Advancing Patient-Centered Pediatric Care Through Health Information Exchange: Update From the American Health Information Community Personalized Health Care Workgroup

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ABSTRACT
The Personalized Health Care Workgroup of the American Health Information Community was formed to foster a broad, community-based approach to facilitate the incorporation of interoperable, clinically useful, genetic/genomic information and analytical tools into electronic health records, to support clinical decision-making. The Personalized Health Care Workgroup has developed a series of use cases that outline the informational needs of multiple stakeholders (eg, patients, clinicians, organizations, and systems) and describe the information systems necessary to connect these stakeholders at multiple levels. These use case scenarios offer a guide for standardized data elements and architecture that enable interoperability (content sharing) among different formats of patient electronic health records. Pediatrics 2009;123:S122–S124

ADVANCES IN THE scientific understanding of health and disease, coupled with technological achievements to integrate health information across different systems, have opened the door to health care practices focused on individual patient needs. Personalized approaches to health care that are focused on individualized and biologically based differences among patients offer the potential to improve the quality and accuracy of patient care while streamlining its delivery. However, systemic barriers and challenges to adapting personalized medicine approaches to clinical settings necessitate multilayered policy interventions. To provide federal leadership for this transformation, the US Department of Health and Human Services recently undertook its Personalized Health Care Initiative, based on the cornerstones of an understanding of the genetic basis of disease, widespread health information technology (HIT), increased effectiveness, and improved quality of care. As a result of this initiative, health care practices should be better able to prevent, to preempt, and to predict disease and should empower consumers to participate in decision-making. As presented in a recently published US Department of Health and Human Services report, the Personalized Health Care Initiative supports the transmission of basic scientific research on the molecular and genetic “fingerprints” of disease predisposition and progression through health care information exchange to improve patient care. The initiative has 4 initial goals, namely, (1) to link clinical and genomic information to support personalized health care (PHC), (2) to protect individuals from discrimination based on unauthorized use of genetic information, (3) to ensure the accuracy and clinical validity of genetic tests performed for medical application purposes, and (4) to develop common practices for accessing genomic databases created through federally sponsored programs.

For pediatric health care, outcomes research may lead to new approaches to prevention, may enable anticipatory guidance and other behavioral interventions, may provide opportunities to address health disparities, and may facilitate consumer (parental) engagement in health care. By encouraging the development of standards for data elements in electronic health records (EHR), the initiative promotes the incorporation of information from genetic tests, such as newborn screening tests, pharmacogenetic assays, and molecular genotyping of pathology specimens. Moreover, the initiative’s multifaceted approach contributes to the concept of the medical home, an integrated comprehensive system of primary health care services that focuses on the child’s well-being within a family context.

In addressing the linkage of genetic and clinical information, several efforts are underway to enable electronic exchange of information to support health care providers’ and consumers’ needs. In 2005, the American Health Information Community (AHIC) was established by the Secretary of Health and Human Services to develop standards and to improve networking capabilities necessary to accelerate the integration and adoption of HIT standards into vendor EHR platforms. In 2006, a PHC Workgroup of the AHIC was formed to foster a broad,
community-based approach to facilitate the incorporation of interoperable, clinically useful, genetic/genomic information and analytical tools into EHRs, to support clinical decision-making. Framing its discussions within the context of genetic/genomic testing, family health history, confidentiality, privacy, and security, and clinical decision support, the PHC Workgroup is assessing the needs of HIT developers, implementers, and users. To this end, the PHC Workgroup has developed a series of use cases that outline the informational needs of multiple stakeholders (eg, patients, clinicians, organizations, and systems) and describe the information systems necessary to connect these stakeholders at multiple levels. These use case scenarios offer a guide for standardized data elements and architecture that enable interoperability (content sharing) among different formats of patient EHRs. The AHIC process is based on the development of use cases that address the needs of all stakeholders for certain types of information and the actions that may be taken as a result of the availability of the information (a prototype AHIC use case that outlines information flow from clinical assessment to management is available at www.hhs.gov/healthit/documents/PersonalizedHealthcarePrototypeUseCase.pdf).

Standards related to common genetic tests and a core data set for family health history are being developed to facilitate the interoperability of various HIT platforms, which would increase the utility of platforms that use these standards. Therefore, EHR vendors would have an incentive to incorporate these standards and concepts into their products. As these products are implemented in primary care, an individual’s health record would become more portable. In addition to providing the individual with greater control over his or her record, this portability could facilitate appropriate access by multiple health care providers for care applications. The platforms supported by this approach could facilitate health information exchange and maintain flexibility for clinicians, allowing them to use a broad array of HIT tools in their practices. In addition to facilitating standards development, AHIC recommendations provide incentives for adoption through the use of federal purchasing power to require that financial and health care transactions use standardized certified EHR systems.

Interoperability standards to facilitate the electronic exchange of genetic, biochemical, and auditory newborn screening test results could affect pediatric health care directly by improving the interface between population-based health screening and individual primary care treatment. The exchange of newborn screening information is currently more complicated than the situation encountered with other types of standard medical tests, such as routine blood chemistry tests, because of the diversity of state-based newborn screening processes and privacy laws. At present, there are no vendor-, state-, or public health laboratory-based information systems that support direct exchange of newborn screening information with providers and patients, although many states have established registries that are Internet-accessible. The development of HIT standards could establish a foundation for broad-based use of the EHR for reporting of newborn screening results and associated information to guide patient management and could improve communication between public health laboratories, health care providers, hospitals, referral centers, and state registries. By considering the interests and needs of each of these stakeholders when developing use cases, the AHIC PHC Workgroup can stimulate discussion regarding the specific needs of newborn screening.

The prioritization activities of the PHC Workgroup augment the work of other HIT standards development and HIT organizations, including the Systematized Nomenclature of Medicine Clinical Terminology group, Health Level 7, and the Clinical Data Interchange Standards Consortium. These groups are currently developing standards and nomenclatures to incorporate electronic laboratory data associated with genetic/genomic testing into the EHR. To avoid duplication of effort, the AHIC PHC Workgroup recognizes that the development of a working set of interoperable standards for newborn screening information must take into account the efforts that are currently underway.

Standards also would facilitate the deployment of clinical decision support, an approach that provides clinicians, medical staff members, and patients with individually tailored, interactive, electronic information that can be filtered or presented at appropriate times to enhance health and health care. Clinical decision support tools, such as electronic alerts and reminders, clinical guidelines, order sets, patient data reports and dashboards, documentation templates, diagnostic support, and clinical workflow tools, can support the dissemination of newborn screening information. These tools have the ability to educate providers and patients and to inform medical management at the point of care. The development and deployment of clinical decision support tools must consider the needs of the individual clinical practice, including specific practice needs, information workflow, and the practice environment.

In the case of newborn screening test information, a typical use case may include several components. First, a panel of metabolic, genetic, and biochemical assays are performed as mandated by state requirements. This information, gathered by using institutional protocols and standard operating procedures, is reported to the health care provider and is transmitted to state public health registries. It is then accessed by the appropriate clinicians to develop a care management plan, supported by educational material and clinical decision support tools. On the basis of this information, the clinician may order additional laboratory tests, each of which has an associated flow of information. The laboratory performs the tests, develops a report, and transmits this information back to authorized health care providers. While the clinician uses this new diagnostic screening test information to inform patient management, the information also may support the efforts of case managers who are assigned as necessary. The screening tests results prompt confirmatory tests to be performed and/or interventions to be initiated. In addition, this information is captured in public health registries that gather and analyze epidemiological data. In this scenario, the clinician and the
parent have access to this information via the EHR. Throughout this process, however, the parent must be informed and empowered with respect to medical management but must feel confident that information is being exchanged privately and with appropriate levels of security.

This hypothetical example illustrates the spectrum of stakeholders involved when information about newborn screening results is exchanged. The AHIC PHC Workgroup recognizes that newborn screening information is one component of a larger body of related data for pediatric patients, including immunizations and well-child examinations. Development of standards for the electronic exchange of this information among appropriate parties represents the first step in a pathway for communities as they develop local HIT platforms to organize their health care delivery.

The development of interoperable systems and standards for the exchange of information on genetic, biochemical, and auditory newborn screening tests could affect pediatric health care directly. The electronic exchange of such information would improve the interface of population-based health screening with individual primary care treatment. Resolving the numerous issues of interoperability, confidentiality, security, and utility of electronically exchanged information will take time and necessitate the cooperative efforts of all sectors of the health care enterprise. However, overcoming barriers to health information exchange could improve health care by empowering parents in the management of their child’s health care, enhancing information transfer efficiency, and reducing systemic burdens.

Building on these priorities, additional data elements for primary pediatric care, such as growth and development milestones, immunization records, nutritional information, and other primary pediatric health care elements, need to be addressed for standards development. As HIT development and adoption proceed in parallel with policies that facilitate information sharing and protection, improvements in quality of care should occur through health care decision-making that is evidence-based and patient-centered.

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