

White Paper ■

## Advancing Personalized Health Care through Health Information Technology: An Update from the American Health Information Community's Personalized Health Care Workgroup

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**Abstract** The Personalized Health Care Workgroup of the American Health Information Community was formed to determine what is needed to promote standard reporting and incorporation of medical genetic/genomic tests and family health history data in electronic health records. The Workgroup has examined and clarified a range of issues related to this information, including interoperability standards and requirements for confidentiality, privacy, and security, in the course of developing recommendations to facilitate its capture, storage, transmission, and use in clinical decision support. The Workgroup is one of several appointed by the American Health Information Community to study high-priority issues related to the implementation of interoperable electronic health records in the United States. It is also a component of the U.S. Department of Health and Human Services' Personalized Health Care Initiative, which is designed to create a foundation upon which information technology that supports personalized, predictive, and pre-emptive health care can be built.

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### Setting Policy for Standards Development: The Role of the American Health Information Community's Personalized Health Care Workgroup

The inclusion of genetic/genomic information in electronic health records should inform the determination of disease risk, appropriate drug dosing to avoid adverse events, and

selection of effective treatment.<sup>1–3</sup> As clinical applications of this information become more prevalent, genomic technologies will increasingly impact health information technology (IT) platforms, particularly electronic health records (EHR) developed within the health care system and personal health records (PHR) controlled by individuals. Both types of records may include elements of family health history and an individual's genetic/genomic makeup. Innovative strategies are needed to manage the diverse genetic/genomic data required to realize the benefits of individualized approaches to health care. The application of health IT to support the effective integration of genetic/genomic information in routine clinical care will require broad access, appropriate privacy and security measures, and data storage and transmission capabilities to connect the patient, laboratory, clinician, and researcher. As health care providers and consumers use EHRs and PHRs to support health care management and decision-making, there will be an increasing need for standards, best practices, and accepted protocols for efficient test ordering, performance, reporting, and interpretation of genetic information.<sup>4</sup>

Realizing the potential of personalized medicine in clinical practice will require multilayered policy interventions to overcome systemic barriers and challenges.<sup>5,6</sup> To provide Federal leadership for this transformation, the U.S. Department of Health and Human Services has recently undertaken its Personalized Health Care Initiative.<sup>7</sup> As part of this Initiative, the American Health Information Community's (AHIC)<sup>8</sup> Personalized Health Care (PHC) Workgroup is work-

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ing to inform policy on the development of interoperable standards, a stepping stone to the deployment of the processes, databases, and methods that will underpin future health care practices.

The AHIC was established in 2005 to accelerate the adoption of health IT through standards development and improved networking capabilities. The Office of the National Coordinator for Health IT<sup>9</sup> provides support for the AHIC as well as coordination of U.S. Department of Health and Human Services activities for the development and nationwide implementation of an interoperable health IT infrastructure. In acknowledgement of the already-rapid pace of adoption of genetic/genomic tests and individualized approaches to health care, the PHC Workgroup of AHIC was established in 2006.<sup>10</sup> This Workgroup is charged with fostering 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 for the clinician and consumer. To this end, the PHC Workgroup is assessing the needs of health IT developers, implementers, and users.<sup>11</sup> The goal is to promote development of technical platforms that will reduce duplicative efforts, enable interoperable local applications, and provide an economic incentive for vendors to include genetic/genomic and family health history data in their health IT systems.

The PHC Workgroup's vision is a consumer-centric health system in which diagnostic, treatment, and management plans are customized based on a variety of factors, including culture, environment, preferences, personal and family health histories, and the individual's unique genetic/genomic makeup. This vision embraces the notion that consumers who have detailed information about their individualized options will participate more actively in the management of their health care practices. Underpinning the vision is the confluence of two powerful forces, the development of health IT and rapid advances in the basic understanding of the relationships between health, disease, genetics/genomics, and treatment options. Knowledge of an individual's genetic/genomic information may provide an exceptionally powerful tool to assist with disease prediction, diagnostic accuracy, targeted treatments, medication dosing, and health management.<sup>12</sup> However, the rapid development of commercially available genetic tests and other genomic technologies will almost certainly outpace both the availability of effective interventions for many conditions identified and the health care professional's acquisition of sufficient knowledge to guide their appropriate use.

The PHC Workgroup includes representation from a broad array of communities—consumers, clinicians, academic and Federal research institutions, Federal and private health care providers, diagnostics developers, pharmaceutical companies, and health care payers—that recognize that an individualized approach to health care can improve quality and outcomes. Achieving this personalized approach will require basic research, evidence development, evaluation of prevention and intervention protocols, and health maintenance activities. Workgroup members recognize that the transition toward a personalized approach to health care will require significant changes in health care delivery but believe that this enterprise offers tremendous potential to

improve care at all levels, especially at the interface between the health care provider and the patient.

### **Advancing Health IT Standardization and Adoption**

The AHIC has developed an iterative process to provide incentives to develop and adopt a diverse range of health IT products throughout the health care sector. This process provides context for detailed policy discussions, standards harmonization, certification considerations, and architecture specifications necessary to advance the national health IT agenda. Through the AHIC, workgroups have been convened to assess specific health information needs in seven areas: (1) consumer empowerment; (2) population health and clinical care connections; (3) chronic care; (4) electronic health records; (5) confidentiality, privacy, and security; (6) quality; and (7) personalized health care. Rather than developing a software system specific to the AHIC, the workgroups develop recommendations to address their broad and specific charges. This approach engages the Office of the National Coordinator for Health IT to develop use cases based on these recommendations that outline the needs of multiple stakeholders (e.g., patients, organizations, and systems) and describe the flow of information and the requisite information systems necessary to connect them at multiple levels. To date, 13 use cases have been published, each focusing on the exchange of information between organizations and systems rather than the internal activities of a particular organization or system, or the development of a specific software system.<sup>13</sup> The use cases strive to provide sufficient detail and context to support detailed policy discussions, standards harmonization, certification considerations, and architecture specifications. Candidate workflows within each use case describe how various perspectives interact and exchange information within the context of an overall workflow.

Based on the use cases, the Health Information Technology Standards Panel (HITSP)<sup>14</sup> then determines which standards have been developed for the requirements identified in the use cases. The HITSP is a cooperative public-private partnership whose mission is to achieve a widely accepted and useful set of standards to enable interoperability among different information systems, software applications, and networks. Established in 2005 based on a response to a Request for Proposals issued by the U.S. Department of Health and Human Services, HITSP is a standards organization accredited by the American National Standards Institute. The HITSP evaluates existing standards that are in use and works to harmonize them or identifies gaps that require additional standards development.

Following these use-case development and standards harmonization processes, the private, nonprofit Certification Commission for Healthcare Information Technology (CCHIT)<sup>15</sup> can then reference these priorities and standards as it develops specific compliance criteria and inspection processes for health IT systems. Founded in July 2004 in response to the Framework for Strategic Action released by the National Coordinator for Health IT, the Commission represents a collaboration of three health IT associations: the American Health Information Management Association, the Health Information and Management Systems Society, and the National Alliance for Health Information Technology. The

Commission rigorously tests software from applicant companies to establish that their systems can support and perform the required functions, exchange information with other systems, and maintain data confidentiality and security. Certification signals that an electronic health record system has met baseline requirements for application in clinical care, thereby accelerating adoption of compliant products by providers. As such, the certification process is an essential component of the broader strategy that includes AHIC, HITSP, and the development of a Nationwide Health Information Network architecture.

In drafting these use cases, the Workgroup recognizes that many organizations (e.g., Health Level Seven (HL7), Systematized Nomenclature of Medicine (SNOMED), Clinical Data Interchange Standards Consortium (CDISC) are currently developing standards and nomenclatures (e.g., Logical Observation Identifiers Names and Codes (LOINC), EHR-Lab Interoperability and Connectivity Specification (ELINCS) to accommodate the electronic handling of genetic/genomic information. These efforts have underscored the importance of bridging the clinical and research enterprises by fostering productive collaborations between Federal agencies, academic institutions, and standards development organizations. Although much work has been done to advance these genetic/genomic standards, the field continues to evolve in response to new technologies. Use cases were designed to accommodate current tools, with the understanding that novel approaches will adjust the workflows. The Workgroup therefore considers these use cases to be works in progress; as more genetic/genomic tools become integrated into primary care, discussions will expand to address the temporal and logistical constraints that these tools will impose.

### Priorities Identified by the PHC Workgroup

The PHC Workgroup holds monthly discussions informed by testimony from experts in standards development, genetics/genomics, laboratory testing procedures and systems, privacy concerns, tools and standards for family health history, and commercial and Federal EHR systems. A complete timeline of PHC activities and deliverables is provided in Table 1, and links to all PHC documents cited in this manuscript are provided in the Appendix (available as an online supplement at [www.jamia.org](http://www.jamia.org)).

In March 2007, the Workgroup outlined priorities for investigation and developed a vision of PHC from four user perspectives: the consumer, the clinician, the researcher, and the health plan/payer. Following this visioning session, the group identified the four priority areas of genetic/genomic tests; family health history; clinical decision support; and confidentiality, privacy, and security issues. The vision summary and priorities documents (available at [http://www.hhs.gov/healthit/ahic/healthcare/phc\\_archive.html](http://www.hhs.gov/healthit/ahic/healthcare/phc_archive.html)) were presented to the AHIC on April 24, 2007, and recommendations related to genetic/genomic tests and family health history were accepted by the AHIC on July 31, 2007.<sup>16</sup> These recommendations included:

- Developing a use case for PHC that describes the clinical use of common genetic/genomic tests in conjunction with family health history

**Table 1 ■ Timeline of AHIC PHC Workgroup Activities and Deliverables (October 2006 to March 2008)**

Date	Activity/Deliverable
October 2006	PHC Workgroup formed
March 2007	Visioning session and priority areas (Genetic/Genomic Tests; Family Health History; Confidentiality, Privacy, and Security; and Clinical Decision Support) identified for subgroup formation
April 2007	Vision and priorities presented to AHIC; Confidentiality, Privacy, and Security Subgroup formed
May 2007	Genetic/Genomic Test and Family Health History Subgroups formed
June 2007	Draft Genetic/Genomic Test Matrix completed
July 2007	First set of recommendations in the areas of genetic/genomic tests and family health history presented to and accepted by the AHIC
August 2007	Prototype PHC Use Case published for public comment
September 2007	All-day testimony on clinical decision support relevant to PHC
October 2007	Family Health History Core Dataset Report and Confidentiality, Privacy, and Security Subgroup white paper presented; Newborn Screening subgroup formed
January 2008	Draft PHC Detailed Use Case and Family Health History Dataset Requirements published for public comment
February 2008	Second set of PHC recommendations in the area of newborn screening presented to and accepted by the AHIC; Pharmacogenomic subgroup formed
March 2008	Final PHC Detailed Use Case and Family Health History Dataset Requirements Summary published

AHIC = American Health Information Community; PHC = personalized health care.

- Establishing a minimum core dataset for family health history
- Engaging with the U.S. Department of Health and Human Services and other Federal health care providers to support research activities to develop an improved knowledgebase of genetic information.

Efforts to date in these priority areas are summarized in the following sections. Each area features technical and research issues that require ongoing discussions and input, and updates on these efforts will be communicated and submitted in a timely fashion.

### Genetic/Genomic Tests

To incorporate clinically useful genetic/genomic information into the EHR, the Workgroup recommended developing a PHC use case that describes the process of performing a genetic/genomic test using current standards of care.<sup>11</sup> This process can be segmented into three distinct phases: (1) the preanalytic phase, which encompasses such events as determining which genetic/genomic test, if any, is appropriate to answer the clinical question being asked, collecting an appropriate sample, and transporting it to the test site;



(2) the analytic phase, which involves sample analysis; and (3) the postanalytic phase, which includes reporting and interpretation of results. The use case addresses the specific information needs and integrated data flow in these phases of genetic/genomic tests. Looking to the future, the Workgroup recognizes that chip-based genomic analysis techniques are evolving toward routine clinical application, and future standards activities will address workflows that incorporate these platforms.

To facilitate this use case development and the subsequent standards harmonization and identification process, the PHC Workgroup has developed a matrix describing the characteristics of genetic/genomic tests based on the type of biological analyte (e.g., DNA, RNA, protein/metabolite). This matrix categorized the type of output and type of analyte, and the workflow involved in the preanalytic, analytic, and postanalytic stages for each of these types of output. For example, a test examining DNA could include a full genome scan, a full genome sequence, a single gene sequence, or single nucleotide polymorphism (SNP) analysis. By examining the information requirements of various test types across all three phases of the testing process, a consensus list of common data needs was developed.<sup>11</sup> These resources will be used to support the development of standard metrics, terminology, language, and workflow processes.

### Family Health History

In addition to including genetic/genomic test information in the EHR, the PHC Workgroup recommended that the use case describe the incorporation of family health history to guide clinical care. Family health history is essential to interpret genetic/genomic data and will inform the need for genetic testing; therefore, combining genetic/genomic information with family health history will be necessary to fully capture predictive information that can promote preventive action and early detection of disease. Moreover, including family health history requirements in data standards repositories will expand the research potential of the data and facilitate the continuity of standards between clinical and research applications. To enable this process, the PHC Workgroup recommended that a multistakeholder workgroup, including the private sector, Federal health care providers, and Federal Public Health Service agencies, be formed to develop a core minimum data set and common data definitions for primary care collection of family health history information. This core data set was prepared over several months of meetings and was presented to the PHC Workgroup in October of 2007. The core data set is arranged in two main tables.<sup>17</sup> The first lists 28 data elements that the group thought should be incorporated into the family health history capabilities of PHRs and EHRs along with annotations describing the complexities of including particular items. In many cases, the group reached consensus on concepts or functions that should be represented in the EHR, but there were divergent views on how to achieve this. The second table identifies 13 additional items that the group thought should be optional for inclusion in the EHR. In some cases, elements were considered optional because of a lack of consensus among members about their value.

The AHIC PHC use case, which was released in final form on March 21, 2008, focuses on the exchange of personal health, family health history, and genetic/genomic testing information between consumers and clinicians in two scenarios: clinical assessment; and genetic testing, reporting, and clinical management.<sup>18</sup> Initially, the patient provides a family health history that is maintained in a PHR, and upon interaction with a health care provider, the information can be accessed and used by the clinician to develop a diagnostic plan. This plan may be shaped by a process that prioritizes information to inform the clinician about options. Based on this information, the clinician may order genetic/genomic tests. A genetic testing laboratory receives and captures the test orders and any necessary accompanying information. The laboratory performs the tests, develops a report, and transmits this information back to authorized health care providers. The clinician, along with a genetic counselor, can utilize this new diagnostic information to inform patient management. In this scenario, the clinician and the patient have access to this information via the EHR or PHR; as such, the information becomes embedded in these records.

### Confidentiality, Privacy, and Security

The Workgroup has drafted materials that discuss confidentiality, privacy, and security issues as they pertain to genetic/genomic test information in the EHR.<sup>19</sup> Characteristics of genetic/genomic test information were identified that should be considered when developing policies about information protection, including predictive capability, immutability, uniqueness, historical misuse, variability in public knowledge and perspective, impact on family, temporality, and ease of procurement of genetic material. Although any single characteristic may not be unique to genetic/genomic information versus other health information, these characteristics are relevant to consider holistically when determining appropriate protection of genetic/genomic test information. The Workgroup has also described how genetic/genomic data access should likely be treated as similar to other "sensitive" information in the EHR for the immediate future, the appropriateness of data masking or controlled access to sensitive information such as genetic/genomic test information, and required disclosure considerations. Additionally, the group described how masking of genetic/genomic test information should only be viewed in the context of broader discussions of sensitive information in the health record, rather than as a standalone issue. This potential inclusion will necessarily require discussions of the definition of "sensitive" information, technical implementation issues, transition processes to ensure adoption and adherence, adherence verification processes and penalties for potential non-compliance, and balancing patient control with appropriate access by health care professionals. Finally, the Workgroup has also considered how genetic/genomic information may be exceptional with respect to permissible use (regardless of the right to access). To this end, specific considerations should be made for protections against the misuse of genetic test data (e.g., discrimination) and regarding the use of such data for research purposes (e.g., proper disclosure of the risk of personal identification and the need to prohibit data mining and aggregating techniques designed specifically to circumvent individual privacy protection).

## Clinical Decision Support

The PHC Workgroup has also engaged a wide variety of stakeholders, including commercial vendors, payers, providers, Federal agencies, and researchers regarding clinical decision support. This is conceptualized as a mechanism that provides clinicians, medical staff, and patients with individually specific information that can be filtered intelligently or presented at appropriate times to enhance health and health care. It encompasses a variety of tools and interventions, including electronic alerts and reminders, clinical guidelines, order sets, patient data reports and dashboards, documentation templates, diagnostic support, and clinical workflow tools.<sup>20</sup> Currently there is no systematic process to develop, disseminate, and incorporate evidence-based practice information within the clinical community. As a consequence, years may be required to develop and incorporate guidelines into daily clinical practice. Additionally, clinical decision support tools will be crucial to encourage the appropriate use of genetic technologies in clinical practice by providing information about the choices of action at the point of care. As knowledge about genetic information and health is evolving rapidly, the consumer and provider will require clinical decision support tools to remain current with best-practice guidelines and evidence-based medicine concerning genetics and genomics. Additionally, the development and deployment of clinical decision support tools must consider the needs of the clinician, including specific practice needs, information workflow, and practice environment.

The initial goals of these discussions are to improve understanding of the issues that clinical decision support tools may address, the challenges facing developers of these tools, the processes used to develop evidence for clinical decision support, how they can be engineered to fit into the natural workflow, and how these tools can support the goals of PHC. Although there is a substantial need for such tools to support widespread clinical use of genetic/genomic information, there is also the recognition that clinical decision support as a field is early in its development. These preliminary discussions have provided several key points of potential engagement for future recommendations to the AHIC. Keeping with the PHC Workgroup's charge to focus on the individual consumer, patient preferences for interventions and health services must be considered as clinical decision support tools are developed. By engaging the consumer in the health care process, some of the responsibility for decision making could be assumed by the consumer, empowering the individual to play an active role in his or her health management. This approach may be particularly useful in using clinical decision support to ensure effective use of predictive genetic/genomic information, in which preventive services can minimize progression to acute health crises.

Currently, the wide deployment of clinical decision support is hampered by the uncertainty of how vendor-based EHR systems can integrate these tools into their individual systems. Likewise, acceptance of automatically deployed messages in clinical practice is hampered by lack of information regarding which types of interventions work in given situations, how users react to clinical decision support-deployed messages, and how these tools effect outcomes. Given these issues and the

central role of the patient in the success of clinical decision support systems, the PHC Workgroup has designated clinical decision support as a priority focus area for future efforts and will continue to inform policy in this most critical area.

## Future Workgroup Activities

Although the PHC recommendations and documents describe a wide variety of standards and interoperability issues for genetic and genomic information, certain genetic tests will require somewhat different information needs. For example, to advance understanding of genetic and other congenital conditions on a population-wide basis, data standards are needed for the screening of newborns for metabolic, genetic, and hearing-related disorders. The Workgroup has developed a strategy to promote interoperable exchange of newborn screening results and confirmatory diagnoses that will help to identify, develop, and encourage adoption of appropriate standards by instrument manufacturers, public health laboratories, and EHR vendors. Recommendations describing the information needs for newborn screening were accepted by the AHIC on February 22, 2008.<sup>21</sup> In addition, the Workgroup will continue to address ways to facilitate the integration of new pharmacogenomic tests (e.g., panels for cytochromes P450) into the EHR. These tests offer the potential to guide treatment selection and dosing regimens for a wide variety of agents and conditions. These efforts focus on addressing the compatibility of standards across the clinical and research enterprises and will inform the development of standards that are interoperable between these applications.

## Conclusion

The AHIC PHC Workgroup has assessed issues and needs for promoting standard reporting and incorporation of medical genetic/genomic tests and family health history data in EHRs. The Workgroup has examined and clarified a range of issues related to this information, including interoperability standards and requirements for confidentiality, privacy, and security, in the course of developing recommendations to facilitate its capture, storage, transmission, and use in clinical decision support. Based on recommendations from the Workgroup, the Office of the National Coordinator for Health IT is developing a use case to guide the introduction of genetic/genomic testing and family health history information into the EHR and PHR, thereby empowering the patient in his or her health care, improving information transfer efficiency, and reducing system-wide burdens. This effort will inform development of local level health IT systems to aid communities as they adapt to meet emerging opportunities to provide patient-centric health care practices.

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