



Public Health Data Standards Consortium

Pediatric Electronic Health Record: Public Health Perspectives

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GLOSSARY
(in alphabetical order)

- Care Setting** The physical location or entity providing health care.
- CDC** Centers for Disease Control and Prevention. [1]
- CHI** Consolidated Health Informatics (CHI) is one of the eGOV initiatives aimed to establish a portfolio of existing clinical vocabularies and messaging standards enabling federal agencies to build interoperable federal health data systems. About 20 department/agencies including DHHS, VA, DOD, SSA, GSA, CDC and NIST are active in the CHI governance process. CHI standards will work in conjunction with the Health Insurance Portability and Accountability Act (HIPAA) transaction records and code sets and HIPAA security and privacy provisions. [2]
- DHHS** Department of Health and Human Services
- DoE** Department of Education
- DSTU** Data Standard for Trail Use – DSTU – term used by the Health Level 7 (HL7) standards development organization
- Electronic Health Record (EHR)** is information, assembled and maintained in an electronic format which pertains to the health status of an individual and the health services delivered to an individual. The EHR <concept> is standardization in the field of information for health, and health information and communications technology to achieve compatibility and interoperability between independent systems, to ensure compatibility of data for comparative statistical purposes (*e.g.*, classifications), and to reduce duplication of effort and redundancies. [3]
- Electronic Health Record System (EHRS)** includes “(1) longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual; (2) authorized users; (3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for health care delivery. Critical building blocks of an EHR system are the electronic health records (EHR) maintained by providers (*e.g.*, hospitals, nursing homes, ambulatory settings) and by individuals (also called personal health records).[4]
- Electronic Health Record Infrastructure**
Databases, programs, software, hardware, servers, firewalls, access rules, Virtual Private Network (VPN) linkages, and web browser capabilities of the electronic health record system.

JHH Johns Hopkins Hospital

HD Health Department

Health Care Provider (HCP) is a person licensed, certified or otherwise authorized or permitted by law to administer health care in the ordinary course of business or practice of a profession, including a health care facility. This includes primary care providers, other physicians, nurse-practitioners, physician assistants, etc. [5]

Health Level Seven (HL7) An application protocol for electronic data exchange in health care environments.

Health Level Seven, Inc. A standard development organization that supports the development and maintenance of the HL7 protocol. [6]

HRSA Health Resources and Services Administration. [7]

PCP Primary care provider

PHDSC Public Health Data Standards Consortium. [8]

PMR Patient medical record

DHMH Maryland Department of Health and Mental Hygiene

Registry a centralized public health data file pertaining to a defined set of health records for a particular population, *e.g.*, cancer registry, immunization registry, blood lead registry. Registry is a common data source used in public health to assist a health care practice in providing appropriate care to a population of patients and/or to evaluate the effectiveness of public health intervention.

SOW Statement of Work

Use Case A term used in informatics. It is defined as a description of actor responsibilities, operations, and system interactions that produce a single goal [9], *i.e.*, a description of a sequence of events related to a certain problem (domain), participants of these events and their interests/needs.

EXECUTIVE SUMMARY

One of the promises of widespread adoption of an interoperable electronic health record is that information will flow readily between clinical settings and public health. An outcome of such a system would be that each will be able to improve the effectiveness and efficiency with which they do their jobs.

This project is a first small step toward understanding what it would take to achieve easy information exchange between clinical and public health organizations. This project focuses on four illustrative areas of mutual interest to pediatrics and public health in order to build a framework to look at where we are and what needs to be done to enable the goal of easy and valuable information exchange to occur. This early step compares information requested by a state health department (Maryland) with information available from a large pediatric provider in that state (Johns Hopkins Hospital). The four clinical areas used as examples—newborn screening, immunization, growth and development, chronic disease care—have the potential for bi-directional information exchange, not only for public health surveillance but also for feeding timely information back to the provider. The task involved mapping public health and provider forms in order to better understand issues around standards, protocols for exchange, and gaps in data content.

Background

Because of the automation of clinical data – inpatient and increasingly outpatient -- public health programs stand at the threshold of change in the way in which they can gather surveillance data, the amount and quality of data gathered, and in the ways they can influence case management and direct patient care. Public health authorities will have more reliable, quicker, and broader access to data. Increased access and timeliness corresponds to better care and health policy decisions. The term, Electronic Health Record (EHR), not only refers to the generic concept of such computer-based systems (EHRs), but includes the idea that a single patient's medical information may be stored in multiple systems, with data standards enabling the appearance of a single source. The EHR, therefore, is a pivotal instrument in integrating clinical and public health data systems. [10]

The Department of Health and Human Services (DHHS) is interested in facilitating the development of the EHR.[4,11] Because children are not merely small adults and their needs differ from those of adults, specific attention needs to be paid to the requirements for a pediatric EHR. In 2001, the American Academy of Pediatrics (AAP)' Task Force on Medical Informatics' report on the special requirements for electronic medical record (EMR) systems in pediatrics stated that "an essential function of a pediatric EMR system is to facilitate care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective".[13] HRSA's Maternal and Child Health Branch (MCHB) has an interest from the public health perspective in the development of the pediatric EHR (PEHR) because the PEHR-based systems could enhance the integration of child health information systems and facilitate the assessment and prompt provision of appropriate services to insure an optimal healthy start for all children and improve the health of all children.[12] The needs of HRSA's programs are just one example among many public programs that could benefit from easy extraction of clinical data for program impact monitoring.

Children have unique developmental needs and their parents and caregivers have information needs that can be different from those of adults. Pharmacologic factors, including age-based variability in absorption, metabolism and excretion of drugs as well as physiologic factors, such as the universal need for weight and body surface area considerations, also make any process in pediatric patients different than in adults. During early childhood, a child more likely has multiple visits to the physician. Children see multiple specialists. Public health agencies can be involved in providing care to children. Because of children's size, age and types of diseases they are more often in need of acute care. And they often can't communicate the symptoms. Timely access to patient history information from various settings can be critical for a child healthcare. The characteristics of pediatric care that differ from adult care need to be captured completely and correctly in PEHR systems so that pediatricians, other providers and public health authorities can benefit from the automation of clinical and developmental child health information.

HRSA's Maternal and Child Health Bureau and health professional organizations such as the AAP and the American Academy of Family Physicians (AAFP) are participating in the development of the pediatric EHR. [14,15] The HL7 Pediatric Data Standards Special Interest Group (SIG) is also working on the draft standard for trial use (DSTU) for pediatric EHRs. These efforts are mainly focused on the EHR specifications for the clinical encounters. HRSA/MCHB also recognizes the need to address the information needs of public health as its systems link to the pediatric EHR and to complement the on-going PEHR development effort by identifying special requirements for public health systems and data in pediatric care to support clinical care/public health interactions via the PEHR-Public Health (PEHR-PH) system.

Project Purpose

The project described in this report contributes to the definition and development of the pediatric EHR from public health perspectives (PEHR-PH). The PEHR-PH is seen as a two way clinical and public health information interchange for the purpose of providing the best health care service to children.

This project is a first small step toward understanding what it would take to achieve easy information exchange between clinical and public health organizations. This project focuses on four illustrative areas of mutual interest to pediatrics and public health in order to build a framework to look at where we are and what needs to be done to enable the goal of easy and valuable information exchange to occur. This early step compares information requested by a state health department (Maryland) with information available from a large pediatric provider in that state (Johns Hopkins Hospital). The four clinical areas used as examples—newborn screening, immunization, growth and development, chronic disease care—have the potential for bi-directional information exchange, not only for public health surveillance but also for feeding timely information back to the provider. The task involved mapping public health and provider forms in order to better understand issues around standards, protocols for exchange, and gaps in data content.

Approach

We analyzed the compatibility of public health data requests with data that are currently recoded in the pediatric medical record by cross-mapping clinical and public health data exchange activities (and the reverse) to align data and information important to both public health and clinical medicine, such that a data element in one system has secondary reuse value in the other.

HRSA suggested four clinical areas (domains) for the analysis. These represent diverse examples of public health programs that are aimed at serving infants from the day of birth. They also benefit from continuous collaboration between clinical setting and public health program staff. These were:

- (1) newborn screening,
- (2) immunization,
- (3) growth and development (*e.g.*, obesity- related), and
- (4) chronic disease care (*e.g.*, asthma care).

In this report the term domain is used because multiple activities and/or information systems may be used to support public health program's operation within the clinical area to achieve its disease prevention and health promotion goals.

We examined data forms currently required and collected by a public health agency relating to the four selected pediatric domains. The data were compared with how the same or similar data are stored within the clinical record forms. Numerous forms were analyzed and from the deconstruction of the forms a metadata database was constructed. [16] We next focused on identifying common data concepts, data fields and formats within these concepts used by both clinical and public health systems. In addition, we conducted the analysis of how the data are exchanged between the clinical setting and public health program.

Results

1. Common data concepts - Cross-mapping of clinical and public health data from forms that are currently in use by clinicians and public health programs shows that pediatric data housed by the clinical system is a significant source of data for public health program systems. Similarity/identity of data concepts used in clinical care and public health related to an individual patient care allows alignment of these data concepts to support the continuum of data interchange between clinical and public health settings via the EHR in the future. The analysis of the data needs of the four selected public health domains suggests that there is significant overlap in data concepts across domains, *i.e.*, 59% of data collected in clinical settings on individual patients are present in all four domains. Similarities of data needs across domains were greater than the differences. Many of data fields today are free text, and are ripe for future structured data standards to improve their utility.
2. Effectiveness and efficiency in data interchange – (a) Analysis of workflow relating to how data is exchanged between clinical setting and public health programs shows that significant efficiency improvements can be made in the case where clinical information systems automatically populate public health registry databases. (b) “Enter once, use many times” remains one of the most important concepts in good information system design. If interoperable systems are introduced the problem of redundant data capture is eliminated. .

Barriers

Some barriers to progress in the implementation of the PEHR-PH and information interchange were identified:

- Lack of evidence on Return on Investment is slowing adoption;
- Because of low computer literacy of health care providers large investments will be required for EHRS installation and personnel training as well as for enabling bi-directional data exchange between clinical and public health settings;
- Public and clinical data are presently stored in silos which fragment and disaggregate the data;
- Societal fears of losing privacy must be addressed carefully. While privacy generally must be protected, particularly sensitive information, *e.g.*, genetic, mental health and behavior, must be the subject of special protection..

Future Agenda

1. **Cross-mapping Public Health and Clinical Care Data** – Cross-mapping public health data needs – present and future – against data that are either available today or could be made available from the clinical EHRS is a necessary step. The emergence of health information exchanges, like the one in Indianapolis, compel public health agencies to be clear about the specific data requested and the precision and coding of the data. Mapping the public health program data needs will assist public health and clinical health care information exchange. There is the potential that in the near future regional health information organizations (RHIOs), *e.g.*, Indiana Health Information Exchange, will automate individual patient data via EHRS in a way that provides a single data feed to public health.
2. **Standards** - There is a need for standardization of data and process definitions. The public health community should continue to participate in the standard development efforts, *e.g.*, Continuity of Care Record (CCR) standard that are under development by the ASTM E31 Committee on Healthcare Informatics [17], and the pediatric EHR content standard. Mapping is necessary from SNOMED-CT to classifications more typically used in public health, *e.g.*, ICD-9-CM (and eventually ICD-10-CM). In addition, the development of protocols and implementation guidelines is needed to enable health care providers and public health practitioners (a) to formally adopt the standards, standardized vocabularies and data formats and (b) to integrate them into the workflow for provision of care to an individual patient and for public health services to improve community health outcomes, where they both practice.
3. **Overcoming Data Silos in Public Health** - Integrating currently separate public health databases will have benefits for both public health and clinical practitioners. The richness of data from providers populating public health databases is squandered if the data ends up being fragmented in public health agencies. Therefore, efforts to precisely identify how RHIOs and new technologies can remove silos will be rewarded. Integrating newborn screening, hearing screening, immunization systems with vital records, environmental health data, *e.g.*, lead (blood lead registries), communicable disease registries, Women, Infant, and Children (WIC) program systems, Early Intervention Programs, etc. will improve case management by public health staff as well as support medical home initiatives of AAP and HRSA/MCHB.

INTRODUCTION

As patients' clinical data are increasingly stored in computer-based systems, health care providers and public health practitioners will have quicker and easier access to more reliable, data that will allow them to identify and address the health care needs of individuals and communities. The term, Electronic Health Record (EHR), not only refers to the generic concept of such computer-based systems (EHRS), but also includes the concept of a patient's medical information being stored in multiple systems, with data standards enabling the appearance of a single source. The EHR, therefore, is a pivotal instrument in integrating clinical and public health data systems. [10]

It is recognized that the needs of children differ, in many ways, from those of adults, so that specific attention should to be paid to the requirements for a pediatric electronic health record (PEHR). In 2001, the American Academy of Pediatrics (AAP)' Task Force on Medical Informatics' report on the special requirements for electronic medical record (EMR) systems in pediatrics stated that "an essential function of a pediatric EMR system is to facilitate care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective".[12]

Children have unique developmental needs and their parents and caregivers have information needs that can be different from those of adults. Pharmacologic factors, including age-based variability in absorption, metabolism and excretion of drugs as well as physiologic factors, such as the universal need for weight and body surface area considerations, also make the developmental treatment process in pediatric patients different than in adults. During early childhood, a child more likely has multiple visits to the physician. Children are seen by multiple specialists; they are more often in need of acute care. Public health practitioners are also involved in direct care and/or case management. Children often can not communicate symptoms. Timely access to patient history information from various encounters and care settings can be critical for child healthcare.

The HRSA's Maternal and Child Health Bureau and AAP are participating in the development of the PEHR. [14,15] The HL7 Pediatric Data Standards Special Interest Group (SIG) is also working on the draft standard for trial use (DSTU) for pediatric EHRS. These efforts are mainly focused on the EHR specifications for the clinical encounters.

A well developed PEHR-PH system will enable HCPs to (1) to transmit patient data to public health agency's programs via electronic communication channels for the provision of care, population-based assessments and policy development; and (2) have real-time access to community- and population-level information including notifications and alerts generated by public health programs.

Examples of Pediatric Public Health Programs

The AAP's Newborn Screening Task Force [18] identified public health agencies and other government programs that serve infants in the first month (neonatal period) and/or first year of life (Table 1). These programs include similar components, *i.e.*, screening, follow-up and evaluation. Some of them, *e.g.*, newborn screening, also require continuous close collaboration between HCPs and public health staff to deliver health care services.

Table 1. Public Health Programs that Serve Infants in the First Year of Life

Program Type	Program Name
Screening Programs for Health and Developmental Risks	Prenatal Screening and Follow-up
	Newborn Metabolic Disorder Screening
	Newborn Hearing Screening
	Supplemental Nutrition Program for Women, Infants and Children (WIC)
	Outreach, Case Management, and Home Visiting Programs
Programs for Infants with or at Risk for Special Health Care Needs	High-risk Children Follow-up Programs
	Early Intervention Programs
	State Genetic Services Programs
Registry and Data Programs that Include Infants	Vital Registration
	Immunization registries
	Blood Lead Registries

The AAP Task Force' report [18] indicated that these public health programs usually operate independently of one another. Challenges for accomplishing the integration of these programs are: (a) varying timeframes for operation of each program, *i.e.*, newborn hearing screening is conducted at birth, newborn metabolic disorder screening – at 36-48 hour of age, filing electronic birth certificates may take 2-3 weeks; (b) definitions for eligibility, *i.e.*, universal newborn screening and means-dependent WIC eligibility; (c) demands and constrains imposed by categorical funding agencies, and their priorities; and (d) programs can be administered by different agencies within state government. These differences can lead to the inefficient use of resources and frustration among families and HCPs asked to provide the same information on multiple forms of varying formats to various public health programs. Information systems that support these programs may be insufficient, redundant, and not-interoperable. The resulting duplication of effort increases costs, burden families, providers and public health practitioners, and create redundancy in data management systems. The current systems do not allow easy aggregation of patient's information. Improved coordination and integration of information systems is needed.

The AAP Task Force' report formulated two questions [18]:

1. What is the optimal framework for integrating or coordinating public health systems for early childhood assessment and follow-up? and
2. What is the role of information technology as part of efforts to improve program coordination?

The promise for the future is to (1) use the PEHR-PH system as the framework for integrating (a) clinical-based systems and public health information systems in pediatric care, and (b) public health information systems within health agency; and (2) use the PEHR as the vehicle to transmit standardized information from the originating source (clinical and/or public health) to pediatric health care data warehouses (clinical and/or public health) where all authorized participants can access the information and use it to meet their own specific needs.

This vision for an integrated PEHR-PH system necessitates the development of standardized content of the clinical and public health data and information and the encoding of information with standardized vocabularies.

Project Goals and Objectives

The overall goal of this project is to assure that the development of the pediatric her takes account of public health perspectives (PEHR-PH) to create a two way clinical and public health information interchange for the purpose of providing the best health care service to children. Specifically, it contributes to the development of the specification requirements for the PEHR-PH system by analyzing the compatibility of public health data requests with data that are currently recoded in the pediatric medical record.

The objectives of this project are the following:

1. To contribute to the definition of the PEHR-PH data content by (1) identifying candidate data from existing pediatric and public health sources (forms) that need to be exchanged between clinical settings and public health programs; and (2) analyzing the workflow that supports this exchange;
2. To validate the identified PEHR-PH data concepts and elements (fields, variables) and data exchange workflow using experts in pediatric care and public health child health programs.
3. To suggest next steps for moving forward the development of the PEHR-PH content standard and integrating it into the on-going national PEHR development process.

Approach

Data housed within clinical EHR systems offer potential for (1) use by public health authorities to support public health service delivery and policy development, (2) enabling health services research, and (3) providing real-time information from public health agency to HCPs related to individual patient care and population health outcomes. To realize this potential, public health and clinical care information systems must speak the same language. This requires that data and information important to both public health and clinical medicine be aligned, such that a data element in one system has secondary reuse value in the other. This alignment needs to support, and take into account the continuum of data interchange.

The alignment can be achieved through mapping public health and clinical data exchange activities (and the reverse). This represents a very large task. There are two basic approaches that can be taken: (1) identifying available clinical data that meet the public health reporting requirements; and/or (2) taking public health reporting requirements, and finding the clinical data available to fulfill those requirements. The work described in this report is formative to the field because it endeavors, using both these approaches, to create a systematic framework upon which further development of PEHR-PH can be pursued.

The following steps were taken to facilitate this task. They were:

- Step 1. Create an inventory of data sources (forms) used in clinical and public health settings related to the selected public health programs.
- Step 2. Examine data currently required/collected by the selected public health programs compared with how the same or similar data are stored within the clinical record.

- Step 3. Propose data concepts – that is, classification for groups of data – that link public health data with data in the clinical record.
- Step 4. Examine how public health data presently derive from the clinical process.

Selected Public Health Domains

HRSA suggested four clinical areas (domains) for the analysis. These represent diverse examples of public health programs that are aimed at serving infants from the day of birth (Table 1). They also benefit from continuous collaboration between clinical setting and public health program staff. These were:

- (1) newborn screening,
- (2) immunization,
- (3) growth and development (*e.g.*, obesity- related), and
- (4) chronic disease care (*e.g.*, asthma care).

In this report the term domain is used because multiple activities and/or information systems may be used to support a public health program's operation within the clinical area to achieve its disease prevention and health promotion goals. For example, newborn screening programs includes newborn bloodspot screening and newborn hearing test; chronic disease care domain include asthma, diabetes, etc. The term domain is broader than a public health program as an administrative entity within a public health agency. The brief description of each domain is provided below.

Newborn Screening for heritable and congenital disorders is a mandated public health program aimed at the early identification of conditions for which early and timely interventions can lead to the elimination or reduction of associated mortality, morbidity, and disabilities. The program includes 6 components: (1) screening, (2) immediate follow-up (3) education (4) diagnosis confirmation, (5) immediate and long-term care, and (6) evaluation of all components.[18] About 4 millions infants born each year in the US are screened for a varying number of disorders depending on state requirements.[19] The survey of pediatrician practices identified the following barriers to gaining access to newborn screening results: infants born in a hospital where physician does not have privileges; new transfers to the practice; infant born in other states; personnel time to track results; parents notified before primary care pediatricians; name change; and absence of direct communication system linking the state newborn screening program to the primary care physician.[21] The results of the Newborn Hearing Test are often required to be recorded on the same form with the information on the Newborn Metabolic Disorder bloodspot screening test.

Immunization is critical to control many infectious diseases including polio, measles, diphtheria, pertussis (whooping cough), rubella (German measles), mumps, tetanus, and *Haemophilus influenzae* type b (Hib). While the US currently has near record low cases of vaccine-preventable diseases, the viruses and bacteria that cause them still exist.[21] CDC is continuing the investment to assist states in developing immunization information systems (registries[22]) - confidential, computerized information systems that collect vaccination data within a geographic area.[23] By consolidating vaccination records from multiple health-care providers, generating reminder and recall notifications, and assessing clinic and vaccination coverage, registries serve as key tools to increase and sustain high vaccination coverage.[24]. The Healthy People 2010

objective is to increase to 95% the proportion of children aged <6 years who participate (*i.e.*, have two or more vaccinations recorded) in fully operational, population-based immunization registries. [25,26]

Growth and Development (specifically obesity-related) domain was selected for analysis because the dramatic increase in the prevalence of childhood obesity in the US and its resultant comorbidities associated with significant health and financial burdens, warrant strong and comprehensive prevention efforts. Interactions between genetic, biological, psychological, socio-cultural, and environmental factors clearly are evident in childhood obesity. [27] Early recognition of excessive weight gain relative to linear growth should become routine in pediatric ambulatory care settings. Body Mass Index (BMI, kg/m^2) should be calculated and plotted periodically to monitor child's predisposition to obesity. [28]

Chronic Disease Care (e.g., asthma) domain was selected because of increasing incidence of childhood asthma that now affects close to 5 million children in the United States.[29] Asthma is one of the leading diagnoses in acute care visits.[30] Some of the common asthma triggers are: infections in the airways; viral infections of the ear, nose, and throat; other infections (such as pneumonia); indoor and outdoor air pollution; cigarette smoke; cold air, dry air and sudden changes in the weather; allergens; pollens; dust (house dust mites); animals; mold; exercise; and emotional stress.[29] Both HCPs and public health agencies are currently working on understanding the causes of increased asthma incidence by monitoring cases of disease via statewide Asthma registries.

METHODS

Create an Inventory of Data Sources

To create an inventory we investigated available data sources (forms) used in clinical and public health settings related to the selected public health domains. The inventory was based on the review of a total of 15 paper forms by the Johns Hopkins Hospital (JHH) and the Maryland State Department of Health and Mental Hygiene (DHMH). The clinical forms have been developed over time as a product of clinicians' needs to provide care consistent with professional standards for quality care, and not as a product of needing to communicate results to the State. The DHMH forms have been developed over time as a product of legislation and regulation and public health practice needs.

We reviewed forms used for documenting information on well child care through the following types of pediatric services/visits: (a) Delivery and newborn course, (b) Health maintenance and well child care, and (c) Scheduled visits/continuity of care. These three services/visits comprise the core functions of health supervision [31] and represent care provided to children that differs from that provided to adults. The forms were reviewed in the order that represents the information flow across the typical schedule of patient visits that covers a period from a child's birth through the first 5 years of life (Fig.1).

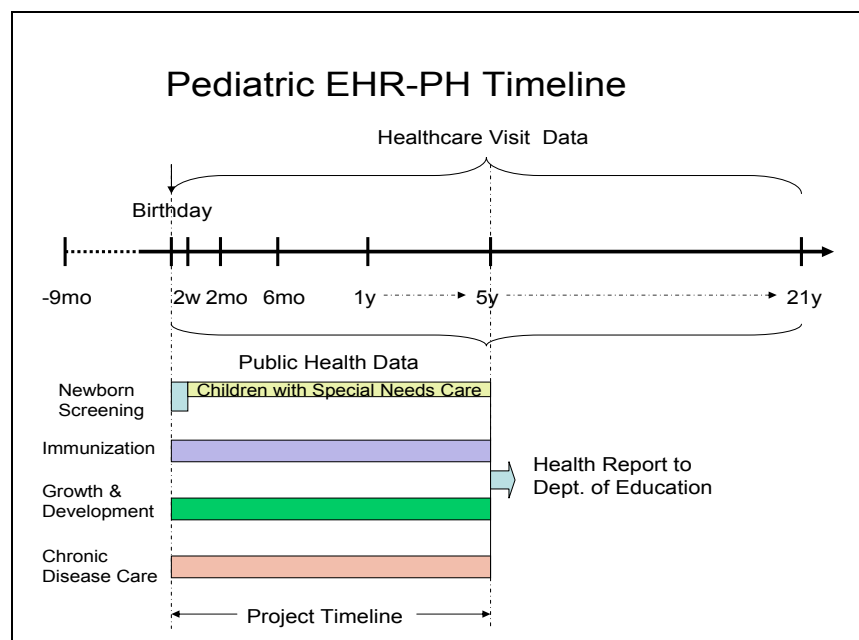


Fig.1. Pediatric EHR-PH Project Timeline Showing the Time Period in the Life of the Typical Child Addressed by the Current Project.

Examine Data across Clinical and Public Health Forms

To examine data currently required/collected by the selected public health domains compared with how the same or similar data are stored within the clinical record, we analyzed the form content and constructed a metadata database. [16] Using tactics developed in clinical medicine (*e.g.*, via HL7), we focused on identifying common data concepts, data fields and formats within these concepts used by both clinical and public health systems.

We mapped data concepts (*e.g.*, Patient Demographics), data fields (*e.g.*, Patient Name) and their data elements (*e.g.*, Last Name, First Name), and formats required by the forms for those fields and elements. Identical data fields on the forms were selected and grouped under data concepts that they represent. Because the name of a field can be labeled differently in different forms (*e.g.*, Patient Address, Address, Child's Address), we used our judgment and/or expert advice to decide if these fields in fact represent the same data concept, (*e.g.*, address where patient resides) before linking these fields across forms.

To view the variety of formats used to describe the same data field across forms, the data format for each data field was recorded including units of measure, *e.g.*, MM/DD/YY; XXX-XXXX; grams; cm; etc. In some cases, the following terms were used to describe the data format:

- “Free text” – no instructions are given on the form on how to record data in the field;
- “Check” – recorder has one choice to select among variables listed (*e.g.*, Yes/No; Positive/Negative, Passed/Fail, etc.), also called “radio button” in the user interface literature;
- “Check box” – recorder has multiple choices to select among variables listed (*e.g.*, check all that apply);
- “Letter/Numbers” or “Numbers” – used code formats.

A Blank field in our database means that data field is not present on the form.

Data fields were grouped by data concepts, *e.g.*, Hospital of Birth; Primary Care Setting; Health Agency; Patient Demographics; Family Demographics; Patient Medical History, etc. To group fields across forms, we focused on the intentions of the fields that is, what data concept was each field aiming to convey. These concepts emerged, in a bottom-up fashion, from the review of the forms and were in turn grouped by four subjects - the Patient; the Patient Visit; the Care Setting; and the Form - as the primary entities/participants in the data generation/communication process. To validate the data concepts that emerged we compared them to the standards for electronic exchange of clinical information across the federal government adopted by the CHI Initiative. [2]

Propose Data Concepts that Link Public Health Data with Data in the Clinical Record

The data concepts that emerged were mapped back to the four selected domains. Two of the selected domains have data definitions for public health reporting defined by the national and Maryland State statutes, *i.e.*, newborn screening and immunization. Two other domains, *i.e.*, growth and development and chronic disease care, do not have national standards for reporting. So, we used our judgment to identify data concepts that are relevant to describe the last two domains.

Analysis of overlap of data fields across forms was conducted within one data concept - Patient Demographics - as an example.

Examine How Public Health Data Are Derived from Clinical Process

The workflow diagrams for data interchange between clinical care setting and public health agency's programs for the four selected public health domains were constructed to represent (a) the current status of data interchange as well as (b) a recommendation for how data could be exchanged in the future via the PEHR-PH system.

Limitations

In order to reduce the scope of this pilot project to a manageable size we impose the following limitations.

1. We used the forms from one clinical care setting – Johns Hopkins Hospital - and one state health department - the Maryland State Department of Health and Mental Hygiene.
 - a) Clinical data collection is driven by clinical needs, which may not vary significantly between providers and institutions as well as by payer requirements, which also provide some standardization across clinical data sources. However, JHH is a large provider, and its work practices may not generalize to other providers.
 - b) Due to legislative differences among states and significant variability in public health practices by health agencies, DHMH data collection practices may not be used by other states. Also, state health department practices are different from local health department (LHD) practices. The LHD practices were not reviewed in this project.
2. We did not validate the form content against the national guidelines, *e.g.*, AAP, AAFP, US Preventive Services Task Force, National Guidelines Clearinghouse, etc. These forms were developed by highly reputable institutions (JHH and DHMH) with the strong Internal Review Board (IRB) processes. Whether or not they are in compliance with those guidelines, they represent examples of forms in current use.
3. All forms included in the study are paper-based forms. Only in one case - the JHH Encounter Form - information can be partially available electronically for the subsequent visits.
4. We focused on a period of life between a child's birth through the first 5 years of life (Fig.1). The prenatal time period is excluded, because of the complexity of including the mother's record (*i.e.*, adult care) and the availability of pertinent prenatal information on delivery room records; the period after the 5th birthday is excluded because school enrollment imposes other information needs that are beyond the scope of this effort.
5. The analysis included forms used for a well child care and did not include data sources for children with special needs care. Care for children with special needs brings another aspect of clinical care and public health interaction that should be addressed in the future.
6. The analysis is based on the three routine types of pediatric services/visits as follows: delivery and newborn course, health maintenance and well child care, and scheduled visits/continuity of care. However, children interact with healthcare at many other settings, *e.g.*, acute care (sick office visits), emergency rooms visits, kindergarten, inpatient care, public health clinics, etc. Valuable data will go uncaptured if these settings and types of care are not included in the scope of the development of PEHR-PH in the future.

Peer-review Process

The peer-review of the report was conducted by the Technical Panel that includes representatives from a pediatric hospital, a small health care provider setting, a state public health agency and a local public health agency.

RESULTS

Inventory of Data Forms

Attachment 1 presents the inventory of data forms analyzed in this project such as eight clinical forms and seven forms from public health programs relevant to the four selected domains.

Common Data Concepts: Cross-mapping of Clinical and Public Health Data

A total of 331 data fields from 15 forms were mapped (Attachment 2). They comprise 21 data concepts under 4 subjects: Form, Care Setting, Patient, Patient Visit. The choice of specific data concepts and data fields included in the concept emerged from the following. First, we used the order in which data concepts and data fields appear on the actual form. Second, in case when the data field exists only on one form, we used our judgment to place this field under a certain data concept. Data fields within a data concept were grouped under data concepts sub-classes. For example, under the “Patient Medical History” data concept, the “Birth History” sub-class is described by 9 data fields including Birth Weight, Length, Gestational Age, APGAR, etc. Another example can be the “Immunization” data concept in which the “Exemption” consists of 4 data fields: Medical Contraindications, Permanent/Temporary Condition, Until <Date>, Religious Objection (Attachment 2).

The data concepts, data concept sub-classes and their data fields that emerged from the analysis were consistent with the CHI recommendations [2], *e.g.*, Clinical Encounters, Demographics, Immunization, Diagnosis and Problem List, etc. Analysis also shows that CHI terminology is not always consistent with terms used in the analyzed forms. For example, in Demographics, the term “Customer” is used by CHI not the term “Patient” that is used in the analyzed forms.

Public Health Data Needs for Selected Domains. Table 2 represents data needs across the four selected public health domains. The data needs are described by 17 data concepts that emerged from the review of forms under the three subjects: Care Setting, Patient, and Patient Visit. To depict granularity of data needs across four selected domains, Table 2 also displays a total of 21 sub-classes that emerged within the following three data concepts of the subject “Patient”: Family Demographics (n=5), Patient Medical History (n=12) and Family Medical History (n=4). Further analysis of data needs across domains was based on 17 data concepts plus 21 data concept sub-classes.

The data needs for the selected domains are described as follows: (1) newborn screening - 11 data concepts plus 6 data concept sub-classes (45%); (2) immunization - 10 data concepts plus 2 data concept sub-classes (32%); (3) growth and development - 17 data concepts plus 21 data concept sub-classes (100%); and (4) chronic disease care - 16 data concepts plus 21 data concept sub-classes (97%).

Ten data concepts (59% of a total of 17 data concepts) are present in each domain, *i.e.*, all 3 data concepts of the Care Settings subject; and 2 of the 7 data concepts of the Patient subject; 5 of 7 data concepts of the Patient Visit subject. Three data concepts and 6 data concept sub-classes are present across all three domains. One data concept (Anthropometry) and 13 data concept sub-classes are present across at least 2 domains. Only one data concept, Economic, is present in one domain – Growth and Development (Table 2).

Table 2. Examples of Data Concepts in Pediatric EHR-PH That are also required on Forms in Public Health Domains

Subject	Data Concepts	Sub-Classes of Data Concepts	Domains			
			Newborn Screening	Immunization	Growth & Development	Chronic Disease Care
CARE SETTING	Hospital of Birth		√	√	√	√
	Primary Care		√	√	√	√
	Health Agency		√	√	√	√
PATIENT	Patient Demographics Anthropometry Health Insurance		√	√	√	√
					√	√
				√	√	√
	Family Demographics	Mother	√	√	√	√
		Father			√	√
		Parental Relationship			√	√
		Legal Guardian			√	√
		Siblings			√	√
						√
	Patient Medical History	Birth History	√		√	√
		Newborn Examination	√		√	√
		Infant/Child Examination			√	√
		Medical Problems	√		√	√
		Pertinent Development History	√		√	√
		Maternal History			√	√
		Hospitalizations			√	√
		Surgeries			√	√
		Past Illnesses			√	√
		Injuries			√	√
		Current Medications	√		√	√
		Immunizations		√	√	√
Family Medical History	Conditions/Family Members			√	√	
	Social History for TB			√		
	Child Risk Factors			√	√	
	Household/Close Contact Risk Factors			√	√	
Economic			√			
PATIENT VISIT	Service Type		√	√	√	√
	Physical Exam		√	√	√	√
	Laboratory Analysis/Tests		√		√	√
	Diagnosis		√		√	√
	Procedures		√	√	√	√
	Recom./Restricted Activities		√	√	√	√
	Health Education		√	√	√	√
TOTAL: 17+21=100(%)	No. of Data Concepts = 17	No. of Sub-Classes = 21	11+6(45%)	10+2(32%)	17+21(100%)	16+21(97%)

There are data fields that appear only on public health forms, *e.g.*, “Ethnicity” and “Census Tract #” (Attachment 2 and Table 3). These data are not recorded on the clinical forms, but, their reporting is requested by the public health agency. We informally reviewed the ability of HCPs to provide information on these two subjects. “Ethnicity” proved poorly defined: one respondent provider assumed it referred to religion. “Census Tract”, a key concept for public health agencies, is data that are unknown or effectively unavailable to clinicians.

Overlap between Clinical and Public Health Data. We analyzed the overlap of data fields within one of the data concepts – Patient Demographics – across forms (Table 3). Overall percent overlap across all selected data fields within clinical forms (n=8) was 64%, public health forms (n=7) - 61%, all forms (n=15) together – 56%. For some data fields percent overlap is significantly higher. For example, the “Date of Birth” field appears in 6 of 8 clinical forms (75%) and 7 of 7 public health forms (100%) with overall percent overlap across forms of 87%. The “Patient Name” field appears in 6 of 8 clinical forms (75%) and 6 of 7 public health forms (86%) with overall percent overlap across forms of 80%. The “Patient Address” is recorded on in 4 of 8 clinical forms (50%) and 5 of 7 public health forms (71%) with overall percent overlap across forms of 61%. The “Race” field appears in 4 of 8 clinical forms (50%) and 3 of 7 public health forms (43%) with overall percent redundancy across forms of 47% (Table 3).

Table 3. Overlap in Patient Demographic Data Across Clinical and Public Health Forms

Data Fields	Overlap Across Data Fields					
	Clinical Forms		Public Health Forms		TOTAL	
	# of Forms = 8	Overlap (%)	# of Forms = 7	Overlap (%)	# of Forms = 15	Overlap (%)
History #	7	88	2	29	9	60
Patient (Pt) ID	7	88	1	-	8	53
Additional Pt ID (Mother’s SS#)	3	38	3	43	6	40
Date of Birth	6	75	7	100	13	87
Place of Birth	1	-	1	-	2	13
Patient Name	6	75	6	86	12	80
Sex/Gender	5	63	5	71	10	67
Race	4	50	3	43	7	47
Ethnicity	0	-	1	-	1	-
Patient Address	4	50	5	71	9	61
Phone Number	4	50	3	43	7	47
Census Tract #	0	-	1	-	1	-
Average		64		61		56

It should be noted that two public health forms for newborn screening and all clinical forms, except the Encounter Form, have an area on the top of the form for the addressograph stamp (Attachment 2). This stamp includes patient ID (*i.e.*, medical history ID), name, and date of birth. However, forms with the addressograph stamp still have fields to record the same information. While addressograph is aimed to eliminate the handwriting of Patient ID, Name, Date of Birth on the form it does not eliminate the data entry of these data in the patient medical record databases at each encounter.

The overlap of data fields across clinical forms, public health forms, and across all forms raises an issue of data formats. Most of data field records exist in “Free text” format (Attachment 2). Attempts were made to use structured data formats in some forms. These structured data formats, if they exist, are not consistent across forms. For example, Date of Birth in some public health forms is recorded as “ / / ; MM/DD/YY; Month,Day,Year; Mo__ Day__ Year__.” Race is recorded in a free text format across clinical forms and in following multiple choice formats across public health forms: (a) Check: White/African American/Asian/Native American/Other; (b) Check: White/Non White; and (c) Check: African American, White, Asian/Pacific Islander, Native American, Biracial/ Multiracial, NR/Unknown, Other. Although free text can be parsed, it is difficult, time consuming and not very accurate.

How Public Health Data Derive from the Clinical Process

The patient data in the provider’s office can be stored as a paper-file system or as an electronic patient medical record (EPMR) data system/database (DB). For example, in Johns Hopkins Hospital, each department included in this project has EPMR data systems, *i.e.*, JHH Labor and Delivery Ward’s EPMR - *Marquette System*TM (Attachment 1, Forms 1-3), and JHH Outpatient Pediatric Harriet Lane Clinic’s EPMR – *Clicktate System*TM (Attachment 1, Forms 4-8). However, these systems were custom-made for each department and do not currently allow for electronic data interchange between them. A mother and her child discharged from the JHH Labor and Delivery Ward are provided with a paper discharge record for the infant (Attachment 1, Form 3) that she is supposed to bring at the first routine visit to the JHH Outpatient Pediatric clinic or other primary care provider.

Clinical Setting/Public Health Agency Data Exchange - Current Status.

The Hospital of Birth sends forms to the following DHMH programs (Attachment 1: Forms 9-12, respectively):

	Childs’ Age	Form Type	DHMH Office
1	After 24 hours at discharge (usually 36-48 hours)	1 st Newborn Screening Form with the Blood Spot Sample (including the Newborn Hearing Test results)	Office for Genetics and Children with Special Health Care Needs
2	At discharge	Infant Identification and Referral Form	Division of Vital Records
3	At discharge	Report on <i>hepB</i> #1	Center for Immunization
4	At discharge	Sentinel Birth Defect Report	Office for Genetics and Children with Special Health Care Needs

The Outpatient Pediatric Clinic/Provider sends forms to the to the following DHMH programs (Attachment 1: Forms 14, 12, and 15, respectively):

	Childs’ Age	Form Type	DHMH Office
1	2 week (1-4 weeks), usually at 1 st visit	2 nd Newborn Screening Form with the Blood Spot Sample	Office for Genetics and Children with Special Health Care Needs
2	Continuously as per the immunization schedule	Report on Immunizations	Center for Immunization
3	5 year of age to enroll a child in to kindergarten	Health Inventory	Maryland Department of Human Resources

Fig. 2 represents two scenarios of data exchange between clinical setting and public health agency. The first scenario (Fig.2a) shows the current workflow for data reporting from the HCP's patient medical record system (Patient DB) at the Hospital of Birth to four public health programs DBs/registries relevant to the selected domains: Newborn Screening DB, Vital records DB, Birth Defect Registry and Immunization Registry.

The following eight data management activities are performed at the clinical encounter to populate Patient DB:

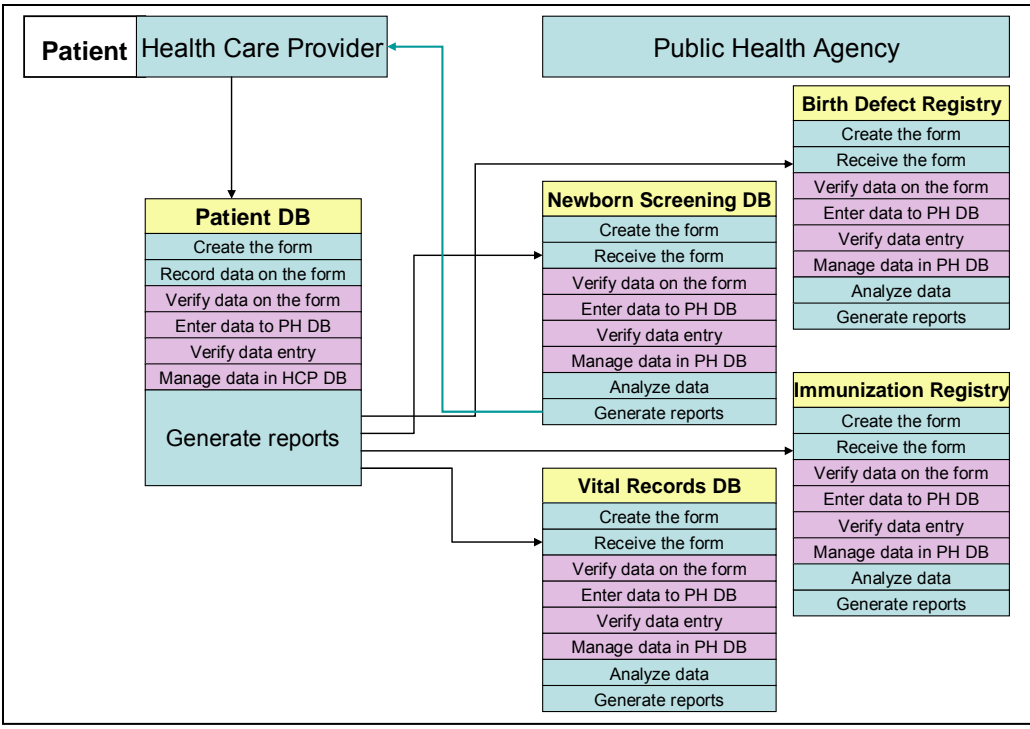
- 1 - Create the form;
- 2 - Record data on the form;
- 3 - Verify data on the form;
- 4 - Enter data to the HCP's Patient Database;
- 5 - Verify data entry;
- 6 - Maintain data in the DB;
- 7 - Conduct data analysis;
- 8 - Generate reports.

Activity 8 - Generate reports - includes tasks of filling out forms (a) for internal use, *i.e.*, reimbursement forms; (b) to provide educational materials to patient, *e.g.*, immunization leaflet; and (c) to fill forms for external users, *e.g.*, public health agencies as described above. While some internal reports are generated electronically, data interchange with other departments within a setting, another clinical care setting and public health agency are mostly done via paper forms sent by mail, fax or courier.

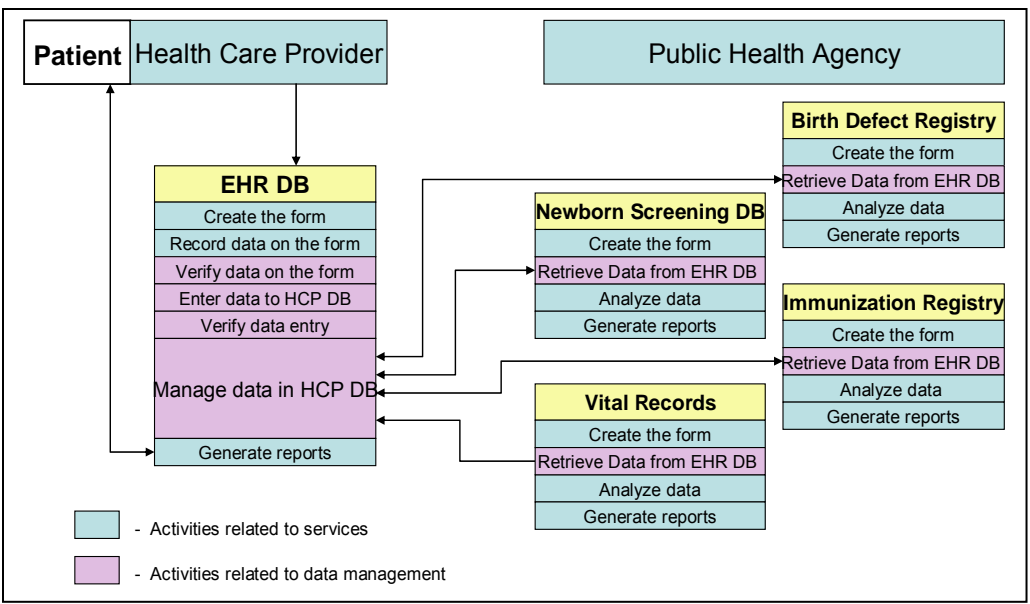
The external forms are created by receiver, *i.e.*, state public health agency. Significant efforts are required to collect them from HCPs including legislative interventions to facilitate the data reporting process, *e.g.*, mandating newborn screening specimens in the State of Maryland.

The HCP reports data to several public health programs within an agency that requires completion of different forms for different programs at different times. Optimization of this process by combining data from different programs into one paper form is not an easy task. For example, the DHMH added the hearing test result to the 1st hereditary metabolic disorder form (Attachment 1, Form 9) to be able to receive newborn data from the Hospital of Birth on one form. This practice is also in use in other states. However, recoding information on both tests on one form creates a burden for the HCPs because it is not supported by their workflow. The newborn hearing test and blood spot specimen collection is conducted by different specialists and at different points in time, *i.e.*, at birth and before discharge, respectively. In some cases, the HCP sends data to both local and state public health agencies on the same subject simultaneously, *e.g.*, city immunization registry and state immunization registry which use different forms.

Each program within a public health agency has its own customized data system/DB designed to meet programmatic needs. While databases within one program can be interoperable, *e.g.*, DHMH Newborn Screening and Infant Hearing Screening databases, systems from different programs are silo-type and not interoperable, *e.g.*, DHMH Newborn Screening, Immunization Registry and Vital Record. The data interchange between programs, if any, is paper-based.



a



b

Fig.2 Workflow for Data Interchange between Clinical Setting and Public Health Agency: a – current workflow; b- EHR-based workflow.

Each public health program completes the same cycle of eight data management activities to input data into their customized data systems as follows:

- 1 - Create the form;
- 2 – Collect the form (instead Record data on the form from the HCP Patient DB);
- 3 - Verify data on the form;
- 4 - Enter data to the DB;
- 5 – Verify data entry;
- 6 – Maintain data in the DB;
- 7 - Conduct data analysis;
- 8 - Generate reports.

Fig.2a captures the duplication of data management activities, i.e., repeated data input, across HCP and public health settings.

Clinical-Public Health Data Interchange: EHR-Based Option. Fig.2b represents a scenario of data interchange based on the PEHR-PH system. It shows that data management activities 2 through 6 are now performed at the HCP setting that maintains patient's EHR. Public health programs can retrieve data specified in their program-specific forms from the HCP's EHR System on as needed basis. This data retrieval will in turn support "Data analysis" and "Generate reports" activities within the public health program. HCP can have direct access to the results of public health data analysis and reports of interest, *e.g.*, community- and population-based health assessments, etc. Public health updates and/or alerts can be sent in real-time to the HCP office via the Web to inform about overall health status in the community (s)he serves.

DISCUSSION

Project Findings

Inventory of Data Forms created in this project (Attachment 1) contains seven forms used by the four public health programs (newborn screening, vital records, birth defects registry and immunization registry) that are relevant to the four selected domains. This inventory can further grow to include forms from other public health programs that are entering the child's life course, e.g., the blood lead test results forms reported to the state Blood Lead Registry; Emergency Department reports on injuries sent to the state Trauma Registry; HCP reports to the chronic disease state registries, e.g., Cancer Registry, Asthma Registry, Diabetes Registry, etc.; HCP reports to the communicable disease surveillance program. This data sources/form inventory, if grows, will help define specification requirements for a comprehensive list of public health data systems to be populated via the PEHR-PH system.

Cross-mapping of Clinical and Public Health Data from forms that are currently in use by JHH and DHMH (Attachment 2) shows that pediatric data housed by the clinical system is a significant source of data for the four selected public health domains (Table 2). Similarity/identity of data concepts used in clinical care and public health related to an individual patient care across selected domains (59%) allows aligning these data concepts to support the continuum of data interchange between clinical and public health settings via the PEHR-PH systems in the future. Example of overlap of 56% of demographic data fields across clinical care and public health forms (Table 3) suggesting that efforts to eliminate this overlap by a single electronic record would be worthwhile.

Documenting the similarities across clinical and public health data and data overlap can be useful for data linkages in the absence of a unique identifier across forms. This strategy is in use in a data linkage project at the University of Tennessee. [33]

Analysis of data fields across forms suggests further analysis of data concepts meaning and hierarchy to capture domain data needs in the PEHR-PH. For example, the Immunization registry form (Attachment 1, Form #12) does not record data on the current use of medication; therefore, "**Current Medications**" is not checked as data needed for the Immunization domain (Table 2). Current medication use, however, can cause "**Medical Contraindications**" - a section on the Immunization form where the information about current medication can be recorded in a free text format, so child can be exempt from a particular immunization.

Another example is **Allergies** data. Currently "Allergies" data are recorded in a check box format on the New Patient History Form (Attachment 1, Form 5) under the "Past Illnesses" data concept sub-class together with five other illnesses, i.e., chicken pox, asthma, eczema, high lead, anemia. It is also recorded on the Health Inventory Form (Attachment 1, Form 15), in a Yes/No check format, followed by the free text description if Yes is checked. Taking into account potential medical problems due to allergic response to a certain medication, consideration should be given for having a separate data sub-class "Allergies" under the Patient Medical History data concept as it exists for Injuries or Immunization in the pediatric EHR.

One data concept, *Economic*, was identified as domain-specific, *i.e.*, growth and development (Table 2). The family *income* data is requested on two forms such as the New Patient (Attachment 1, Form 5) and the Infant Identification and Referral (Attachment 1, Form 10). While the income is an important indicator of health care delivery outcomes that affects every domain of care, it is sensitive information that patient/parent-respondent usually hesitate to provide. The information on family income however can be obtained indirectly from the *Health Insurance (Payer)* information that is a consistent data concept used in the four selected domains. Payer information is also important for policymakers to evaluate health care delivery and services and for researchers examining effects of payment policy. It is necessary to compare data across different insurers, however, reporting standards for payer information is lacking across public health programs. [34]

The "*Race/Ethnicity*" data are of concern. According to the Office of Management and Budget, ethnicity is defined as "Hispanic or Latino" or "Not Hispanic or Latino"[35] - this is how "ethnicity" data are presented in federal data sources (survey data) - although it can be defined with greater details, *e.g.*, Mexican American, Cuban, Puerto Rican under the Hispanic category, and hundreds of other non-Hispanic ethnicities. A number of national surveys, including some CDC and Maternal/Child Health databases, are listing *ethnicity* as "Hispanic or Non-Hispanic ancestry" to complement the race (Caucasian, African-American, etc.) category. In other databases race and ethnicity fields are present, but the ethnicity field is not completed.

The Population Health Panel on Race, Ethnicity and Socioeconomic of the National Committee of Vital and Health Statistics discussed the reasons for confusion about race and ethnicity. [36] *Race* is the categorization of parts of a population based on the physical appearance of people due to particular historical, social and political forces. It has no genetic basis. To understand the biological variation among humans, the idea of a cline is used - a single trait genetic gradient over space and different environments. *Ethnicity* is the quality of being from an ethnic group, a sub-cultural group of a multicultural society, usually based on a common national or tribal heritage. Culture is learned, not inherited, and it is based on multiple factors and influences. Ethnic groups are not necessarily tied to specific geographic locations. Both ethnicity and race are subjective and situationally variable. Not everyone in an ethnic group shares the same culture; race does not equal ethnicity; and not all ethnic group members are necessarily the same race.

The Panel stressed that while these are social constructs, race and ethnicity are important for data collection because they are significant in health and in society. From research perspectives race does say something about one's position in society and in power hierarchy, it can be used to study biases and understand health risks, discrimination and disparities. Ethnicity is useful in understanding behavior. Research shows that these variables do make a difference on health, notably in research showing the effect of race and sex on provider behavior. Therefore, it is important to collect data on race and ethnicity. [37] However, further efforts are needed to agree upon the terms, a standard format to record race and ethnicity data and how to use them to monitor and improve population health.

Can HCP provide the "*Census Track #*" data? Census track data can be seen as a less granular representation of data pertaining to the patient's residence. Because unidirectional translation of residence information exist (street and zip code can be translated into census track, however the

reverse is not true), census track data should be considered meta-data, *i.e.*, residence information. The “Census Track #” information is needed for the aggregated data analysis for community-level health assessments and prevention interventions in public health.

HCP’s record contains patient address data including zip code number (Attachment 2 and Table 2). Patient does not usually know in which census track (s)he resides. Sources beyond patient medical record should be considered in identifying census track data that is available via the US Census Bureau Web-site and can be automatically linked to public health databases. However, public health systems may lack resources to do so, therefore, additional efforts are needed to have census data linked to these systems.

Analysis of Data Interchange between Clinical Care and Public Health programs shows the repeated data input at each clinical and public health encounter (Fig. 2a). Eliminating repeated data input of the same information both in clinical and public health systems via the EHR-PH (Fig.2b) can improve data accuracy, reduce time needed for data to become available and cost of labor, so the HCP can spend more time addressing healthcare needs for his(her) patient and the public health officer can focus on his(her) primarily tasks – the analysis of data and the development, implementation and evaluation of preventive interventions.

The PEHR-PH systems can help building bi-directional data and information exchange between point of care and public health programs. In general, current information return from public health agency to HCP is limited, *e.g.*, due to the lack of infrastructure to provide real-time data and/or lack of understanding what public health data could be of interest to the HCP. The scope/content of real-time data interchange between HCP and public health can be determined by the nature of healthcare needs for a certain disease and the role of public health program(s) in addressing these needs. For example, the Newborn Screening program requires public health agency to report back to provider the test results as well as to provide a follow-up for children with abnormal results. For sickle cell anemia patients in Maryland, DHMH nurses are working with HCPs as one healthcare team providing health education and other services to patient and his(her) family. Fig.2a shows that information flows back from public health agency’s Genetic Disorder DB to the HCP. However, this communication is conducted via phone, mail, and fax. Web-based access to patient-related information is not available, *e.g.* in Maryland, due to HIPAA regulation that requires to conduct this exchange through secure channels that might not be compatible with or not available in public health agency and/or HCP office.

In the PEHR-PH systems data and information should flow both ways between HCP and public health officer to help coordinate patient care and community health efforts. For example, in the State of New York, the Electronic Birth Record (EBR) is currently in use. [37] In most hospitals it runs as a separate database or silo. With an EHR, the EBR might be automatically filled in and electronically sent to the state after verification by the HCP. Once the data is in the statewide EBR, HCPs should be able to access information in the State database if given permission by the parents. The EBR may be used to start the community health database. Building upon the EBR, pediatric EHR-PH system may further supplement or modify/verify the EBR as needed so late consequences of prenatal history or birth problems not apparent at birth such as cerebral palsy or retinopathy of the premature or mental retardation or late detected genetic problems such as cystic fibrosis can be added. Further, the prenatal EHRS can be integrated into the EBR and the

PEHR. Our analysis of the forms shows that public health forms call for a significant amount of maternal history data (*i.e.*, 40 data fields, 12%).

The PEHR-PH system can populate databases of other public health programs (Table 1) in addition to the four examples on Fig.2. The State of New York has a separate congenital malformation database that similarly could get information from the PEHR and be validated by continued information flow from the EHRS on diagnosis, development and testing over the first few years of life. Similar benefits might be achieved by integrating the EHRS with public health databases for lead (blood lead registries), infectious disease reporting, WIC, Early Intervention Programs (programs to help stimulate the development of high risk infants and pre-schoolers), public health nurse visits to high risk families, Child Protective Services (CPS), and home health care of high needs infants or preschoolers (with birth problems and/or chronic disease). [37]

An Indianapolis Network for Patient Care (INPC) can be considered as a potential prototype of clinical care/public health data interchange via the PEHR-PH system.[38] Started in 1972, the system currently includes all nine counties and the state public health department, HCPs at 20 sites, 300 specialists and 30 public school clinics in the Indianapolis metropolitan area. The INPC enables automated communication between HCPs and public health practitioners on a daily basis for reportable disease data. It was shown that “INPC’s laboratory reporting component captures up to 5 times more data than traditional paper- or fax-based reporting methods, and conveyed information in the timely fashion across a broad spectrum of reportable diseases”.

The PEHR-PH systems can also enable patient/parent/caregiver to have real-time access to his/her EHR. The *Health Inventory Form* (Attachment 1, Form 15) included in this analysis is usually completed by every provider for the Department of Education for every child of five years of age to enroll in a kindergarten, pre-school or school. Currently in Maryland, it is a 4 page paper form that is given to a parent to bring to the Department of Education’s office. We selected this form for analysis because its content represents a summary of a child’s health status at five years of age and can be considered as a prototype of a so-called Patient Health Report (or Card). The Patient Health Report (Card) can serve as a patient medical history summary that patient/parent/caregiver can access via the EHR system. The *Health Inventory Form* also represents a part of the HCP workflow and is a tool of communication between HCP and another agency – Department of Education - which should be thought of as a public health stakeholder in the PEHR-PH system development process.

Needs for Standardization. Given the similarity and overlap of data needs across clinical and public health forms, the variety of data formats across forms, the need for further aligning meanings of concepts in clinical medicine and in public health, the benefits of eliminating the repeated data input and of bi-directional data interchange between clinical and public health data systems, there is a need for standardization. The exact type of standardization cannot yet be recommended. Three complimentary strategies are possible: (1) engagement with the clinical community and use of clinical standards; (2) development of public-health specific standards; (3) defining an interface between the two communities.

The similarity/identity of clinical and public health data needs demonstrated in this study suggests that public health should be involved in the clinical data standardization effort and work towards the adoption of (1) current clinical standards, *e.g.*, HL7 messaging standard and LOINC laboratory data standard and (2) clinical terminology standards, *e.g.*, SNOMED - Clinical Terms (SNOMED-CT) and other vocabularies in the Unified Medical Language System (UMLS).

Public health community should also participate in the further standard development efforts in clinical care, *e.g.*, Continuity of Care Record (CCR) standard that is under development by the ASTM E31 Committee on Healthcare Informatics [17], and the pediatric EHR content standard. Mapping is necessary from SNOMED-CT to classifications more typically used in public health, *e.g.*, ICD-9-CM (and eventually ICD-10-CM). In addition, the development of protocols and implementation guidelines is needed to enable HCPs and public health practitioners to (a) formally adopt the standards, standardized vocabularies and data formats and (b) integrate them into the workflow for provision of care to an individual patient and for public health services to improve health outcomes of the community, where they both serve.

Consideration also should be given to including the capacity to capture functional status information using the International Classification of Functioning, Disability and Health - Children and Youth (ICF-CY) codes. The ICF-CY is in the final stages of pilot testing and will provide an international standard for important domains not covered by International Classification of Diseases (ICD) standards but nonetheless very important for developmental assessments, etc.[39] Given the adoption of ICF by the World Health Organization in 2001, its consideration as a standard within the CHI, and the current sparse use of such information, the ICF-CY could definitely boost the PEHR-PH to the forefront of public health models. For example, in the State of Tennessee, there are efforts underway to incorporate ICF-CY within the electronic child health profile projects. [33]

With regards to standardization of population-based data and data sources that are beyond the clinical encounter, *e.g.*, occupational health data, environmental data, housing data, etc., the following efforts are needed within the public health community: (1) to define data sources that are of interest for public health services and research beyond clinical data sources; (2) conduct an inventory of current standardization efforts within these sources; and (3) integrate these efforts in the clinical data standardization processes. These efforts are critical for the development of public health vocabulary standards that might include vocabularies and terminology standards that are beyond clinical vocabularies.

Towards EHR Systems - Barriers to Overcome

Ultimately, the PEHR-PH strategies ought to improve the health care and population-based services delivery and in turn health of patients and the public's health. Patient information will be available in diverse sites, tools such as clinical decision support and provider order entry tied to EHRs will reduce medical errors. Health care payers are to gain as well. By obtaining aggregated community- and/or population-level information electronically, they will be able to plan healthcare costs and service delivery. And government and public health agencies who are eager to obtain data to fulfill their mandated tasks will be winners. There are, however, barriers that have to be overcome in order to implement integrated EHR-PH systems. Some of those barriers are described below.

Cost-Benefit Factors. The Return on Investment for those making the investment in EHRS has not been proven. The group that pays the largest price tag for the implementation of EHRS, i.e., purchasing, maintenance and most importantly change in workflow, is HCPs. There is an assumption that better practice of medicine as enforced by EHR-based clinical decision support would reduce malpractice claims, however at this point there is no evidence that large insurers are reducing malpractice insurance rates based on implementation of EHRS.

Our analysis shows that HCP and public health practitioner are burden with a huge data collection and communication effort (Fig.2a) for which they are rewarded (at least at present) with little or no benefit. Communicating data to public health agencies and from public health agency to HCP is not reimbursed. Unless, HCPs are convinced that the introduction of EHRS offers tangible benefits to their practice, implementation will continue to lag behind other countries.

Computer Literacy of HCPs. The 2003 survey with significant selection bias towards computer literate providers, shows that only 24% of family practitioners use a computer-based system to maintain patient record. Because of low computer literacy of HCPs large investments will be required for purchasing EHRS, data entry and personnel training. Data entry is a time consuming practice. For a busy physician any additional requirements of data entry exceeding the already existing work processes would be a significant burden and would pose a major barrier. In order for the EHR to assist public health agencies in extracting relevant data as well as producing population assessment information, the additional burden to physicians must be minimal or their must be built in incentives to the physician or provider that will generate value for the clinician. Another critical issue is to assure that EHRS products that are available for provider's office can support bi-directional data interchange between HCP and public health agency via electronic channels.

Silos-based Infrastructure. Barriers are now present in data stored in different "silos" in different formats that should eventually be integrated and interoperable. This equally relates to clinical setting "silos" and public health "silos". While clinical "silos" are mostly of an administrative nature, public health "silos" (Table 1 and Fig.2) are also of a knowledge-based nature and therefore could be even more difficult to overcome. Over the last 40 years, a categorical disease-specialized domain approach has been utilized in public health, i.e., communicable diseases, lead poisoning, injury, community-based mental health, substance abuse, bioterrorism, etc. [40] In addition to the early childhood programs listed in Table 1, public health agencies provide services (personal health and population-based health) in over 20 various programs.[41]

This domain-specific organization of public health is currently supported by the structure of funding allocations, by the organizational structure of public health agencies, by training of the workforce, by the structure of data collection and by information system development and operation. [42] "The current system of categorical programs, including independent information management systems, may serve the objectives of individual programs. However, on a broader level, it is inefficient, requires collection of duplicative information, and leads to fragmented services. [18]

In addition to the programmatic fragmentation of public health, there is an organizational diversity of public health agencies that follow state political structure of jurisdictions and/or the public health services delivery workflow. There are four models for organizational structure in public health: (1) public health is represented by balanced infrastructure of both state and local health agencies; (2) the state health agency plays the key role in delivering services to communities; (3) local health departments take the leading role; and (4) health coalitions - public/private partnerships - provide delivery of public health services, *e.g.*, immunization coalitions – community-based groups that include parents. [43]

We presented workflow and dataflow within the four selected data systems of a public health agency (Fig.2) without specifying the type of agency, *i.e.*, State, Local or Public/Private partnership. In fact, in Maryland, different public health programs operate under different models. The Newborn Screening is a state health program. The Immunization Registries (IRs) exist in local health departments as well as at the state health agency - DHMH. While the Baltimore City Health Department has an electronic IR that allows an electronic data transfer from HCPs, *e.g.*, JHH, there is no electronic data exchange between HCPs and DHMH' IR as well as between DHMH and BCHD IRs.

Programmatic fragmentation and organizational diversity of public health are the main challenges to the implementation of EHR-PH system for the integration of clinical and public health data and systems.

Privacy and Security Measures. Societal fears of losing privacy via EHR systems must be addressed. In particular, sensitive information, *e.g.*, genetic, mental health and behavior, must be kept confidential and can be made available for confidential use on a strict need to know basis only. [12] To protect individuals from identity theft and to ensure the privacy and security of data in EHRS, biometric identity verification, PIN (personal identification numbers), smart cards, or communication devices (*i.e.*, registered/linked computers) may be used depending on the level of sensitivity of the data and the security needed. This will take a new commitment by society to secure and defend cyber space and give up some privacy for the benefit of the common good. Laws, rules and regulations must be designed to ensure that privacy will be protected within statewide databases, *e.g.* STD databases, and that private information will only be used by a n authorized personnel to prevent disease outbreaks and other public health threats. Releasing information to others unnecessarily must be avoided. [37]

Future Agenda

We suggest that the development of the PEHR-PH systems should include the following activities:

1. **Cross-mapping Public Health and Clinical Care Data** – Cross-mapping data needs (present and future) of other public health domains against data that are either available today or could be made available from the clinical EHRS is a necessary step for the PEHR data content standard development process. Mapping the public health program data needs will enable the public health and clinical health care information exchange via the EHR-based regional health information exchange organizations.
2. **Standards** - The public health community should continue to participate in the clinical care standard development efforts, *e.g.*, pediatric EHR content standard, Continuity of

Care Record standard, ICD-9/ICD-10-CM, SNOMED-CT and LOINC terminology standards and messaging standards. In addition, the development of protocols and implementation guidelines is needed to enable health care providers and public health practitioners (a) to formally adopt the standards, standardized vocabularies and data formats and (b) to integrate them into the workflow for provision of care to an individual patient and for public health services to improve community health outcomes, where they both practice. Standardization efforts should take into account the information structures of other RHIE stakeholders to allow the flow of relevant information to the EHRs, *e.g.*, environmental data, housing data, geographic data, ecological data, etc.[10]

3. **Overcoming Data Silos in Public Health** - Integrating currently separate public health databases will have benefits for both public health and clinical practitioners. The richness of data from providers populating public health databases is squandered if the data ends up being fragmented in public health agencies. Therefore, efforts to precisely identify how integrated EHR-PH systems can remove silos will be rewarded. For example, further work is needed to better understand the programmatic and organizational relationship between state and local health departments in terms of workflow and dataflow. Understanding commonalities of dataflow and workflow across (1) public health programs, (2) various organizational structures of health agencies and health coalitions and (3) the entire health care delivery system is a key step in integrating health-related data and systems.

CONCLUSIONS

This report represents a structured approach for describing data interchange between clinical care providers and public health agency for the purpose of contributing to the development of the EHR-based pediatric care. In this effort we are not determining what the information needs of public health in general are, but exploring a way to better understand what data requests from public health perspectives could be obtained via the PEHR systems in the four selected domains of pediatric care, *i.e.*, newborn screening, immunization, growth and development and chronic disease care, and where the PEHR would have to be supplemented to enable this exchange. This project can be considered as a first step in the development of a minimum data content requirements for the pediatric EHR from public health perspectives.

This work is based on the comparison of data forms and data interchange between one clinical care setting (JHH) and one public health agency (DHMH). However, we believe that our approach can be generalizable to other clinical settings and public health agencies. While the work organization in various clinical settings and in turn in various public health settings vary, the mission and content of pediatric care provided by both clinical care and public health are common – to serve the best interest of the patient. In this context, our approach in understanding of commonalities of data concepts across clinical care and public health programs can be useful for other clinical settings and public health agencies to better understand the clinical care/public health data interchange via the EHR-based systems. The same approach is currently under consideration by the HL7 PEHR SIG to be used for the development of the pediatric EHR data standard.

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ATTACHMENT 1: Form Inventory

#	Form is Generated at			Form Name	Form ID	Care Setting	
	Child's Age	Visit Type	Setting Type			Clinical Setting/ Agency	Department/Division/ Office
Hospital of Birth							
1	0	Delivery and newborn course	Hospital of Birth	Delivery Room Note		Johns Hopkins Hospital	Labor & Delivery
2	0			Record of Newborn Infant	06-936-0006		
3	36-48 hours			Physician Discharge Orders	15-040001		
Pediatric Outpatient Clinic/Pediatrician							
4	<i>Each Visit</i>	Health maintenance & well child care/ Scheduled visits	Outpatient	Encounter Form	JHH 04-7029	Johns Hopkins Hospital	Harriet Lane Outpatient Clinic
5	<i>1st Visit</i>			New Patient History Form	JHH-04-659-0004		
6	2 weeks (1-4 weeks)			2W	JHH-X04-0001-2W		
7	2 month			2M	JHH-X04-0002-2M		
8	6 months			6M	JHH-X04-0004-6M		
Public Health Agency							
9	After 24 hours: 36-48 hours	Delivery and newborn course	Hospital of Birth	Hereditary Metabolic Disorders (Initial Specimen) and Hearing Test Results	DHMH 77	DHMH Family Health Admin.& Laboratories Administration	Office of Genetics and Children with Special Health Care Needs (OGCSHCN)
10	36-48 hours		Hospital of Birth	Infant Identification and Referral	DHMH 4349		
11	72 hours		PH Agency	Certificate of Live Birth	DHMH 15		
12	36-48 hours		Hospital of Birth	Maryland Immunization Certificate	DHMH 896	DHMH Community Health Admin.	Center for Immunization
13	36-48 hours + 5 days of discharge		Hospital of Birth	Sentinel Birth Defects Report	DHMH 272	DHMH Family Health Administration	Birth Defects Reporting and Information System, OGCSHCN
14	2 weeks (1-4 weeks)	1 st Scheduled visit	Outpatient	Hereditary Metabolic Disorders (Subsequent Specimen)	DHMH 79	DHMH Family Administration.& Laboratories Administration	OGCSHCN
15	5 years	Scheduled visit	Outpatient	Health Inventory	OHR/CCA 1215	Department of Human Resources	Child Care Administration

ATTACHMENT 2. Map of Pediatric Clinical and Public Health Data Concepts by Form (provided as a separate Excel spreadsheet)

APPENDIX: Copies of the Clinical and Public Health Forms Used in the Form Inventory
(provided as hard copies)