting, but as grantees began examining their system they found shortfalls.

- Well child preventive care – not supporting identification/notification of age specific screening/preventive care opportunities for patients.

- Quality measures – often the EHR did not accurately reflect what was happening clinically. Some important pieces of data were not located in discrete fields within the EHR which made the data electronically unreportable. Data not located in a discrete field is often placed in a notes section which shows as a blob of text when queried making it impossible to extract and report.

- Linking of familial records – this was often not possible within an EHR system (ex. Linking birth mother records to baby records).

- Challenges to link bi-directionally with registries (such as immunization registry – PA SIIS).

- Specialized scales and scoring – not supporting APGAR scores, breast milk drug compatibility categories, weight based dosing, and specialized growth charts for children with special needs (such as Down’s Syndrome).

- Dental – the inability to store information regarding dental referrals, compliance, dental home, etc. Dental referrals are part of EPSDT and there is no way to document or track those referrals.
Perspectives on functionality/flexibility of EHR’s

Numerous areas of functionality and flexibility present itself to electronic health records. These areas discussed included product development, standards, implementing EMRs, support expertise, connecting to HIE’s, chronic disease registries, immunization registries, workflow and workforce development. Below are some of the perspectives from respondents regarding these areas.

- One of the issues regarding functionality is the support of higher volume that pediatrics see compared to other specialties. Roughly adult physician family med/internal medicine may see anywhere from 1-3 patients per hour typically. Pediatrics this can be 3-6 per hour! Having an EMR that can support increased volume is a challenge and still is able to capture the structured data and quality metrics to move forward is a challenge from a workflow perspective.

- Special requirements (immunization –nationally) capture and exchanges and states supported EMR.

- Connecting HIE and chronic disease registries similar to the age of the populations. Same challenges regardless of the age/populations.

- Standards – Built regarding templates and embedded decision support is very complex for weight based system and not mature enough to do this successfully yet.

- Support expertise – Inpatient side not under pediatric language unique aspect (pediatric oncology is unique in terms of medication, chemotherapy dosing, and care protocols involved. Hard to understand not just adults.

- What shows up in emergency department care protocols can’t apply the same standards of care between children and adults.
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- Implementing EMR’s: For success, there needs to be a close relationship between experienced physician leadership, administrative leadership and IT leadership. Need physician experts involved in the implementation. Providers do not know what they do not know. Ongoing training is absolutely necessary.

- Workforce Development: Physician to Physician training and peer to peer training. Expense of this is the challenge. Training follow-up to ensure consistency in workflow.

- Product development -- Pediatrics not a priority market except for Children’s hospitals, the latter dominated by EPIC which is not a great fit in the office.

- Standards -- HL7 standards for pediatrics evolving, have them for Vital Records, Newborn Screening, EDHI, immunizations, labs.

- Implementing EMR’s-- REC’s have been helpful for those pediatricians pursuing MU; some vendor support is provided, depending on product and some practices benefit from a hosted model to avoid having their own IT support.

- Connecting to HIE’s -- Has not been a priority except in states that have Medicaid Health Homes and HIEs that are developed such as NY, MI, RI- not PA or NJ.

- Address workflow and efficiencies.
• Chronic disease registries -- Obesity as a condition being tracked in BMI measures often added to an immunization registry or child health system at the state level.

• Predictive analytics...done in-house that practice/do something with a trend not partnering with their system. Outpatient standpoint as it relates to pediatrics such as asking the question, “How many patients are obese?” What are the numbers and are there some correlation between demographics such as race, geography, socio economic status and use the information that exist outside to do some analytics.

• ?? Alert?? Is there is something important to be brought to my attention?

• Look at things in broad general categories (support better care) let’s say for asthma...How can I manage that and reduce severity. Knowing patients asthma and hospitalization would-be useful information. But for most people don’t have the time or the resources to do decision support,

• Controller medication that is prescribed to them.

• Decision support tools to write rules...pregnant, but from a data...and readily available but there are some onsite builds.

• Asthma, it should be as useful for a practice...how many other patients....deliver care...education specialist? Expand to have a pulmonologist? When I do an examination? Is there a problem?

• Obesity is an issue as EMRs to have a weight to prompt such as patient has not had a cholesterol check, blood presser check, even pre-diabetic. When we enter the
weight...the nurse is entering the weight. This patient is obese...search no record in PROMTS. Doesn’t take much.....age? Also BMI for you...why can’t it alert you.

- History...depends on the outpatient perspective. Are they filling out when it gets in to the record or when? Family history taking a look of the family to understand the patient. Social history that influence should live in the medical record on its own. Area and accessible (diabetes, obesity). Outpatient, they are given to fill out so the physician can refer to it.

- Is there a patient in the waiting room and tables in the waiting room, portal to put that into the medical record?

- Patient engagement/consumer engagement positive, as we put it in place the families will have an easier connection to request an appointment, not readily accessible like LAB/Radiology reports.

- Challenge for us technology, use their portal, but those patients use these portals and working with the family and the education and access to their physician.

- How we deliver medicine...more consumer/insurance delivered and providing portals, good thing, and having access on-demand to facilitate medical care. Inclusion for meaningful use requirements. We can make recommendations for patients, but the patients still need to do something. Patient portal if the 1) access the portal, and 2) means to access the portal.

- Some will use it but there will be a percentage that will use it infrequently. Determent? Some things we can’t control...but can’t make them use it.

- KID – can’t do it but the patient to kid patient portal.
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- Pediatrics – social issues, don’t have custody, protective services, influence these numbers.

- App for a kid…preventive medicine aspects for a kid. Not being afraid of exercise, eat properly, diet, and chronic conditions…tied to exercise…reward, did you take his medicine.

- Diabetes, chronic conditions use as an EDUCATION!

- Vendors and creating education for patients/child’s. Developing patient portal….release with limited functionality.

- Ideal world with up-to-date information and consistent contact information.

- School nurse information…Allowing to send to school nurse (medication notes, special instructions, parent being able to send it out. Not have to call to not oversight of school nurses. And school must be able to receive that using either an APP or Portal for school nurse.

- Scheduling patients, (Cerner is beginning) to know who my patients are, assist with calendars, cancellations and help manage workflow of the office can help deliver care. There is a need for integrated system, as EPIC which does do some scheduling and counting how many patients.

- Special needs (OT, PT, therapy, speech therapy, high risk kid’s early intervention providers, special education needs,) and home care agencies, TPN orders and special follow-up care, home care agencies that they should be able to see. Obviously they may need to transfer/available of information.
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- Patient chart is paper from ....HIE will be able to help. UPMC to import the Pediatric Alliance primary care docs, brought back into Cerner.

- Standards – should be set at national level.

- Pennsylvania’s CHIPRA grantees are able to electronically extract and report 14 of the CMS core pediatric quality measures directly from the EHR. They were able to accomplish this by standardizing the extracted data through the use of flat file layouts developed for this purpose. CMS should be involved in developing a national standardized set of data extraction file layouts.

- Support expertise – In looking at the seven CHIPRA grantees, approximately 40% report their EHR vendor appears overwhelmed with trying to support Meaningful Use. With the vendor’s attention focused on MU, when an EHR issue arises with implementing a pediatric upgrade often the users are informed those particular issues aren’t supported by MU and the client will have to wait until the vendor has time to assist. Some of the CHIPRA grantees have hired outside contractors to assist with the implementation of pediatric elements to their EHRs.

- EHR Program - 109 of 230 pediatrician respondents that completed a survey in the EHR incentive application and received EHR incentive payments for program year 2011 reported working with the Regional Extension Centers (RECs). 536 of 772 of the pediatrician respondents that completed a survey in the EHR incentive application survey and received EHR incentive payments stated they need technical assistance help to meet MU requirements.

- Connecting to HIE’s – 513 of 774 pediatricians respondents that completed a survey in the EHR incentive application and received EHR incentive payments state they do not know about PA’s HIE activities.

- Chronic disease registries – HIE strategy could begin allowing these could be set-up, Dental registry, sickle cell, asthma.

- Immunization Registries – many vendors are not supporting bi-directional exchange of information which allows the physician to query information from the registry. All too
often vendor upgrades are needed. Usually, the vendor upgrades are tied to Meaningful Use and if a hospital is ready to connect, a vendor may reply that the upgrade won’t be available until a particular stage of MU.

- EHR Incentive Program – 168 Pediatricians (as of March 18, 2013) report they submitted to an immunization registry according to the MU requirements.

- Workflow - Experience with CHIPRA shows that when IT changes are made to support a pediatric function in an EHR, changes in workflow often occur. Sometimes a pediatric function is available in an “adult” EHR, but it hasn’t been implemented due to the changes in workflow that will take place. Several of the CHIPRA grantees have been able to use the services of the REC to aid them in implementing changes to their workflow. The assistance provided by resources of this type can be very valuable to struggling practice sites.

- Workforce Development – This is another area that has strong implications on the implementation of changes to the standard EHR. Staff must be trained how to use the new feature and how it will affect workflow and other features within the EHR. With the CHIPRA hospitals, where EHR changes are rolled out system-wide, training can affect several hundred employees.
Funding Issues

- Economic priorities on ambulatory side are the same with any primary care practice. Expensive and impacts productivity for a period of time. Difficult decision to implement. MU & Stimulus $, Anti - trust (stark) to front 80% but it circles back, MU for pediatric practices can’t rely on the stimulus dollars.

- Over $11 million (3/18/13) have been issued to Children’s Hospitals and Over $24 million (as of 3/18) in EHR incentive payments have been issued to Pediatricians; eHealth pod supporting BH which supports HIE between and other practices.

- In the first four years of the CHIPRA grant, CMS has awarded $7,677,839 to the PA partners for their work with technological improvements to the delivery of children’s healthcare. CHIPRA funding will continue to be a resource through February 2015 when our total award will reach $9,777,361.

- From the pediatrician perspective, EMR funding money should be no object. Every dollar invested comes back multiplied. Institutions that limit investment in the implementation phase limit the revenue that EMR’s can produce. More funding should be applied to projects that involve data collection from parents during initial registrations and prior to visit. The savings in time, materials and work force would be substantial. From the technologist perspective, considering the current state of our country’s financial crisis, funding should cease in its current construct and be translated into tax breaks or tax burdens. If you comply you get a tax break if you don’t you pay a penalty; that being said, standards and ways to validate compliance must be easy enough as not to be a financial burden for government.

- Clinical – healthcare is delivered as a whole...often been ignored, funding, reimbursement and primary care fields, to a subspecialist are undervalued. This is different with adults, as they have been at the forefront of development. Preventive aspects is undervalued! However, with good preventive medicine, their entire lifetime. Because of that, most pediatrician, always underrepresented, and fought very hard to have our voice heard. A lot of the criteria, MU ....targeted at adult program. Tends to be a large amount of $ go with the biggest thing and how that is delivered.

- Criteria for MU set up for adults, don’t apply because of patient populations. As a whole, people to primary care are often unrecognized. Transition of care to adult providers (chronic) sickle cell, cystic fibrosis (primary oncologist, hemotogist, transfer care). Normal kids outgrown their pediatrician, then disappear and go to college. Insurance
have been an issue for 18 not going to (Invincible patient). Once college...hard to control those kid. Stay in different state...transition records across different states.

- Funding for mining the data and predictive analytics. Large electronic health records with huge capability...normal workload. Microsoft office. Help you to do Outlook...communication, email, etc...EHR management of your day very well.
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Future Issues

- Adolescent Privacy -- Transitioning children from pediatric, to adolescent to adult medicine- a transition of care activity not being discussed

- Patient Portals, these issues again surface as parents as proxies for the more clinical information available raises the privacy information more.

- Future – need to improve clinical decision support to systems with Pediatrics

- Weight based dozes, alerting

- From the pediatrician perspective, privacy and safety are serious legal concerns of adolescent care and I don’t see a good answer to that problem yet that can be universally applied. From the technologists perspective, without top down standards, management and oversight there is no clear path ahead.

- From the pediatrician perspective, I believe EMR’s in their next phase should integrate data collection directly from parents on issues like safety, psychosocial, parental stress and children stress. Tools are already available from the American Academy of Pediatrics with screening questionnaires. From the technologists perspective – If we would step back and look at our ability to collect and maintain data at the individual, family, community, state and national level we have such an opportunity for reform through technology. Until we do that we are skeet shooting the problem.

- As a whole, companies do not seem to be committed to peds.

- Future issues include:
  a. Adolescent Privacy
  b. Connecting to statewide HIE
  c. Standardized fashion
  d. Operational privacy
  e. Temple engagement strategy – dental

- Adolescent Privacy- Not an EMR issue. Our job with the EMR is to not make it worse. Possibly selective printing through a printing wizard to screen out the sensitive information.
The following are the main conclusions drawn from the contributors.

**Electronic Medical Records -- Challenges specific to Pediatrics**

- **Measurements** – Challenges around weight based system issues such as fluid rates, medications doses & transfusions for neonatal infants.
- **Medications** – Most clinicians do the math conversions in their head due to lack of appropriate software templates. More precision is needed for ambulatory and inpatient orders especially those that deal with complex medications.
- **Charts** – Today they are still mostly paper charts and stored in only one location. When physicians practice at multiple locations, they may have the chart in one primary office but on weekend/nights when the physician may work from a central site to maximize physician coverage, the charts are not at the new location. This results in a lack of information about past medical history, drug allergies and working medicines causing physician frustration.
• Emergencies – Today when children show up at the emergency department, ED departments' EMR care protocols can’t apply the same standards of care for children as they do for adults.

**Technical Support** – Vendors don’t understand or have knowledge of pediatric language with unique aspects such as pediatric oncology which can use different terms for medication, chemotherapy dosing, and care protocols.

**Standards** – Limited standards, lack of software support regarding pediatric templates & embedded decision support tools.

**Funding** – Physician who are part of a larger healthcare organization indicated that healthcare IT systems priorities seem to be driven by Meaningful Use dollars incentives. Since many pediatric community-based practices rely on payer mix (low percentage of Medicaid) they don’t qualify for the Medicaid incentives and can’t even apply. As a result, these pediatricians/physicians are given a low priority by health systems and vendors for ambulatory EMR while adult practices appear to have higher priority to maximize incentives.

Patient Portals -- Issues surface as parents serve as proxies for children which raises issues of clinical information available with technical considerations for adolescent privacy.

**Reported Shortfalls**

• Well child preventive care – not supporting identification & notification of age specific screening/preventive care opportunities for patients.

• Quality measures – often the EHR did not accurately reflect what was happening clinically. Some important pieces of data were not located in discrete fields within the EHR which made the data electronically unreportable. Data not located in a discrete field is often placed in a notes section which shows as a blob of text when queried making it impossible to extract and report.

• Linking of familial records – this was often not possible within an EHR system (ex. Linking birth mother records to baby records).

• Challenges to link bi-directionally with registries (such as immunization registry – PA SIIS).

• Specialized scales and scoring – not supporting APGAR scores, breast milk drug compatibility categories, weight based dosing, and specialized growth charts for children with special needs (such as Down’s Syndrome).
• Dental – the inability to store information regarding dental referrals, compliance, dental home, etc. Dental referrals are part of EPSDT and there is no way to document or track those referrals.
6.0 APPENDIX

A.1 – Project Director

Dr. Chris Cavanaugh is President of Pathseekers II, Inc., a consulting and executive coaching company specializing in higher education, healthcare, and non-profit organizations. In a consulting capacity, she serves as the Executive Director of the Pennsylvania E-Health Initiative (PAeHI), a "think tank" collaborative focused on using information technology to improve health care quality, efficiency, and safety since 2010. PAeHI conducts conferences, events, workshops, and convenes a collaboration of diverse volunteer stakeholders focused on HealthCare IT to identify, educate, and communicate the values of Information Technology across the Commonwealth and beyond.

Previously she was the Director of Training and Professional Development at George Washington University. She has taught doctorate, graduate and undergraduate courses via multiple delivery methods (online and face-to-face) in such areas as Institutional Advancement and Women in Higher Education at GW and Human Performance Technology and Program Evaluation at the University of West Florida. She continues to serve on numerous doctoral dissertations. She has worked extensively in both the corporate and non-profit sectors including over sixteen years at IBM specializing in the higher education, healthcare, and the non-profit, public sectors. Some of her accomplishments include being a Senior Professional in Human Resources (SPHR), Certified Performance Technologist (CPT), American Council on Education Fellow and has received over $1 million in research grants and contracts as principal investigator, in addition to serving as a Hospital Board of Trustee (as co-chair).

She received her BS degree in business management from the University of Maryland, and her MBA (specialization in organizational development) and EdD (specialization in virtual learning environments) from the University of West Florida. She has extensive teaching experience in program evaluation, educational research, institutional advancement, marketing research, human performance technology, and leadership. She has written and presented nationally and internationally on several topics in business and leadership, workforce development, economic development, military linkages, higher education, and healthcare. Published in 2010, she co-edited a three-volume series entitled Aging in America. Her recent professional and community engagements included Harrisburg Rotary (Paul Harris Fellow), chairing the Women's Fund/Mastermind Group of Harrisburg and with the United Way of the Capital Region and chairing the Professional Development Committee for the Council of Fellows at ACE. She is a member of numerous professional organizations (ACE, SHRM, ASTD, ISPI, PDK and HIMSS) and currently teaches master level courses online for Chaminade University of Honolulu and Immaculata University.
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A.3 Interview Questions

1. What is your perspective on the current status of Pediatric Health Information Technology?
2. Where are the gaps?
3. Share with us the “Day in the life of a Pediatrician” or your story?
4. Your thoughts on functionality/flexibility of EHR’s as it relates to the following:
   a. Product development
   b. Standards
   c. Implementing EMR
   d. Support expertise
   e. Connecting to HIE’s
   f. Chronic disease registries
   g. Immunization Registries
   h. Workflow
   i. Workforce Development
5. Your thoughts on funding issues?
6. What do you see as future issues?
7. What else should we be investigating and/or topics to be researched?
8. Who else should we talk to?
A.4 CMS PEHR Model EHR Format – Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA)

Section 401 (f) Development of a Model EHR Format for Children Enrolled in Medicaid or CHIP provision: “demonstrate the impact of the model EHR format for children developed and disseminated under subsection (f) on improving pediatric health, including the effects of chronic childhood conditions, and pediatric health care quality as well as reducing health care costs.” Topics include:

- Activity Clearance
- Birth Information
- Child Abuse Reporting
- Child Welfare
- Children with Special Needs
- Growth Data Requirements
- Immunization
- Medication Management
- New Born Screening
- Parent, Guardian & Family Relationship Data
- Patient Identifier
- Patient Portal
- Prenatal Screening
- Primary Care Management
- Quality Measures
- Registry Linkages
- School Based Linkages
- Security & Confidentiality
- Special Terminology & Information
- Specialized Scales & Scoring
- Well Child & Preventive Care


A.5 Poster Presentation for the 6th Annual Mid-Atlantic Healthcare Informatics Symposium at the Center for Biomedical Informatics at The Children’s Hospital of Philadelphia

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This information was selected and presented as a poster session during the 6th Annual Mid-Atlantic Healthcare Informatics Symposium at the Center for Biomedical Informatics at The Children’s Hospital of Philadelphia (330 attendees and 28 exhibitors) on Friday April 26, 2013.