HEALTH HERITAGE - GenE EMR
A genomic and personalized medicine application for population and public health

Translational & Cross-Disciplinary Research
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Health Heritage - GenE EMR transfers health and genomic data, including family health history, to a personal patient record.

Abstract
The potential public health benefits available from genomics and personalized medicine have yet to be realized. We previously developed Health Heritage, a Web-based family health history application, to provide an easy-to-use tool for consumers to efficiently collect and update their family health history. Combined with evidence-based decision support, Health Heritage can provide recommendations for prevention and risk reduction. Our current project, titled “Building a Genome-Enabled Electronic Medical Record (GenE EMR),” enhances Health Heritage in three primary ways. First: It will include additional personal and genomic risk factors into the decision support to provide recommendations that are even more personalized. Second: Health Heritage will be integrated into multiple electronic medical records (EMRs) and personal health records, thus increasing ease of use and accuracy by both patients and physicians. Third: We will develop ways to, at patient request, electronically share health histories among relatives. Combined, the application is especially innovative in that it encourages more individual control, family network sharing and integrates evidence-based scientific information. This method responds to new goals in health reform by fostering low-cost, rapidly deployable, personalized health care. Any such application must function within our complex scientific, societal, political and regulatory environment.

II. Components of GenE EMR
1) Decision trees to assess risk
2) Dual data collection mechanisms:
   • directly from patients and relatives
   • electronically from provider records
3) Recommendations for prevention, screening and treatment based on risk level
   • Patient-oriented summary
   • Provider-oriented full report
4) Multidisciplinary team to identify ethical, legal, social, economic barriers and solutions.

III. Novel Aspects of GenE EMR and Health Heritage
1) Ability to gather personal and family history data via Electronic Medical Record
2) Identification and evidence tracking of genomic tests (e.g., SNPs) to determine when they should be included in risk assessment decision trees and can be collected for research purposes.
3) Development of the capacity to share records between family members.
4) Identification and explication of the ELSI issues around the electronic sharing health histories among relatives.

Our goal is to make personal medical information more widely available and useful for both individuals and society while providing rigorous privacy control for individuals and families. We have developed an application that transfers documented health and genomic data, including family health history, to a personal health record, thus providing a richer and more useful record than currently available. The application is especially innovative in that it encourages more individual control, family network sharing and integrates evidence-based scientific information. This method responds to new goals in health reform by fostering low-cost, rapidly deployable, personalized health care. Any such application must function within our complex scientific, societal, political and regulatory environment.

Our team integrates expertise from health informatics, computer science, medicine, behavioral science, economics, law, ethics and policy. It will empower providers and patients with knowledge and data to better understand, control and manage their health care.