

Brigham and Women's Hospital  
Family History Project  
2005 – 2007

# Final Report on Phase 1: A Hospital Employee-Focused Family History Project

November 2007

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BRIGHAM AND  
WOMEN'S HOSPITAL



HARVARD  
MEDICAL SCHOOL  
TEACHING AFFILIATE

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# Executive Summary

We live at the dawn of the “Era of Genomic Medicine”. In these times, it is easy to focus on technology-driven aspects of medicine and to overlook the vital role that individuals and families can play in ensuring their own best healthcare. With the introduction of the U.S. Surgeon General’s Family Health Initiative in late 2004, the former United State’s Surgeon General, Dr. Richard H. Carmona, together with Dr. Francis Collins, the Director of the NIH’s National Human Genome Research Institute, helped crystallize a growing consensus among many healthcare experts who believe in the importance of gathering and organizing one’s own family health history for both current benefit and as preparation for a new era where this and other genetic information will help to personalize healthcare.

In mid-2005 discussions were initiated among a group of geneticists at Brigham and Women’s Hospital (BWH) that culminated in the launch of the BWH Family History Project later that year. The vision for this project was provided by Dr. Cynthia Morton, a geneticist and Harvard professor who imagined an institution-wide activity that would help to “change the culture” of our large urban academic medical center. The proposed endeavor would seek to simultaneously engage all employees in gathering their personal family health history and, in addition, it would focus healthcare providers on developing further expertise with an essential tool of human genetics, i.e. the family health history, or pedigree. Simply stated, the project would support the use of the Surgeon General’s data collection tool for employees to record their own personal family health history. For some, this data collection would act as a prelude to involvement in eventual efforts to engage some of the hundreds of thousands of patients of this healthcare center in doing the same. With generous financial support from the Harvard Partners Center for Genetics and Genomics (HPCGG), the National Human Genome Research Institute’s (NHGRI) Education and Community Involvement Branch (ECIB), and the Brigham and Women’s Hospital’s Biomedical Research Institute (BRI), this project was officially launched in November 2005.

From its inception, this project received enthusiastic support from the institution’s leadership including hospital president, Dr. Gary Gottlieb. This support has been expressed in a multitude of ways, but perhaps in no clearer way than a hospital-wide policy to officially allow all employees to use up to twenty minutes of their time “on the clock” to collect and organize their personal family health history independently or with the assistance of the project team.

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Our project team, together with scores of volunteers, worked for a period of approximately fourteen months on the employee-focused phase of this project. Specifically, they reached out to the over 12,000 hospital employees who are spread over more than ten different locations in metropolitan Boston in an array of efforts which are detailed in this document. The main outcomes of this phase of the project are: [1] the participation of approximately one-third of the hospital employees in gathering and organizing their personal family health histories, [2] the gathering of feedback which has helped to strengthen the Surgeon General's data collection tool, "My Family Health Portrait", [3] a contribution to an evolving understanding of how to best gather and organize these databases within healthcare delivery systems, and [4] the establishment of a broad-based clinical research program aimed at developing model systems for integrating family health history, genomics, and healthcare delivery.

We are continuing to carry out new work in this area now aimed at promoting the use of family health history within the patient care arena as well as within communities. With the completion of the "employee focus" in early 2007 we believe that we have set in motion the necessary elements needed to fulfill Dr. Morton's vision of actually changing the culture of the institution.

This report is meant to illustrate many of the educational tools, outreach instruments, and data collection efforts developed during this phase of the project. Our hope is that this model employee-based program will inspire others to build on this work within both healthcare and other institutional settings. Our hospital webpage ([www.brighamandwomens.org/familyhistory](http://www.brighamandwomens.org/familyhistory)) gives a more comprehensive description of our team's efforts in this area of genomic medicine in addition to acting as a clearinghouse for resources on the medical importance of family health history. In addition, we are happy to field any questions that you may have regarding this work; please email us at [familyhistoryproject@partners.org](mailto:familyhistoryproject@partners.org) or contact us at: **BWH Family History Project**, c/o Division of Genetics, Harvard New Research Building Room 455, 77 Avenue Louis Pasteur, Boston, MA 02115.

Thank you for your interest in this work.

**Michael F. Murray, MD**  
Project Director  
BWH Family History Project





# Table of Contents

## I. PROJECT OVERVIEW

- A. Description of Project
- B. Employee-Focused Family History Project Summary - Presented at the 2007 National Meeting of the American College of Medical Genetics
- C. Funding Summary
- D. Project Staff and Project Advisory Teams

## II. APPENDICES

- A. Outreach, Education and Family History Tools
    - 1A. Letter to the Hospital Community from Dr. Gary Gottlieb, Brigham and Women's Hospital President
    - 2A. Family History Project Questions and Answers
    - 3A. BWH FHP "Interactive Center"
    - 4A. BWH FHP Outreach Materials
    - 5A. BWH FHP Media Coverage
    - 6A. Multi-lingual translations of "My Family Health Portrait"
      - 6A1. English
      - 6A2. Spanish
      - 6A3. French
      - 6A4. Portuguese
      - 6A5. Polish
      - 6A6. Chinese
    - 7A. Press Release for the Chinese Language Translation of "My Family Health Portrait"
    - 8A. Worldwide Media Coverage of BWH Family History Project
    - 9A. Family History Websites
      - 9A1. United States Surgeon General's Family History Website
      - 9A2. BWH Public Website
      - 9A3. BWH Intranet Site – Pike Notes
-



- 9A4. BWH Gene Talk
- 10A. Family History and Hard to Reach Populations

B. Hospital and Project Sponsored Events

- 1B. FHP Kick-Off Events calendar
- 2B. 2006 monthly project focus
- 3B. Springtime Family Photo Gallery – Event
  - 3B1. Photo Submission Form
  - 3B2. Photos of Employees with their Families
- 4B. Take Our Children to Work Day – Event
  - 4B1. Informational PowerPoint presentation.
  - 4B2. RADM Kenneth Moritsugu, MD, MPH visit to BWH
  - 4B3. Transcript from National Public Radio (WBUR) interviews with BWH employees during “Springtime Photo Gallery”
- 5B. BWH 2006 “Street Beat” Event
- 6B. BWH FHP’s “Ice Cream Social” Event
- 7B. BWH FHP Project Participation T-shirts
- 8B. Family History Day Ceremony 2007


C. Data Collection Tools and Data

- 1C. Institutional Review Board Application and Notification of Exemption
- 2C. Spring (Preliminary) Participation survey – March 2006
  - 2C1. Survey Instrument
  - 2C2. Telephone follow-up interview of participants
- 3C. Fall (Final) Participation – November 2006
  - 3C1. Survey Instrument
- 4C. Website Visits and Page Views
  - 4C1. Listing of Hits to “My Family Health Portrait” from Partners computers
  - 4C2. Listing of Hits to Brigham and Women’s Hospital Family History Project Internet Website
- 5C. BWH Employee and Project Feedback to “My Family Health Portrait” site on Usability Issues
- 6C. Single Question Survey

D. Additional Project Materials

- 1D. 2005 Proposal to NHGRI-ECIB
- 2D. Sub-study: Self-referral of Adult Patients for Genetic Consultation
  - 2D1. Description of Sub-study and Findings





2D2. Presentation by Monica Giovanni at the 2007  
National Meeting of the American College of  
Medical Genetics

III. ACKNOWLEDGEMENTS

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# I. Project Overview

## *A. Description of Project Details*

### Introduction

In November 2005, a press conference was held at Brigham and Women's Hospital (BWH) in Boston to announce the start of a unique and ambitious project. BWH, a major teaching affiliate of Harvard Medical School, would be offering an opportunity to all of its 12,000\* employees to receive expert support and guidance if they wished to engage in gathering and organizing their own personal family health history. Interested employees would be supported in these efforts in three major ways: first, an easy to use web based or paper based data collection tool would be available to them; second, they could arrange with their supervisors to spend "on-the-job" time dedicated to this pursuit; and third, a full-time staff as well as trained volunteers would be available to answer their questions regarding both operational and content issues.

The data entry tool used in this project was the U.S. Surgeon General's "My Family Health Portrait" which had been launched as a downloadable program in November 2004, and was launched as an interactive web-based program in conjunction with the initiation of the Brigham and Women's Hospital Family History Project (BWH FHP) in Fall 2005.

This family history project had a two-fold agenda; it would seek to be both a public health effort and a research project. The public health aspect of the BWH FHP is based on the notion that knowing your family history has implications for one's health screening and disease prevention when properly recorded and reviewed with healthcare providers. All 12,000 employees were invited to gather and organize their family data in an effort to improve the personal health and the health of their families. To that end, they were invited to spend up to 20 minutes of work time to get started on this task. Given that family history could impact not only the employees but also an estimated five family members for each participant, the potential reach as a public health effort exceeded the employee population. Importantly, participating individuals were in complete control of the data collected and were not asked to share family history data with "the project" as part of this effort. Instead, participants were encouraged to share this information with their families and their personal healthcare providers. The research associated with the project was survey-driven, centering on employee feedback to gauge project participation, and to obtain feedback on "usability of the tool" and outcomes related to its use.


\* Note that the number of hospital employees grew during the project period to an estimated 13,000 at the completion of the project

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## **Key Support**

- The National Institute of Health's National Human Genome Research Institute (NHGRI) was a key supporter of this employee-focused project at many levels and in many different ways. First, the NHGRI's Education and Community Involvement Branch (ECIB) released a request for proposals in 2005 for a "demonstration project on the integration of Family History and Genomics Education Materials and Resources into Communities". The BWH response to that RFP entitled "An Employee Based Family History Project within a Large Urban Hospital" was funded (see Appendix 1D). This contract was a critical support to the launch of these efforts.
  - In addition to the ECIB contract, NHGRI gave support throughout this project period with two visits from Dr. Francis Collins (the Institute's Director) and multiple teleconferences with Dr. Alan Guttmacher (the Institute's Deputy Director). Mr. Vence Bonham and Ms. Sarah Harding, as ECIB administrators of the contract, were engaged throughout the project, and Mr. Larry Thompson and his team provided sustained availability with technical support during the project.
  - Brigham and Women's Hospital, which is home to one of the most powerful Biomedical Research Institutes (BRI) in the world, also supported the project. The hospital's BRI which has total research expenditures topping \$370 million in FY2005 (64% attributed to NIH grants) established a mechanism in 2005 to provide seed money for selected research proposals which were submitted by any of the eight "affinity centers" within the BRI. The Genetics Affinity Center put forth a proposal for the BWH Family History Project, which was funded to support portions of the Phase 1 (employee-focused) and Phase 2 (patient-focused) work.
  - The Harvard-Partners Center for Genetics and Genomics (HPCGG) is a unique center within both Harvard Medical School and the Partners Healthcare System. The Center is composed of faculty with joint appointments at the Harvard Medical School and within the Partners Healthcare System and has the task of bringing genetics to patient care. This center provided salary support for several members of the project team during the project period (see funding summary).
  - The BWH Division of Genetics within the Department of Medicine has a longstanding commitment to genetics research. This academic unit led by Richard Maas (Division Chief) and Nina Zonneville (Administrative Manager) acts as the home within the hospital for this project and provided office space and administrative help throughout the project period.
  - The BWH Hospital executive administrative group was apprised of the plan for the family history project well before its launch. The BWH FHP enjoyed the full
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support of the hospital's executive management group throughout this effort. In addition to the formal approval of the project, many members of the executive committees were among the first participants and strongest advocates for this work.

- The Surgeon General's office provided leadership and support for the project through the help of Drs. Richard Carmona and Kenneth Moritsugu. Dr. Carmona who launched the Surgeon General Office's family history efforts was supportive throughout the project period. Dr. Kenneth Moritsugu visited the hospital in Spring 2006 to participate in project activities and meet with the children of hospital employees to discuss family health history.

### **Outreach and Communication**

The planning team identified two key concepts to communicate to employees right from the start: privacy and autonomy. Participants in this project were being asked to gather and organize their personal family health histories for their own benefit and for the benefit of their families. As such, the goals of the project included protecting the privacy of this information. The Surgeon General's web tool has many built in measures to protect this data including the "https" associated URL and government servers, which do not save the data. In addition this project did not save or analyze the family histories from participants in the project. Participants were free to keep their data private or to share it with family and primary care providers. While there were best use suggestions, participants were free to decide what happened to the recorded data.

In an effort to achieve another project goal, the planning team attempted to utilize as many different modes of outreach as possible, and to work consciously to include those who might be overlooked if the efforts were exclusively computer based. Specifically, direct outreach efforts were made throughout the year so as to engage those employees without computers as a routine part of their job, and those employees who may speak languages other than English as a primary language. These efforts included the distribution of outreach materials throughout the hospital, information booths erected in the hospital cafeteria as well as at offsite locations, data entry sessions in conjunction with the Occupational Health TB screening program, and direct outreach events with environmental, mailroom, and food service workers, among others (see Appendix 4A). FHP staff also worked with Interpreter Services and an outside translation company to translate the "My Family Health Portrait" paper tool into Portuguese, French, Chinese, and Polish for use by those non-native English-speaking groups with significant numbers of employees at BWH interested in participation (see Appendix 6A, 7A).

We received valuable input from employees throughout the project, including multiple hospital employees who told us that due to adoption, they were unable to participate. In an effort to address these comments, FHP staff created a resource for these individuals accessible through the BWH FHP intranet site (see Appendix 10A). Kris DeGraw

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Danna, BWH Director of Volunteer Services, also shared her personal experience as an adopted woman who now has children of her own.

Throughout the project period, specific outreach methods were developed and utilized to reach our diverse employee population. For instance, members of the team who were healthcare providers were used to address other healthcare providers in relevant settings, while our outreach specialists developed relationships key members of the non-healthcare workers.

Multiple venues for computer access were established for those employees without regular computer access or those who wished to have assistance with data entry, including the hospital library, computer learning lab, and our project's Interactive Center (see Appendix 3A). This Interactive Center was established within a high foot-traffic area of the hospital and was equipped with multiple stations with internet access.


A dedicated BWH FHP telephone number with a confidential voicemail box was attained through the hospital's Communications Department. The Director of Interpreter Services at BWH assisted the team in identifying those non-native English-speaking employee groups at BWH. In addition to direct outreach, this input resulted in the establishment of Spanish and French Creole confidential voicemail boxes. The hospital interpreter services team was available throughout the project to translate messages received in either Spanish or French Creole, and to help facilitate appropriate follow up. The BWH FHP established a project specific email account ([familyhistoryproject@partners.org](mailto:familyhistoryproject@partners.org)), as well as hospital intranet and internet pages (see Appendix 9A).

Additional key collaborations in our outreach efforts included working with human resources, public affairs, and the leadership of environmental, transport, and food services. Human resources assisted in outreach to the more than ten non-hospital locations where employees worked as well as providing the opportunity to speak to all newly hired employees during new employee orientation (see Appendix 4A11). Public affairs directed media coverage from outside sources as well as helping to coordinate internal communications (see Appendix 5A, 8A). Given the high percentage of employees in environmental, transport, and food services without routine computer access, the leadership of these groups was particularly helpful in promoting the project by allowing direct outreach to these employee groups.

### **Major Project Events**

The first institution-wide introduction of the BWH FHP came in an open letter from hospital president Dr. Gary Gottlieb to the hospital community (see Appendix 1A). One week prior to the launch of the project, a town hall meeting open to all hospital employees on November 7, 2005 was held. At this meeting the BWH FHP was introduced to the employees by Drs. Gary Gottlieb, Cynthia Morton, and Michael Murray. There was a question and answer period following a brief presentation. Coinciding with this meeting were all-user email blasts and hospital newsletter descriptions of the project

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plan. These emails included “frequently asked questions” about the planned project (see Appendix 2A).

A week later the BWH FHP was officially launched on November 15, 2005 during a national press conference held at BWH [the webcast of that media event is available at <http://www.hhs.gov/familyhistory/>]. During his keynote address, Dr. Francis Collins, director of the National Human Genome Research Institute (NHGRI), demonstrated version 2.0 of the Surgeon General’s “My Family Health Portrait” to attendees. Dr. Rick Mitchell, a pathologist at BWH, talked about his personal diagnosis of colorectal cancer and the benefits of knowing family history details such as that for close family members such as children. Just two weeks later, Dr. Collins returned to BWH on December 1, 2005 to join a panel to answer questions from BWH employees regarding the use of “My Family Health Portrait”.

Following the launch activities the project team worked throughout the year on major project events (see Appendix 1B, 2B), which highlighted the BWH FHP and its goals. Some of those events are highlighted in appendices B1 through B8.

### **Data Collection**

The data from the hospital employees was collected in five ways: direct feedback to project staff in conversation, open employee forums and email exchanges, a preliminary employee survey in late March 2006 (approximately 5 months after the initiation of the project), a final employee survey in Fall 2007 in the closing weeks of the project, and a single question participation ballot which was both emailed and directly distributed at the time of the projects completion. The participation surveys provided an opportunity for all employees to provide anonymous feedback on the usability of “My Family Health Portrait” (see Appendix 2C, 3C, 6C). Specifically, the surveys were structured to obtain information on participation, participant motivation, usability of the tool, experience related to participation, whether the compiled family health history was shared with family members or healthcare providers and the outcome of those interactions. As with any survey driven data collection, there are potential biases in survey responses, however survey and “ballot” participation numbers were sizable and provide valuable insight into the use of this kind of data collection tool.

The project’s Senior Programmer worked with NHGRI’s Information Technology staff to ascertain the number of visits to different project websites. Retrospective analysis showed increased visits to all FHP-associated sites during the project year (see Appendix 4C). This reflected only a portion of total employee visits as many organized their family health history on home computers. The programming teams from HHS and BWH worked together to resolve recognized usability issues identified by employee participants (see Appendix 5C).

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## **Conclusions**

The US Surgeon General's web based "My Family Health Portrait" is a useful tool for gathering and recording family health history. The version that was available during this project period (November 2005 to December 2006) was associated with an estimated 35% participation in its use among a group of over 12,000 hospital employees in Boston. Continuous improvement of this program during the project period and in the months since the completion of this project make it likely that its usability is continuing to improve.

This document is focused on illustrating the nature and scope of the project together with the tools used in the outreach. Two upcoming peer reviewed and published manuscripts will detail more of the data results and analysis. However, we highlight here in this overview two of the more interesting findings in that data. First, an estimated 4,500 (35%) of our hospital employees reported gathering or organizing family health history during this project year. This participation occurred in the presence of a year-long campaign to educate and support the use of the tool but without any specific reward for participation in the project.


Second, we had the somewhat unique opportunity to be able to capture survey data from employees about "non-participation" in the activity of gathering and organizing family health history. Among those who responded via anonymous survey, we found only 11% actively decided not to participate in this activity; instead the overwhelming majority admitted that they simply did not know enough about the activity or had not yet made the time for this task within their busy schedules.

Some barriers to participation were removed through the design of the project, specifically access to support services and necessary data entry tools. Most non-participants suggested they would have participated if they had made time. Future projects of this nature should seek specific methods for motivating participants in this category, such as having primary care providers directly communicate the importance of this activity.

Based on the experience in this project, as well as other family health history work, our team believes that a truly simple tool, i.e. the family health history, which has been long used by health care providers, has the potential to develop into a robust tool for health care decision making in the 21<sup>st</sup> century. In order to fulfill this more vigorous role, the family health history will need to be combined with new computer based information technology as well as new information from human genetic research.

We propose that model systems be developed and validated which focus on these four achievable steps toward a 21<sup>st</sup> century model of "family health history" implementation. [1] The work of entering the primary data, which takes at least 20 minutes of time, needs to be shifted away from health care providers and to patients and their families, who can use programs like "My Family Health Portrait" to save data in a structured and editable





format. [2] The work of editing and refining data needs to be a collaborative process and, when possible, the participants in this process should include multiple family members as well as their health care providers. [3] Healthcare providers who are guiding patients based on family history information need to have computer based decision support in place to provide rapid interpretations of family history data based on the most up to date genetic and genomic information. [4] A universal goal of comprehensive structured family history datasets for all patients should be established. These datasets should exist within provider electronic medical records and patient controlled personal health records. There should be a clear standard that defines a “comprehensive dataset” as one that includes at a minimum all available first and second-degree relatives.

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## ***B. Employee Based Project Summary Presentation***

This PowerPoint presentation was given by Dr. Michael Murray in Nashville, TN on March 26, 2007 at the invitation of the American College of Medical Genetics Program Committee as part of the College's Annual Meeting.

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## A Hospital Employee-Focused Family History Project

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Brigham and Women's Hospital, Boston, MA

American College Medical Genetics  
Nashville, TN  
March 2007

### Also Known As



BRIGHAM AND  
WOMEN'S HOSPITAL  
Family History Project

[www.brighamandwomens.org/familyhistory](http://www.brighamandwomens.org/familyhistory)

## BWH Family History Project

- November 2005 - November 2006
- Encouraged and supported the use of the US Surgeon General's Family History Tool amongst the 13,000 employees of our large academic medical center.
- Goals included:
  - Identify the obstacles to participation
  - Understand what participants do with the information
  - Understand what providers do with the information
- Invaluable support from Senior Hospital Management including allowing all employees 20 minutes of time from their work to work on family history job time

## BWH Family History Project

### Why Hospital Employees?

"Change the culture of the Hospital"

Train the trainer in family history [for future efforts]

Build a model for other hospitals and health care institutions  
[Note: Employees of hospitals comprise over 3.5% of the U.S. workforce and more than 1% of the total U.S. population]

## BWH Family History Project 2005-2006

- Participating employees completely control their own information.
- BWH employees who wish, can deliver information to providers.
- Project was not designed to collect or analyze employee family health histories.
- Project data was survey derived

## DESCRIPTION OF THE PROJECT

### Outreach

including intranet and internet

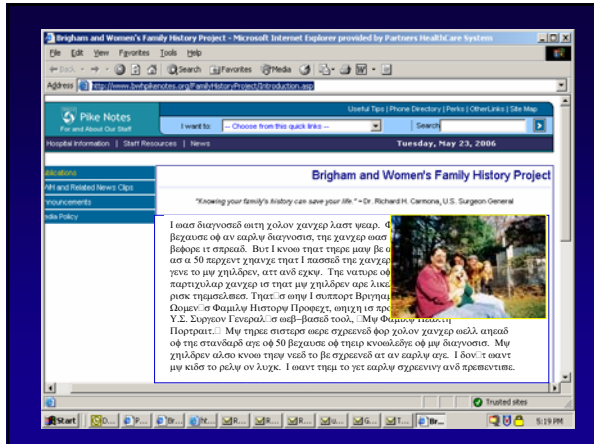
### Education

including talks to employee groups

### Data Entry

including an "family history station"

### Sponsored Events



## DESCRIPTION OF THE PROJECT

### The Team

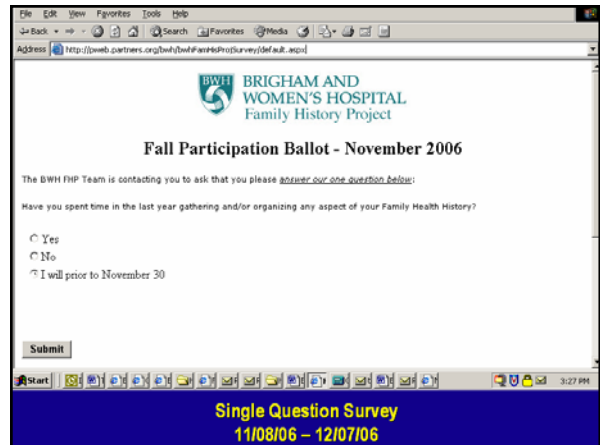
- 0.35 FTE outreach specialist
- 0.35 FTE computer programmer
- 1.0 FTE coordinator
- 0.5 FTE genetic counselor
- dozens of volunteers

## Estimating Employee Participation (November 2005-2006)

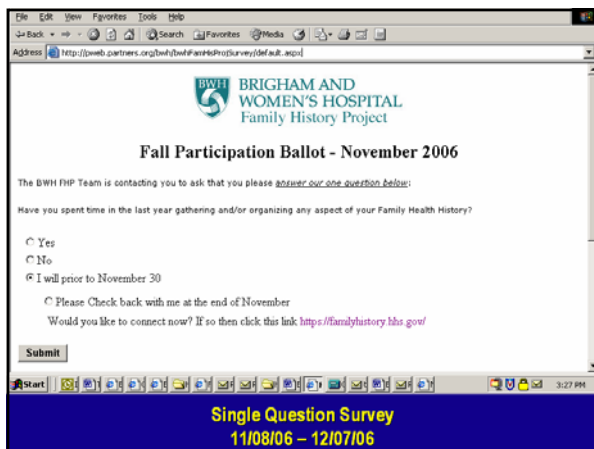
### Distribution of "Single Question Survey"

- [1] "all user" email
- [2] paper distribution to employees without email accounts

*"Have you spent time in the last year gathering and/or organizing any aspect of your Family Health History?"*



Single Question Survey  
11/08/06 – 12/07/06



Single Question Survey  
11/08/06 – 12/07/06

## "Single Question Survey" Results

"All User" email sent on 11/8/6 to 12,767 employees  
1343 responded [10.5%]

Response	Employees	Percent of Responses
Yes	482	36
No	818	61
Check Back	43	3

## Two Major Multi-question Employee Survey Periods

**N = 395 surveys received in first period (March 2006)**

**N = 187 (47%) Completed Family History**  
**N = 208 (53%) Had not completed Family History**

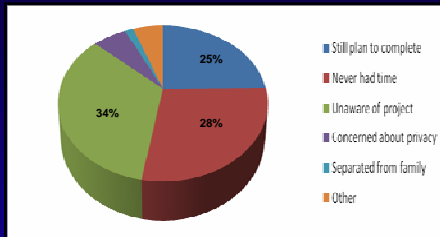
## Two Major Multi-question Employee Survey Periods

**N = 395 surveys received in first period (March 2006)**

**N = 187 (47%) Completed Family History**  
**N = 208 (53%) Had not completed Family History**

**N = 965 surveys received in second period (November 2006)**

**N = 182 (19%) Completed Family History**  
**N = 783 (81%) Had not completed Family History**



**Final Survey Period**

**Reasons for not completing FHP**

## Motivation for completing the Surgeon General's "My Family Health Portrait"

**[check all that apply]**

61% I thought it would be interesting  
 18% I thought it would be fun  
 47% I thought it could be beneficial to my health  
 18% I did it for the sake of a family member  
     3% a parent  
     6% a brother or a sister  
     12% a child  
     4% other  
 18% I was encouraged by my co-workers or supervisors  
 14% Other

## We got people talking

Did you learn anything new about the health of your relatives in the process of completing your family health history?  
 33% Yes

Did you share anything about your health with a relative in the process of completing/collecting your family health history?  
 29% Yes

Would you encourage others to participate in the BWH Family History Project?  
 94% Yes

## We got people talking

21% Discussed with their Health Care Professional

**What happened in that encounter?**

61% Estimated PCP's interest as very high  
 25% Received recommendation of specific lifestyle changes  
 18% Referral to a consultant (most to cardiology or GI)  
 33% Nothing, we didn't even discuss it

## Conclusions

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- Based on survey data we estimate that during our BWH Family History Project:
  - 4,500 employees worked on Family Health History
  - 18% participated based on coworkers recommendation.
  - 21% of survey respondents took family history to PCP
  - Only 11% of people who had not participated had an active reason for not participating.

## What will it take move comprehensive Family History Information into EMR

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- Gathering and organizing of family history data should be done by the patient, not the provider.
- There must be (electronic) tools and decision support for both patients and providers.
- Healthcare providers will need to be specifically motivated to participate.
- Initially, campaigns should be designed around a specific disease for which there are opportunities for intervention.

## Acknowledgements

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- **Financial Support from:**
  - NHGRI- Education and Community Involvement Branch [V. Bonham and S. Harding]
  - BWH Biomedical Research Institute
  - Harvard-Partners Center for Genetics and Genomics
- **Special Thanks to:**
  - Anne Coakley, Karen Holbrook, Peter Zumphe and Phillistine Ongondo
  - The 13,000 employees of BWH



BWH Family History Project  
resources and further description at:  
[www.brighamandwomens.org/familyhistory](http://www.brighamandwomens.org/familyhistory)



### *C. Funding for this Project*

**We gratefully acknowledge the major funding sources for this project; they are:**

**NHGRI (National Human Genome Research Institute)** – The Education and Community Involvement Branch (ECIB) of the NHGRI develops education and community involvement programs to engage a broad range of the public in understanding genomics and accompanying ethical, legal, and social issues. In July 2005 ECIB issued a request for proposals for a “Demonstration Project on the Integration of Family History and Genomics Education Materials and Resources into Communities.” The ECIB chose to fund a proposal that was submitted from BWH entitled: An Employee-Based “Family History Project” Within A Large Urban Hospital (attached as appendix D2).

**BRI (BWH-Biomedical Research Institute)** – The BRI Development Grants offered the opportunity in September 2005 to apply for seed money to allow for “nucleation” of the new BWH-Biomedical Research Institute (BRI) Working Groups. Drs. Maas and Morton, as co-chairs of the Genetics Working Group, supported an effort to use this funding opportunity to apply for internal “matching funds” from the institution. On January 10<sup>th</sup> 2006 notification of funding was received.

**HPCGG (Harvard-Partners Center for Genetics and Genomics)** – This center has supported the Family History Project through ongoing salary support for the Principal Investigator and Project Coordinators as well as through the purchase of computer hardware for Program outreach.

Additional support came from the BWH Division of Genetics and the Brigham and Women’s Hospital.

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## *D. Project Staff*

### **SENIOR STAFF:**

**Michael F. Murray, MD** (*Project Director 2005-2007*) – Dr. Murray is the Clinical Chief of the Genetics Division within the Department of Medicine at Brigham and Women’s Hospital and is on the faculty of Harvard Medical School. He was responsible for directing all aspects of this Project. His contribution to this project was supported with funding from the HPCGG.

**Karen Holbrook, MS, CGC** (*Project Coordinator 2005-2006*) – Ms. Holbrook is a Genetic Counselor in the Adult Medical Genetics Program at Brigham and Women’s Hospital. She coordinated all aspects of this Project and supervised the activities of the volunteers and staff. Her contribution to this project was supported with funding from the HPCGG.

**Monica Giovanni, MS** (*Project Coordinator 2007*) – Ms. Giovanni is a Genetic Counselor in the Adult Medical Genetics Program at Brigham and Women’s Hospital. She helped lead the project sub-study on the use of clinical genetic services, and she assumed the role of project coordinator following Ms. Holbrook’s departure. Her contribution to this project was supported with funding from the HPCGG.

**Phillistine Ongondo** (*Outreach Coordinator 2006*) – Ms. Ongondo assisted in all aspects of the project as a “non-clinical” member of the team, with a strong emphasis on introducing the project to and working directly with BWH employees. She was able to capitalize on her long tenure as a BWH employee to connect with employees throughout the institution. Her contribution to this project was supported with funding from the BRI.

**Peter O. Zumpfe** (*Project Information Technology Director 2005-2007*) – Mr. Zumpfe is a computer programmer with extensive experience in helping create interfaces between programs for clinicians using family history software. His contribution to this project was supported with funding from the NHGRI and the BRI.

### **ADDITIONAL STAFF:**

**Anne Coakley** (*Outreach Specialist*) – Ms. Coakley was a half-time member of the team who contributed to data organization, data entry assistance, and employee outreach. Her contribution to this project was supported with funding from the NHGRI.

**Sharon Orcutt Peters** (*Program Administrator*) – Ms. Peters provided administrative support and aided in the organization of the final report. Her contribution to this project was supported with funding BRI funds.

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**PROJECT ADVISORY TEAM:**

**Brigham and Women's Hospital (BWH)**

**Peter R. Brown** (Vice-President Public Affairs & Communication)

**Robert C. Goldszer, MD, MBA** (Associate Chief Medical Officer)

**John Lew** (Assistant Director of Human Resources)

**Richard L. Maas, MD, PhD** (Chief of the Genetics Division)

**Cynthia C. Morton, PhD** (Director of Cytogenetics)

**Dinah Vaprin** (Director of Public Affairs)

**TECHNICAL SUPPORT:**

**National Human Genome Research Institute (NHGRI)**

**Lynn Baumeister**

**Vence L. Bonham, Jr., JD** (Chief, Educational and Community Involvement Branch)

**Francis S. Collins, MD, PhD** (NHGRI Director)

**Alan E. Guttmacher, MD** (NHGRI Deputy Director)

**Sarah Harding, MPH** (Community Outreach Analyst, Educational and Community Involvement Branch)

**Larry Thompson** (Chief, Communications and Public Liaison Branch)

Note that these advisors contributed to the effort in an ongoing manner during this employee-focused project. We are also grateful to the many other project advisors who contributed expertise and feedback in an *ad hoc* manner.





## II. Appendices

### *A. Education and Outreach*

#### *Appendix 1A. Letter to the Hospital Community from Dr. Gary Gottlieb, Brigham and Women's Hospital President*

Brigham and Women's Hospital's Executive Management Group provided the FHP with their full support, including a letter of support to the hospital community from Hospital President Gary Gottlieb. Dr. Gottlieb's letter was emailed to all BWH staff and was also posted on the FHP's intranet site.