

# History of U.S. Surgeon General's My Family Health Portrait Tool and Standards Development

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Maine Dartmouth Family Medicine  
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# Disclaimers

- I have no known conflict of interest related to this topic.
- This work is that of a cast of thousands.
- Slides presented are largely unchanged. No endorsements in either direction – historical purposes only.

# MFHP in Three Eras

- 2004-2009 V.1 Basic functionality
- 2009-2014 V.2 Interoperability and sharing
- 2014- Current V.3 Interpretation of FHH

# Launch of the U.S. Surgeon General's Family History Initiative in 2004



# Goals of the U.S. Surgeon General's Family History Initiative

1. Increase awareness of family history.
2. Provide tools to gather, organize, evaluate, and communicate family history information.
3. Increase genomics and health literacy to prepare for the coming era of health care.





- [Family History Home](#)
- My Family Health Portrait - Web based
  - [English](#)
  - [Spanish](#)
- My Family Health Portrait - Software
  - [English](#)
  - [Spanish](#)
- [My Family Health Portrait - Paper version](#)
- Before You Start
  - [English \(PDF\)](#) (528KB)
  - [Spanish \(PDF\)](#) (177KB)
- [Frequently Asked Questions](#)
- [On-Line Resources](#)
- [Resource Packet for Health Professionals](#)

## U.S. Surgeon General's Family History Initiative

Health care professionals have known for a long time that common diseases - heart disease, cancer, and diabetes - and even rare diseases - like hemophilia, cystic fibrosis, and sickle cell anemia - can run in families. If one generation of a family has high blood pressure, it is not unusual for the next generation to have similarly high blood pressure. Tracing the illnesses suffered by your parents, grandparents, and other blood relatives can help your doctor predict the disorders to which you may be at risk and take action to keep you and your family healthy.

To help focus attention on the importance of family history, the U.S. Surgeon General in cooperation with other agencies with the U.S. Department of Health and Human Services has launched a national public health campaign, called the U.S. Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history.

In addition to the Office of the Surgeon General, other HHS agencies involved in this project include the National Human Genome Research Institute (NHGRI) at the National Institutes of Health, the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and the Health Resources and Services Administration (HRSA).

### **My Family Health Portrait**

[Access My Family Health Portrait web version](#)

Americans know that family history is important to health. A recent survey found that 96 percent of Americans believe that knowing their family history is important. Yet, the same survey found that only one-third of Americans have ever tried to gather and write down their family's health history.

Because family health history is such a powerful screening tool, the Surgeon General has created a new computerized tool to help make it fun and easy for anyone to create a sophisticated portrait of their family's health.

# V.1 MFHP Characteristics

- Larry Thompson's team in the Office of the Director, NHGRI
- 6 conditions - actionable
- Desktop program, paper – data secure
- Spanish/ English – low literacy
- Pedigree - sharable



## Welcome to My Family Health Portrait

This web site allows you to create a personalized family health history report from any computer with an Internet connection and an up-to-date Web browser. [View a sample report \(PDF\)](#).

Information you provide creates a drawing of your family tree and a chart of your family health history. Both the chart and the drawing can be printed and shared with your family members or your healthcare professional. Used in consultation with your healthcare professional, your family health history can help you review your family's health history and develop disease prevention strategies that are right for you.

[Create a Family History](#)

OR

[Load a Saved Family History](#)

**NEW** [Health care providers](#): Using [these public service announcements](#) learn how increased healthcare provider family history knowledge can improve the health of all Americans.

My Family Health Portrait is compatible with most browsers and operating systems. Please see our [compatibility statement](#) for more information. For users who prefer alternative versions of My Family Health Portrait, the [downloadable software version](#) and [hard copy paper form](#) are available.

**My Family Health Portrait**  
 A tool from the U.S. Surgeon General

en Español

« Back to My Family Save Help with this page

« Back to View Reports View & Print Report as PDF

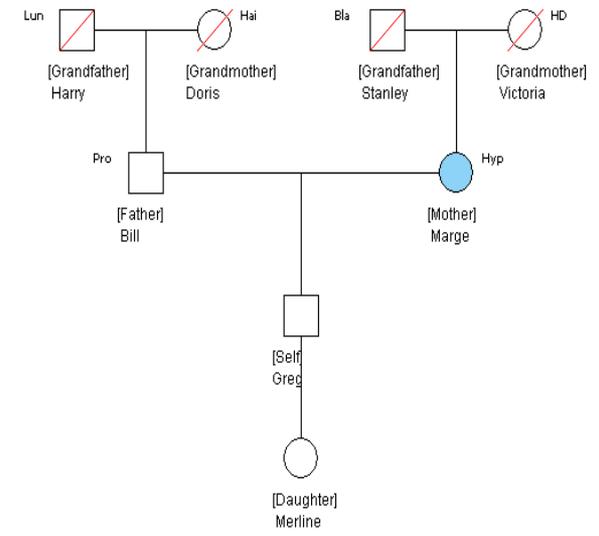
\* Clicking this button generates a PDF file combining your family tree (scaled to fit on a single page) and the chart on the remaining page(s). It should open inside this browser window where you may then print or save it for later use. It's okay to rename the file if desired. If you need a PDF reader, you can [download one here](#) for free.

**My Family Health Portrait - Drawing Report**

Greg - April 1, 2008

Highlighted disease: **Hypertlipidemia**

- Male Family Member     - Family Members with a History of Disease  
 - Female Family Member     - Deceased Family Member  
 HD - Heart Disease    Str - Stroke    Dia - Diabetes  
 Col - Colon Cancer    BrC - Breast Cancer    OvC - Ovarian Cancer



**My Family Health Portrait - Chart Report**  
 Greg - April 01, 2008

*Use this in consultation with your healthcare professional.  
 It can be a valuable tool for discussion, risk assessment, and medical advice.*

**My Stats:** Age: 38 Height: 5' 11" Weight: 175 Body Mass Index: 24.4

[« Back to View Reports](#) [View & Print Report as PDF](#)

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**My Family Health Portrait - Chart Report**

Greg - April 01, 2008

*Use this in consultation with your healthcare professional. It can be a valuable tool for discussion, risk assessment, and medical advice.*

**My Stats:** Age: 38 Height: 5' 11" Weight: 175 Body Mass Index: 24.4

	Still Living?	Heart Disease	Stroke	Diabetes	Colon Cancer	Breast Cancer	Ovarian Cancer	Additional Diseases
<b>Greg</b> [Me]	Yes	No	No	No	No	No	N/A	
<b>Marge</b> [Mother]	Yes	No	No	No	No	No	No	<b>Hyperlipidemia [At age 50-59]</b>
<b>Victoria</b> [Mother's Mother]	No	Yes, 60 and older	No	No	No	No	No	
<b>Stanley</b> [Mother's Father]	No	No		No	No	No	N/A	Black lung [Age unknown]
<b>Bill</b> [Father]	Yes	No	No	No	No	No	N/A	Prostate cancer [60 and older]
<b>Doris</b> [Father's Mother]	No Leukemia at 90	No	No	No	No	No	No	Hairy cell leukemia [60 and older]
<b>Harry</b> [Father's Father]	No Lung cancer at 70	No	No	No	No	No	N/A	Lung cancer [60 and older]
<b>Merline</b> [Daughter]	Yes	No	No	No	No	No	No	

[« Back to View Reports](#) [View & Print Report as PDF](#)

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# V.1 MFHP Characteristics

- Not much thought given to:
  - Standard vocabulary
  - Connectivity
  - Clinical decision support

Cold Fusion??



# American Health Information Community (AHIC)

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**HHS Priorities**  
*for America's Health Care*

AHIC is the public-private collaborative that sets priorities and oversees and/or endorses HIT standards, certification, the National Health Information Network, and policies on a national level.

- Supported through the Office of the National Coordinator for Health Information Technology
- Chaired by Secretary Leavitt and Dr. David Brailer
- Seven work groups are now established involving over 100 experts and stakeholders – Biosurveillance, Electronic Health Records, Chronic Care, Consumer Empowerment, Confidentiality, Privacy and Security, Quality, and Personalized Health Care
- Work groups develop recommendations to the AHIC and subsequently to the Secretary for action
  - Example: Executive Order requiring adoption of certification standards for electronic health records



Department of Health & Human Services  
Office of the National Coordinator for  
Health Information Technology

# American Health Information Community

## Personalized Health Care Workgroup Recommendations

**Douglas E. Henley**  
American Academy of Family Physicians

**John Glaser**  
Partners HealthCare

**July 31, 2007**



# Recommendation Approved by AHIC

## July 31, 2007

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### **Recommendation 1.0:**

The Community should advance the area of Personalized Health Care as a Priority for Use Case Development.

### **Recommendation 2.0:**

An extension to the Harmonized Use Case for EHRs (Laboratory Results Reporting) should be developed to address the specific information needs in the pre-analytic, analytic, and post-analytic phases of genetic/genomic tests. This extension to the use case should additionally address the need for integrated data flow across the pre-analytic, analytic, and post-analytic phases of genetic/genomic testing and address both the EHR and Laboratory Information Systems.

### **Recommendation 3.0:**

A multi-stakeholder workgroup, including the private sector, federal health care providers, and federal Public Health Service agencies, should be formed to develop a core minimum data set and common data definition available for primary care collection of family health history information.



## Recommendations Cont:

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### **Recommendation 3.1:**

Additionally, studies should be performed as part of this collaboration as an evidence-base to determine the validity and utility of family health history risk assessment and management tools, clinical decision support tools, and how clinicians view this information as helpful for informing their medical decisions.

### **Recommendation 3.2:**

Federal agencies in conjunction with private health care organizations with similar interests and expertise sponsoring pilots in the area of family health history should be used to evaluate the core minimum data set and evidence-base developed through Recommendations 3.0 and 3.1. Health care providers involved in these pilots should also examine the feasibility of consumer-clinician exchange of family health history information between PHR and EHR systems. When possible, the pilots should test and implement the standards and architecture identified in the HITSP developed use case.

# Arriving at a core data set for FHH:

- Achieved in 2008 by a public/private task force convened by the AHIC Personalized Health Care workgroup
  - About 40 participants representing a diverse group of 18 stakeholders
- Defined the minimum FHH data elements that every EHR and PHR should be able to capture
- Did not specify data structures/terminologies for these elements

# Sponsoring Federal Agencies

- Indian Health Service
- National Human Genome Research Institute
- National Cancer Institute
- Agency for Healthcare Research and Quality
- National Institute of Diabetes and Digestive and Kidney Disorders
- Office of Rare Diseases, National Institutes of Health
- 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
- Office of the Surgeon General
- Office of the Assistant Secretary for Planning and Evaluation
- Federal Health Architecture (Veterans Health Administration and Department of Defense)



*Position Paper* ■

## New Standards and Enhanced Utility for Family Health History Information in the Electronic Health Record: An Update from the American Health Information Community's Family Health History Multi-Stakeholder Workgroup

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W. GREGORY FEERO, MD, PhD, MARY BETH BIGLEY, DRPH, MSN, ANP, KRISTIN M. BRINNER, PhD,  
THE FAMILY HEALTH HISTORY MULTI-STAKEHOLDER WORKGROUP OF THE AMERICAN HEALTH  
INFORMATION COMMUNITY

**Abstract** Family health history is a complex, multifaceted tool for assessing disease risk that can offer insight into the interplay between inherited and social factors relevant to patient care. Family health history tools in electronic health records can enable the user to collect, represent, and interpret structured data that properly supports clinical decisions. If these data can be made interoperable, important health information can be shared with minimal duplication of effort among entities involved in the continuum of patient care. This paper reviews the efforts by the American Health Information Community's Family Health History Multi-Stakeholder Workgroup to create a core data set for family health history information and to determine requirements to promote incorporation of such information in electronic health records. The Workgroup is a component of the U.S. Department of Health and Human Services' Personalized Health Care Initiative.



# NIH Public Access

## Author Manuscript

*Genet Med.* Author manuscript; available in PMC 2012 January 16.

Published in final edited form as:

*Genet Med.* 2010 June ; 12(6): 370–375. doi:10.1097/GIM.0b013e3181e15bd5.

## Validation of My Family Health Portrait for Six Common Heritable Conditions

Flavia M. Facio, MS<sup>1</sup>, W. Gregory Feero, MD, PhD<sup>1,2</sup>, Amy Linn, BS<sup>1,\*</sup>, Neal Oden, PhD<sup>3</sup>, Kandamurugu Manickam, MD<sup>1,\*\*</sup>, and Leslie G. Biesecker, MD<sup>1</sup>

<sup>1</sup>National Human Genome Research Institute, National Institutes of Health, Bethesda, MD, USA

<sup>2</sup>Maine-Dartmouth Family Medicine Residency Program, Augusta, ME, USA

<sup>3</sup>The EMMES Corporation, Rockville, MD, USA

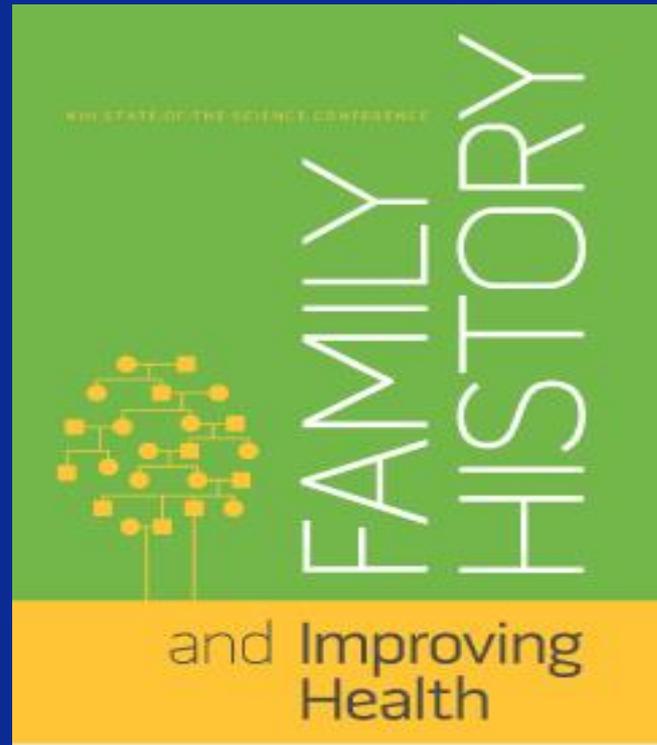
### Abstract

**Purpose**—To assess the ability of My Family Health Portrait (MFHP) to accurately collect family history for six common heritable disorders.

**Background**—Family history is useful to assess disease risk, but is not widely used. We compared the pedigree from MFHP, an online tool for collection of family history, to a pedigree supplemented by a genetics professional.

**Methods**—150 volunteers collected their family histories using MFHP. A genetic counselor

# August 24-26, 2009





# My Family Health Portrait

A tool from the U.S. Surgeon General

## Features:

- Patient completed
- Flexible content
- Generates pedigree
- Able to change 'focus'
- Extensive usability testing and refinement
- Freely available

## Deficits:

- Is not able to collect entire data-set
- Has no linkage to EHR
- Does not interpret information
- Does not use data-base

[www.surgeongeneral.gov/familyhistory/](http://www.surgeongeneral.gov/familyhistory/)

V.2 MFHP



Department of Health & Human Services  
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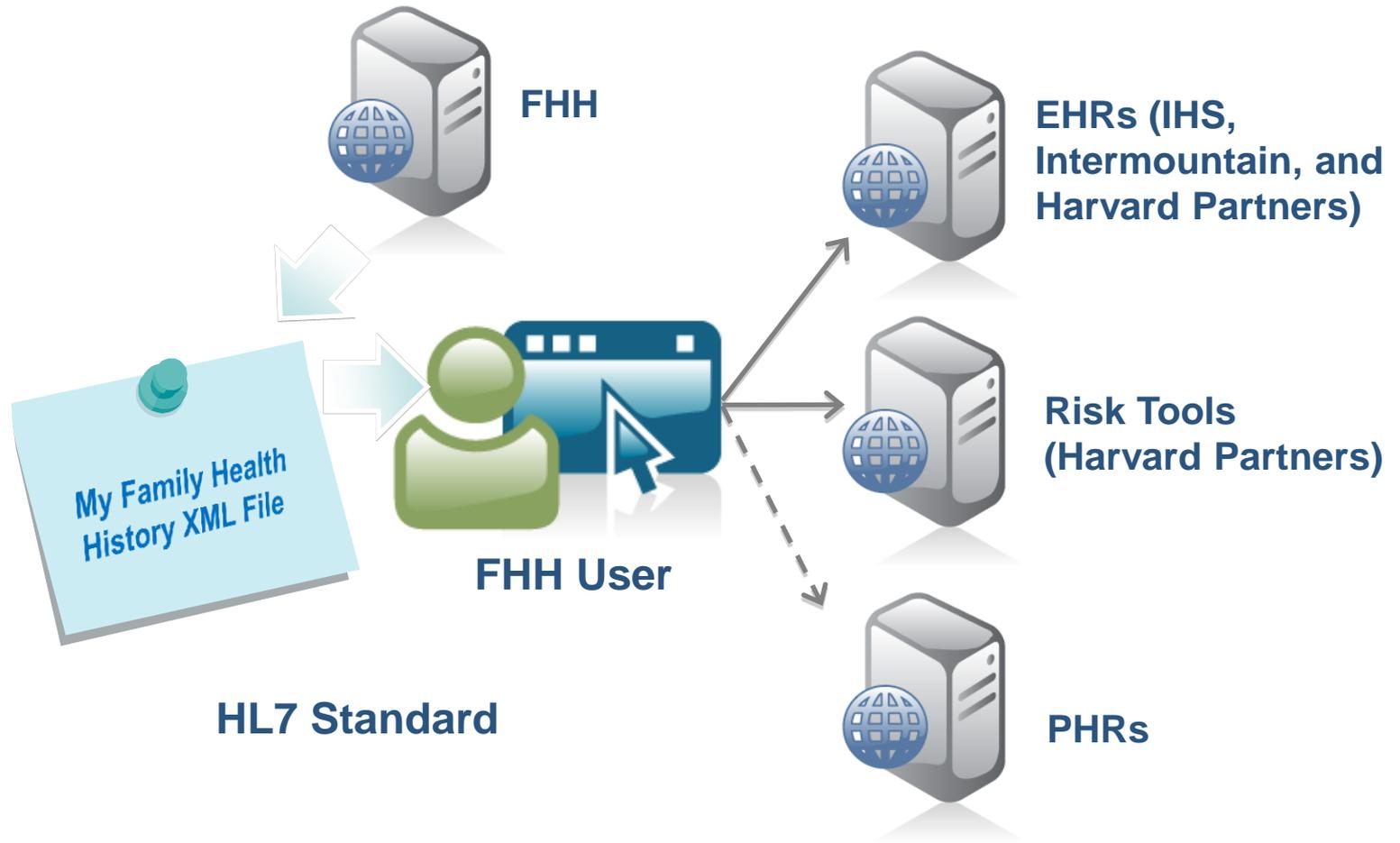
# **Family Health History Initiative**

## **Update for Partners: Status Report & Planning Meeting**

**October 20, 2008**



# Family Health History Interoperability/Portability





## THE HIPAA PRIVACY RULE



# Frequently Asked Questions About Family Medical History Information

---

U.S. Department of Health and Human Services • Office for Civil Rights

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- 1. Does the HIPAA Privacy Rule limit an individual's ability to gather and share family medical history information?**

*No.* The HIPAA Privacy Rule may limit how a covered entity (for example, a health plan or most health care providers) uses or discloses individually identifiable health information, but does not prevent individuals, themselves, from gathering medical information about their family members or from deciding to share this information with family members or others, including their health care providers. Thus, individuals are free to provide their doctors with a complete family medical history or communicate with their doctors about conditions that run in the family.

[www.hhs.gov/ocr/privacy/familyhealthhistoryfaqs.pdf](http://www.hhs.gov/ocr/privacy/familyhealthhistoryfaqs.pdf)

# My Family Health Portrait

Family Health History - Welcome - Microsoft Internet Explorer

File Edit View Favorites Tools Help



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Get Help En Español

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Create a Family History

Open a Saved History File



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start

Inbox - Microsoft Out... FW: power point - Me... NHIN FHH\_PPT\_v5.ppt Family Health History ... Family Health History ...

Trusted sites 12:40 PM

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Home Create New History Open Saved History En Espanol

MY FAMILY SAVE HISTORY VIEW REPORT GET HELP

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Some text to describe what to do now that youve added some family members.

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	DAU	Daughter			
	NBRO	Natural Brother			
	NSIS	Natural Sister			
<b>My Father's Side of the Family</b>					
	PAUNT	Paternal Aunt			
	PUNCLE	Paternal Uncle			
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Import Family History Save Family History

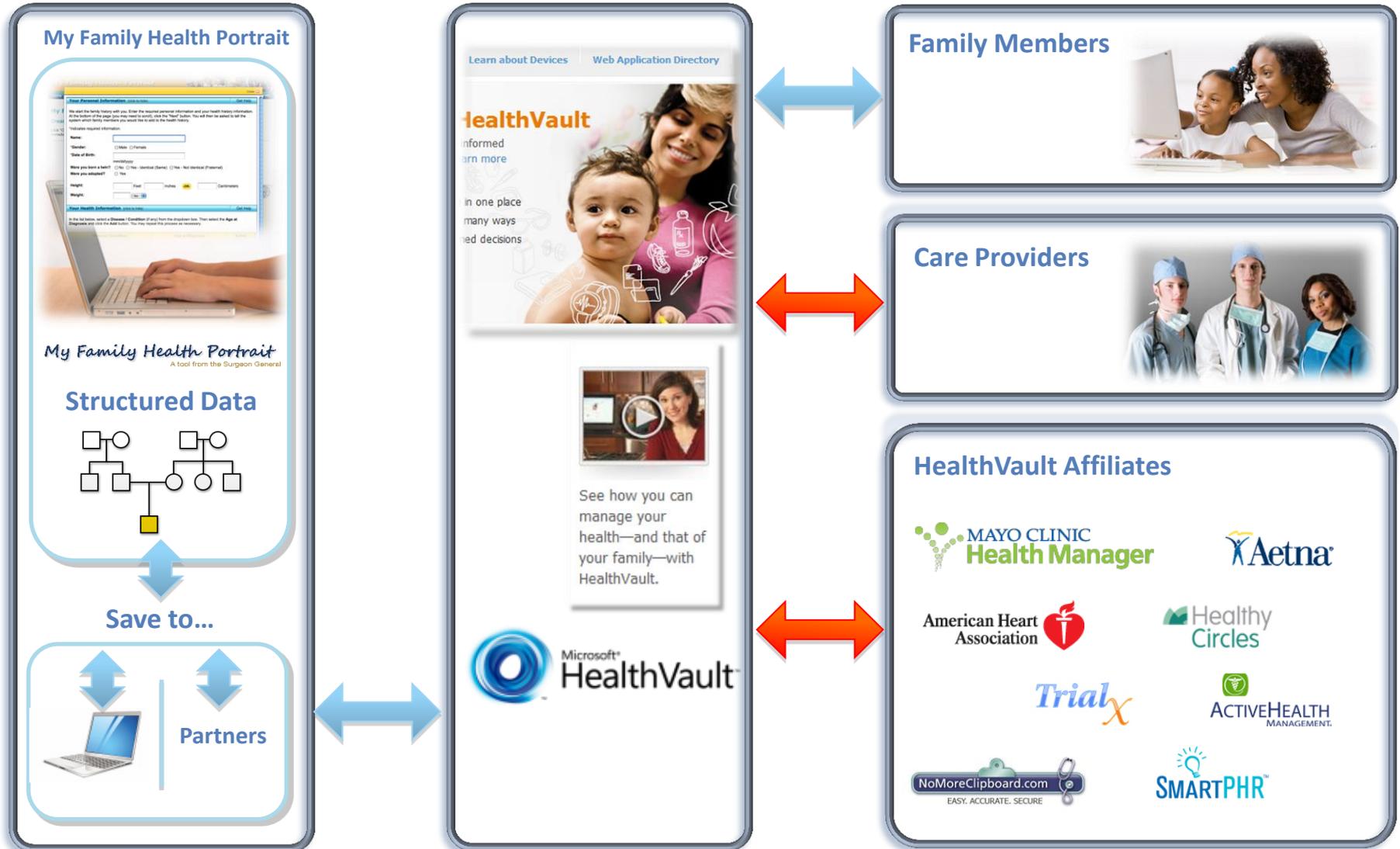
Done demo.5amsolutions.com

# Bottom-line

- Consumer convenience and control
- Standards-driven
- Portability, share-ability
- EHR- and PHR-ready
- Downloadable and customizable

# My Family Health Portrait

Structured Data + Connectivity = *Interoperability*



|  
**HL7 Clinical-Genomics Work Group**  
**The Family History Standard - US Realm Implementation**  
**Guide**

**DRAFT –June5, 2012**

**Pedigree R1 co-editors: Dr. Amnon Shabo (Shvo)<sup>1</sup> and Dr. Kevin S. Hughes<sup>2</sup>**  
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**[please add your name if you contribute to this document]**

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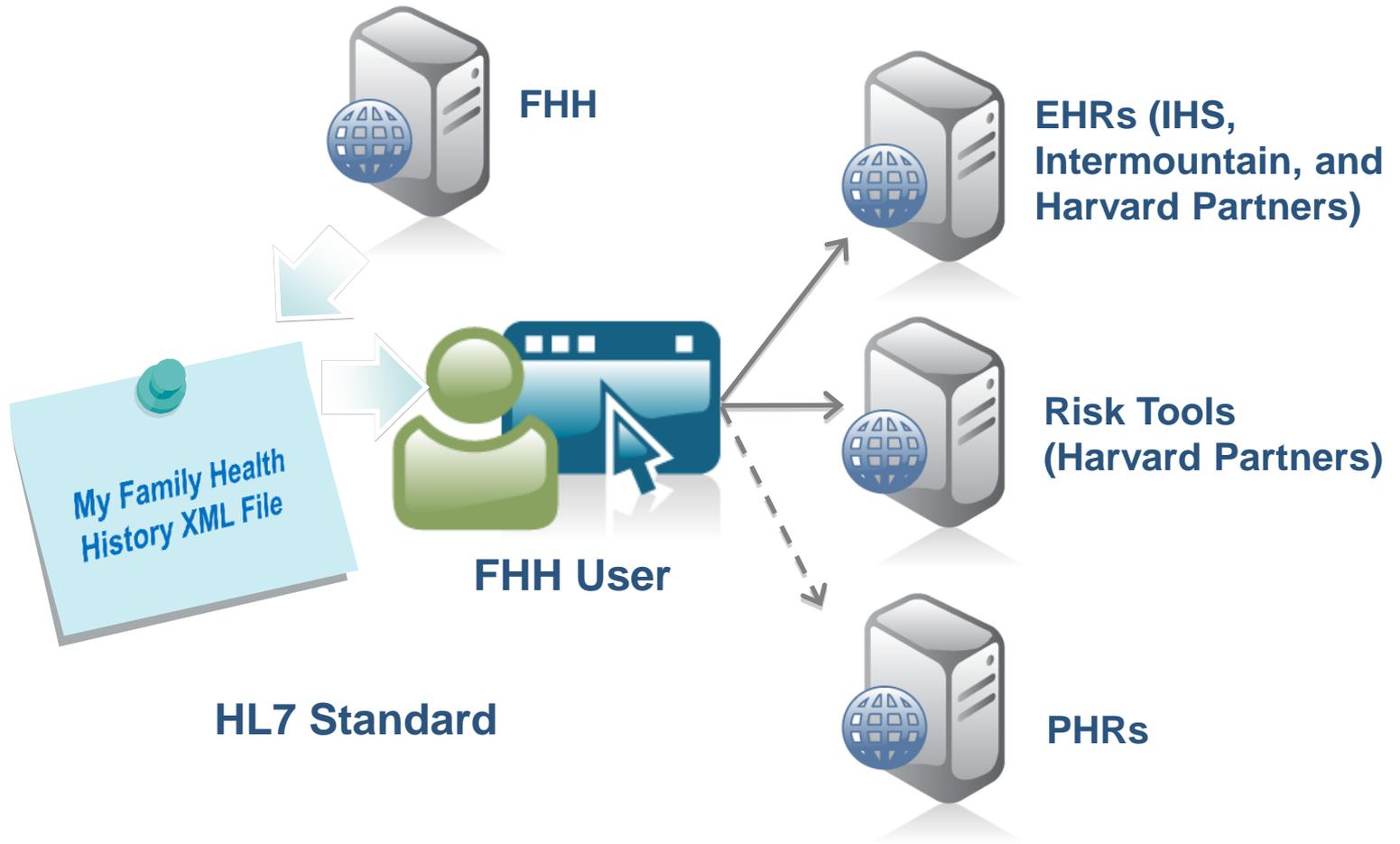
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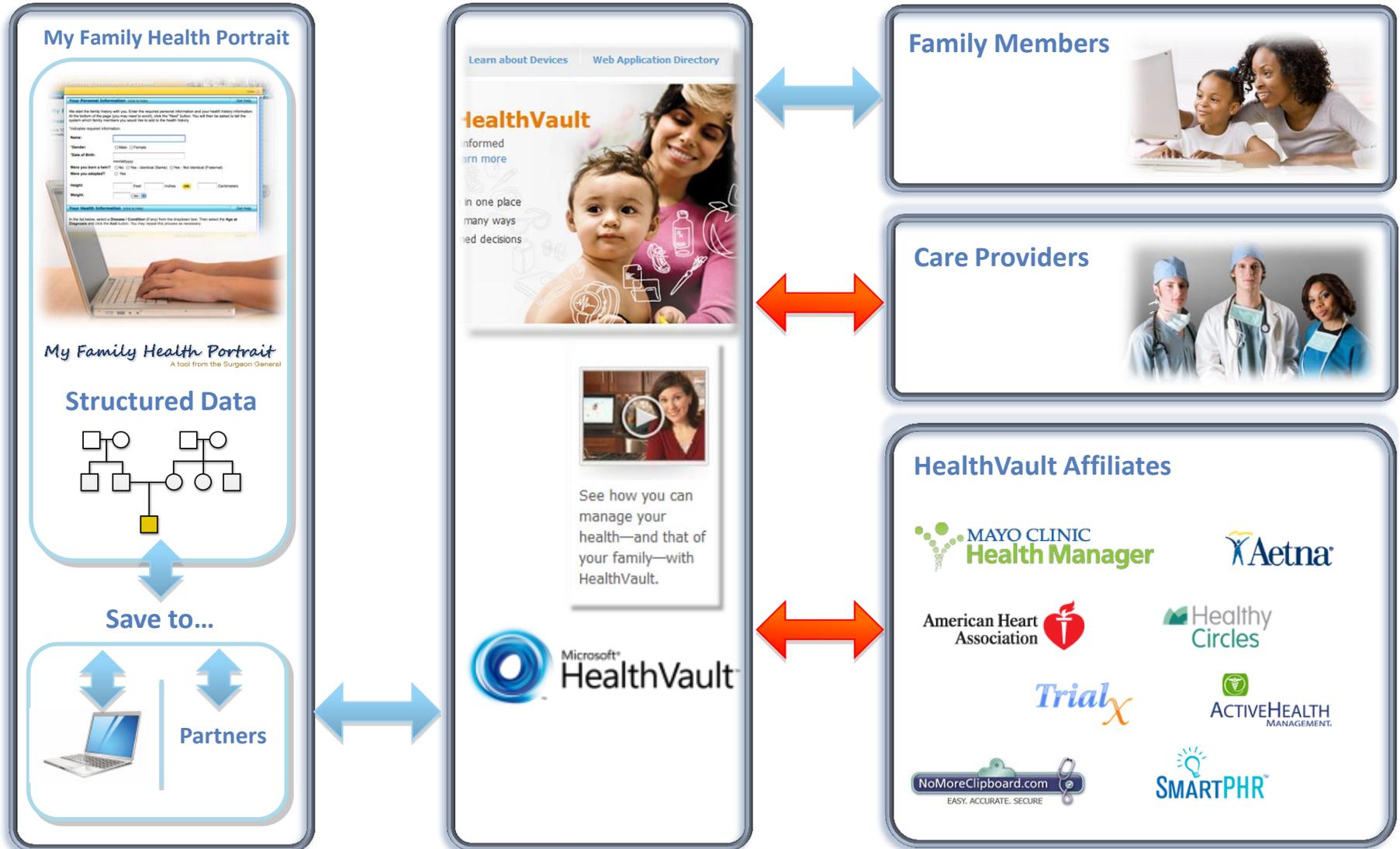
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# Stage 2

## Eligible Professional

### Meaningful Use Menu Set Measures

#### Measure 4 of 6

Date issued: October, 2012

Family Health History	
<b>Objective</b>	Record patient family health history as structured data.
<b>Measure</b>	More than 20 percent of all unique patients seen by the EP during the EHR reporting period have a structured data entry for one or more first-degree relatives.
<b>Exclusion</b>	Any EP who has no office visits during the EHR reporting period.

### Table of Contents

- Definition of Terms
- Attestation Requirements
- Additional Information
- Certification and Standards Criteria

### Definition of Terms

**First Degree Relative** – A family member who shares about 50 percent of their genes with a particular individual in a family. First degree relatives include parents, offspring, and siblings.

## Ideally electronic family health tools would-

- **Collect structured data for CDs**
- **Utilize interoperable data structures**
- **Aid with interpretation**

\*

\*

MFHP now does this!

# V.3 MFHP

[Home](#)[About](#)[National Cancer Informatics Program](#)[NCI Computer Services](#)[Application Support](#)[Contractor Security Guidance](#)

Bioinformatics provides researchers with the tools, information technologies, and analytical methodologies needed to manage the large volumes of data generated by today's genomic studies, large observational studies, and networked clinical trials—and to harvest insights from the information that is collected. . . . from genomics to clinical trials, bioinformatics capacity becomes a critical asset.

*The National Cancer Program: Managing the Nation's Research Portfolio, 2013*

[Learn More](#)

## Mission

The NCI Center for Biomedical Informatics and Information Technology (CBIIT) provides for the appropriate use of data science, informatics, and IT, exemplifying a commitment to customer service, teamwork, pride, professionalism and resulting in optimal support of the NCI's mission to

## News

### **NCI Launches the Genomic Data Commons**

The [Genomic Data Commons \(GDC\)](#), a unified data system that promotes sharing of genomic and clinical data between researchers, [launched on June 6](#). Starting with data from The Cancer Genome Atlas and other studies, the [GDC](#)

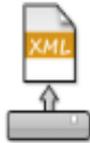




Help

## Load Your Family Health History from a Device

My Family Health Portrait



Load a previously-saved Family Health History file from your computer or a portable storage device, such as a USB drive.

Click Browse. Find and Select the file. Click Open From Computer.

Browse

Open From Computer

## Load Your Family Health History from Google Drive



Load a previously-saved Family Health History file from Google Drive.

You will need to sign into your Google account to continue.

Load from Google Drive

## Load Your Family Health History from Dropbox



Load a previously-saved Family Health History file from Dropbox.

You will need to sign into your Dropbox account to continue.

Load from Dropbox

## Load Your Family Health History from Microsoft HealthVault



Copy family health information from your HealthVault account.

Microsoft HealthVault lets you gather, store, and share health information online.

You will need to sign into your HealthVault account to continue.

Load from Microsoft's Health Vault

to help your close family member get started.

the name in the list.

You cannot remove yourself, your parents, or

ember

View Diagram and Table

Remove Relative



**Calculate your Diabetes Risk**

The Diabetes Risk Calculator

**Calculate your Colorectal Cancer Risk**

The Colorectal Risk Calculator

To find out more about what you can do, click on the 'Get Help' link on the menu bar above.

Delete all Data and Restart

Save Family History for Later Re-use

Add Another Family Member

View Diagram and Table

Name	Relationship to me:	Add History	Update History	Remove Relative
<b>My Family</b>				
Bravo	Self			
	Father			
	Mother			
	Brother			
	Son			
	Daughter			
	Daughter			
<b>My Father's Side of the Family</b>				



Abstract

Send to

*Genet Med*. 2015 Sep;17(9):753-6. doi: 10.1038/gim.2014.179. Epub 2014 Dec 18.

## Preliminary validation of a consumer-oriented colorectal cancer risk assessment tool compatible with the US Surgeon General's My Family Health Portrait.

Feero WG<sup>1</sup>, Facio FM<sup>2</sup>, Glogowski EA<sup>3</sup>, Hampel HL<sup>4</sup>, Stopfer JE<sup>5</sup>, Eidem H<sup>6</sup>, Pizzino AM<sup>7</sup>, Barton DK<sup>8</sup>, Biesecker LG<sup>9</sup>.

### Author information

#### Abstract

**PURPOSE:** This study examines the analytic validity of a software tool designed to provide individuals with risk assessments for colorectal cancer based on personal health and family history information. The software is compatible with the US Surgeon General's My Family Health Portrait (MFHP).

**METHODS:** An algorithm for risk assessment was created using accepted colorectal risk assessment guidelines and programmed into a software tool (MFHP). Risk assessments derived from 150 pedigrees using the MFHP tool were compared with "gold standard" risk assessments developed by three expert cancer genetic counselors.

**RESULTS:** Genetic counselor risk assessments showed substantial, but not perfect, agreement. MFHP risk assessments for colorectal cancer yielded a sensitivity for colorectal cancer risk of 81% (95% confidence interval: 54-96%) and specificity of 90% (95% confidence interval: 83-94%), as compared with genetic counselor pedigree review. The positive predictive value for risk for MFHP was 48% (95% confidence interval: 29-68%), whereas the negative predictive value was 98% (95% confidence interval: 93-99%). Agreement between MFHP and genetic counselor pedigree review was moderate ( $\kappa = 0.54$ ).

**CONCLUSION:** The analytic validity of the MFHP colorectal cancer risk assessment software is similar to those of other types of screening tools used in primary care. Future investigations should explore the clinical validity and utility of the software in diverse population groups. *Genet Med* 17 9, 753-756.

# MFHP- Conclusions

- Millions of users to date
- Some validation work
- Major driver for standards development over time
- Remains the most advanced tool that is entirely within the public domain