

## 'NEXT GENERATION' FAMILY HEALTH HISTORY' New E-based Power for a Proven Medical Tool

**[www.familyhistory.hhs.gov](http://www.familyhistory.hhs.gov)**

***Overview:** In January 2009, the Surgeon General will release a new version of “My Family Health Portrait.” This internet-based tool makes it easy for consumers to record their family health history. The new version of the tool is updated for 21<sup>st</sup> century medicine. It is a standards-based electronic tool, making information easy to share and ready for use in electronic health records (EHRs) and personal health records (PHRs). The tool is also available on an “open source”-type basis, so that other organizations can download and customize it under their own brands.*

### ***Family Health History: Old-Fashioned Approach, or Valuable Tool?***

- As our knowledge of the human genome keeps breaking new ground, we know that most diseases are due to interactions of multiple genes and environmental factors. We are working toward the day when we will have high-tech tools to detect and understand the genetic factors at the molecular level. But that day is many years away.
- In the meantime, almost every patient has available today a free, personalized tool that captures many genetic and gene-environment factors – and can serve as a cornerstone for individualized disease prevention. This valuable, free and well-proven tool is the family health history.
- Family history helps predict risk for health conditions as varied as heart disease, cancer, osteoporosis, diabetes and obesity. More than that, this knowledge can help steer health care to be most effective for each individual. Yet many people are unaware of their families’ health histories, and many health professionals underutilize this information.
- Consumers themselves are aware. In a 2004 survey, 97 percent said knowledge of family health history is important for their health care. Yet only 30 percent had ever collected health information from relatives to develop a family health history.

## ***The Surgeon General Steps In***

- In 2004, the Surgeon General of the U.S. Public Health Service launched a Family History Initiative to help expand the use of this valuable tool. The Initiative included a new web-based tool, “My Family Health Portrait.”
- “My Family Health Portrait” was the beginning of a renaissance for family health history. The tool, which has been downloaded almost 500,000 times, enabled consumers to download the “Portrait” format and fill in information. In November 2004, the Surgeon General declared Thanksgiving to be National Family History Day – a time when relatives can share what they know about their ancestral health histories.

## ***“Next Generation” Tool: The Importance of a Standards-based Approach***

- With advances in electronic health information technology, the time is ripe for a “next generation” family health history tool. Development of a new tool was undertaken following recommendations in 2006 by the American Health Information Community (AHIC), an advisory committee to the Secretary of Health and Human Services for advancing health information technology.
- A next generation family health history tool had to be “standards-driven.” To be useful in the new age of electronic health information, it needed to be based on technical standards that would make it interoperable (able to be securely exchanged electronically) and ready for embedding in electronic health records (EHRs) and personal health records (PHRs).
- Objectives that have been met with the ‘next generation’ tool include:
  - Ø ***SHARING WITHIN FAMILIES:*** Instead of merely providing a print-out format, the new tool enables consumers (at their discretion) to electronically exchange the information with their close relatives.
  - Ø ***SHARING WITH PRACTITIONERS:*** Consumers can share their information easily with health care practitioners. And the information is EHR-ready – compatible for use in electronic health records, where it can be made more useful for improving care.
  - Ø ***OPEN-SOURCE CODE:*** The tool is available in “open-source” format for other organizations to adopt and use under their own brands. The goal is to enable other organizations to help promote family health history taking, customize the tool to their own needs, and even develop compatible value-added services or products – all while preserving the crucial interoperability of the tool and the health information it formatted.

## *New Usefulness for Consumers*

- CONVENIENCE – “My Family Health Portrait,” at [www.familyhistory.hhs.gov](http://www.familyhistory.hhs.gov), makes it easy for consumers to record their family health history. It can be reached on the web when there’s time to complete the tool –typically 15 to 20 minutes. The consumer is not rushed in a waiting room environment. And the information can be made part of a permanent record and easily updated, which means consumers don’t have to keep filling out forms when they see new practitioners.
- CONSUMER CONTROL AND PRIVACY – The tool gives control to the consumer. By going to the tool on the web, consumers get access to software that will organize their information into a “pedigree” or family tree. Their information is never kept or stored by the tool itself – it is returned to them via download into their computer. So privacy of the information-gathering process is guaranteed.
- SHARING – The tool makes it easy to share the information with physicians and other practitioners, at the consumer’s discretion. In this way, the practitioner receives the information in the standard format that makes the information most useful. Consumers who wish to share their information with other family members can also do that easily. Family members can then add information, as well as beginning their own family health history.
- “RE-INDEXING” – A valuable function of the new tool is the capacity to “re-index.” That means when you share your information with a relative, the relative can “re-index” and make himself or herself the subject. That way, relatives can use your information to start their own history, and the information you provide will automatically appear in its proper relationship to the relative.
- DECISION SUPPORT – Family health history that has been formatted by the new tool will adhere to common information standards. That will make the information more useful to doctors and other practitioners. With the information in standard formats, other software tools (often called clinical decision supports) can be used to help the practitioner interpret the results.

## *‘Open Source:’ New Opportunities for Health Organizations*

- DOWNLOADABLE, CUSTOMIZABLE – Health organizations and businesses can download the source code for the new tool, adopt it under their own brand, and customize it to meet their own needs. That can help promote family health history taking, and help it meet special consumer needs.
- NON-COMMERCIAL AND COMMERCIAL – The tool can help non-profit organization in serving their stakeholders. Likewise, businesses can use it serving customers or developing compatible new services or products.

- EASY TO DOWNLOAD – The National Cancer Institute is hosting the new tool through the Cancer Biomedical Informatics Grid (caBIG®), which is a pioneer in sharing open-source materials for research and clinical support. The tool can be downloaded at <https://gforge.nci.nih.gov/projects/fhh/>. A Help Desk is available.

### ***Partners and Early Adopters***

- Some partners or early adopters of the tool and its standard formatting include:
  - ∅ National Institute of Genomic Medicine of Mexico (INMEGEN) – Using the Surgeon General’s tool as its base, the Institute has developed its own version of the tool in Spanish.
  - ∅ Indian Health Service – IHS will develop the capability to accept a file from the new platform into the Resource and Patient Management System (RPMS) Electronic Health Record (EHR) system and participate in the beta-test of the new tool.
  - ∅ Department of Veterans Affairs, Department of Defense –VA and DoD were collaboration partners in developing common technical and functional requirements that will enable future use of the family health history tool and potentially accepting a file produced by the new platform.
  - ∅ Newton Wellesley Hospital, a Member of the Partners Healthcare System, – NWH will accept files from the new platform into the Hughes Risk Assessment Application and EHR and beta-test.
  - ∅ Intermountain Healthcare – IMH will develop the capability to accept a file into the Intermountain Healthcare EHR, then transmit that information into a 3<sup>rd</sup> party Personal Health Record (PHR) and beta-test.

### ***Sponsors***

- Agencies that helped sponsor development of the “next generation” family health history tool include: Indian Health Service; National Human Genome Research Institute, NIH; National Cancer Institute, NIH; Agency for Healthcare Research and Quality; National Institute of Diabetes and Digestive and Kidney Disorders, NIH; Office of Rare Diseases, NIH; Substance Abuse and Mental Health Services Administration; National Office of Public Health Genomics, Centers for Disease Control and Prevention; Office of the National Coordinator for Health Information Technology; Office of Minority Health, HHS; Office of the Surgeon General; Office of the Assistant Secretary for Planning and Evaluation, HHS; Federal Health Architecture (Veterans Health Administration, Department of Defense)