



C. Data and Data Collection

Appendix 1C. IRB Notification of Exemption

A proposal for the Brigham and Women's Hospital Family History Project was submitted to the Institutional Review Board (IRB) of Brigham and Women's Hospital for their review. On November 25, 2005, the principal investigator was notified of the proposal's approval. As the BWH FHP was not designed to either collect or analyze an employee's family health history, the BWH FHP received an "exempt" status from the hospital's IRB.

•
•
•
•
•
•
•
•

1C. IRB Notification of Exemption



Partners Human Research Committee
Partners Human Research Office
116 Huntington Avenue, Suite 1002
Boston, MA 02116
(617) 424-4100

Application: Notification of Exemption

Protocol #: 2005-P-002383/1; BWH

Date: 11/29/2005

To: Michael Murray, MD
Harvard New Research Bldg.
77 Avenue Louis Pasteur

From: Thelma Bennett
PHS Research Management
116 Huntington Ave Suite 1002

Elvira O'Neill for T.D.

Title of Protocol: Brigham and Women's Hospital Family History Project
Version Date: 11/10/2005
Sponsor: NIH-NHGRI National Human Genome Research Institute
IRB Review Type: Exempt
Exemption #: 45 CFR 46.101(b) (2) Use of educational tests, survey procedures, observation, etc. to collect anonymous data.
IRB Approval Date: 11/28/2005


This project meets the criteria for exemption from further IRB review per the regulations found at 45 CFR 46.101(b) (2) Use of educational tests, survey procedures, observation, etc. to collect anonymous data.

Additional review by the HRC (IRB) is not needed. You will not be required to submit annual progress reports; however you may not make changes to this research activity without first discussing them with the Human Research Office (IRB) to determine that such changes are within the parameters for exemption.

•
•
•
•
•
•
•
•

—————

—————



Appendix 2C. Spring (Preliminary) Participation Survey – March 2006

Data collection for the BWH FHP included two separate rounds of anonymous survey-based feedback on the usability of the “My Family Health Portrait” tool. The first of the two survey periods occurred in March 2006, approximately one-third of the way through the project. Surveys were returned either electronically or at drop-off locations within the hospital and off-site locations.

Forty-seven percent of survey respondents answered that they had already completed their family histories using “My Family Health Portrait”.

A group of 24 BWH employees agreed to a follow up telephone conversation. These interviews allowed for better understanding of how to target outreach in the remaining months of the project.

[1] Survey Instrument

[2] Telephone follow-up interview of participants

•
•
•
•
•
•
•
•

2C1. Spring Participation Survey



BWH Family History Project Employee Participant Survey

(it will take approximately five minutes to complete this survey)

Date of this Survey ___/___/___

Age _____
Gender _____ Female _____ Male

Ethnicity or Race (mark one or more)
____ American Indian or Alaska Native
____ Asian or Pacific Islander
____ Black or African American
____ Hispanic or Latino
____ White or European American
____ Other, please specify: _____

1. Which of the following describes your employment at BWH? [check one]
____ Management
____ Health care professional
____ Service
____ Administrative
____ Researcher
____ Not sure
____ Non-employee
2. Did you complete the Surgeon General's "My Family Health Portrait"?
____ Yes
____ No
If no, why not? _____

If you answered "no" to question #2 you may stop here (or go to <https://familyhistory.hhs.gov> to participate now). Thank you for completing this survey.

If you answered "yes" to question #2, please continue this survey.

2C1. Spring Participation Survey

3. What motivated you to complete your family health history using the Surgeon General's "My Family Health Portrait"? [check all that apply]
- I thought it would be interesting
 - I thought it would be fun
 - I thought it could be beneficial to my health
 - I did it for the sake of a family member
 - if you had a family member in mind, was it
 - a parent
 - a brother or a sister
 - a child
 - other [relationship? _____]
 - I was encouraged by my co-workers or supervisors
 - Other, please explain _____
4. How long did it take you to get through the "My Family Health Portrait" the first time? (almost everyone will leave blanks and have "I don't know" answers at first) [check one]
- Less than 10 minutes
 - 10-20 minutes
 - 20-30 minutes
 - 30-60 minutes
 - More than 1 hour
5. How many times have you returned to your family health history document to add or change information? [check one]
- None
 - 1
 - 2-3
 - 4-5
 - More than 5
6. What difficulties did you have in completing your family health history? [check all that apply]
- Discussing the subject of health history with family members
 - Knowing what questions to ask my family members
 - Obtaining the health history information
 - Knowing where or how to enter information
 - Using the computer version of the history tool
 - Other, please explain _____
 - None
7. Would you encourage others to participate in the BWH Family History Project?
- Yes
 - No
8. Did you learn anything new about the health of your relatives in the process of completing your family health history?
- Yes
 - No

2C1. Spring Participation Survey

9. Did you share anything about your health with a relative in the process of completing/collecting your family health history?
- Yes
 - No
10. What did you do with the family health history portrait you created? [check all that apply]
- Kept it to myself
 - Shared it with my health care provider
 - Shared it with my family members
 - which family members did you share it with? [check all that apply]
 - a parent
 - a brother or a sister
 - a child
 - other [relationship? _____]
 - Other, please explain _____
11. How many relatives did you talk to in completing your family health history? [check one]
- None
 - 1
 - 2-3
 - 4-5
 - More than 5
12. If you brought your family health history to your health care provider, which of the following occurred? [check all that apply]
- Discussion
 - Recommendation of specific lifestyle changes
 - Genetic testing
 - Medical testing other than genetic testing
 - Referral to a consultant [check all that apply]
 - Genetic Counselor
 - Medical Geneticist
 - Oncologist
 - Gastroenterologist
 - Cardiologist
 - Endocrinologist
 - Ophthalmologist
 - Other, please specify _____
 - Nothing, we didn't even discuss it
 - I did not bring my family health history to my health care provider if not, why not? _____
13. Are you interested in having a genetics professional (a genetic counselor or medical geneticist) review your family health history with you?
- Yes
 - No
- [If you answered "yes," please provide your contact information:
_____]

2C1. Spring Participation Survey

14. May a BWH Family History Project staff member contact you to discuss further questions related to your participation in this project?

Yes

No

[If you answered "yes," please provide your contact information:

_____]

15. Have you filled out the BWH Family History Project survey before?

Yes [How many other times?]

No

16. What changed your mind, if the last time you filled out a survey you answered "NO" to question 2, "Did you complete the Surgeon General's "My Family Health Portrait"?"

Friends and co-workers described it as a positive experience

I was encouraged to participate by a family member

I am more trusting of the process now

Other, please explain _____

This doesn't apply to me

17. Have you heard of the Surgeon General's Family History Initiative?

Yes

No (Go to 19)

18. If you answered "yes" to question 17, when did you first hear about the Surgeon General's Family History Initiative?

Before I heard about the BWH Family History Project

After I heard about the BWH Family History Project

19. Where did you first hear about the importance of collecting your family's health history?

Television

Newspaper

Magazine

Health Professional

BWH Family History Project

Surgeon General's Family History Initiative

THANK YOU FOR COMPLETING THIS SURVEY!

If you have questions please contact us at 617-525-4777 or familyhistoryproject@partners.org.

If you would like to return your completed survey by interoffice mail, please send it to:
Family History Project
BWH Genetics Division
NRB 466E

2C2. Telephone Follow-up Interview of Participants

1. How did you hear about the BWH Family History Project (be as specific as possible)?
-

2. Did you complete your family history at home, at work, or both?

_____ Home _____ Work _____ Both

3. Did you enter information about any additional diseases [other than the standard six diseases asked about for each family member on the Surgeon General's website] for any family members?

_____ Yes _____ No

4. Have you emailed your electronic family history to any of your family members?

_____ Yes _____ No

5. Did you use the paper version of "My Family Health Portrait" during any of your data collection?

_____ Yes _____ No

6. Do you have any thoughts on how to encourage BWHers to participate in the Family History Project?
-

7. Do you have suggestions for getting BWHers to participate in our fall survey period?
-

8. Please rate your enthusiasm about bringing your family health history to your primary care provider, with 1 being the least enthusiastic and 5 being the most enthusiastic (please be honest!):

_____ 1 _____ 2 _____ 3 _____ 4 _____ 5

9. Using the same enthusiasm scale from 1-5 from the last question, with 1 being the least enthusiastic and 5 being the most enthusiastic, please tell me how enthusiastic your health care provider seemed to be about receiving your family health history:

_____ 1 _____ 2 _____ 3 _____ 4 _____ 5

10. If your health care provider ordered a test or made a referral for you after reviewing your family health history, can you please share those specifics with me?
-

2C2. Telephone Follow-up Interview of Participants

Phone script for people who have received email notifying them that you would be calling:


Hello,

My name is Lauren Ryan, and I'm calling to follow-up with you regarding the preliminary Family History Project survey you completed in March. On that survey, you answered "yes" to the question, "May a BWH Family History Project staff member contact you to discuss further questions related to your participation in this project?". You should have received an email from the Family History Project on _____ informing you that I would be calling to ask you a few follow-up questions about your participation in the Family History Project. This telephone call should take between 10 and 15 minutes. Is this a good time for you?

Phone script for "cold calls"(those employees for whom we do not have an email address):

Hello,

My name is Lauren Ryan, and I'm calling to follow-up with you regarding the preliminary Family History Project survey you completed in March. On that survey, you answered "yes" to the question, "May a BWH Family History Project staff member contact you to discuss further questions related to your participation in this project?". I am calling to ask you a few follow-up questions about your participation in the Family History Project. This telephone call should take between 10 and 15 minutes. Is this a good time for you?



Appendix 3C. Fall (Final) Participation Survey – November 2006

The Spring participation survey was subsequently modified to create the Fall survey, which was distributed in November 2006. Surveys were again returned either electronically, via one of our drop-off location sites, or handed directly to project staff and volunteers.

Approximately three-quarters (73%) of Fall survey respondents were female and 26% were male, which is consistent with the gender distribution of BWH hospital employees (74% female, 26% male). The reasons that majority of non-participating employees reported not yet completing their family histories were either “being unaware of the project” or “a lack of time”. Notably, one-quarter of employees (25%) reported that they still planned to complete their family histories and very few (6%) expressed concerns about privacy.

Over half of the project participants either learned something new about their relatives’ health histories or shared something about their own health with a relative (54% and 58%, respectively). While 55% of respondents kept the family history they created to themselves, 21% shared the information with their health care provider. For the 21% of employees who brought their completed family histories to their health care providers, 61% estimated their provider’s interest as very high, 25% received recommendations for specific lifestyle changes, 18% were referred to a specialist (most often a cardiologist or gastroenterologist) and 33% reported that the family history they brought with them to their appointment was not addressed. Ninety-two percent of respondents reported that they would encourage others to participate in the BWH FHP.

[1] Survey Instrument

•
•
•
•
•
•
•
•

—————

—————

3C1. Fall Participation Survey



BWH Family History Project Employee Participant FALL SURVEY

(it will take approximately five minutes to complete this survey)

Date of this survey ___/___/___

Have you completed this survey previously? ___ yes ___ no

Age _____

Gender _____ Female _____ Male

Ethnicity or Race (check one or more)

_____ American Indian or Alaska Native

_____ Asian or Pacific Islander

_____ Black or African American

_____ Hispanic or Latino

_____ White or European American

_____ Other, please specify: _____

1. Which of the following describes your employment at BWH? (check one)

_____ Management

_____ Health care professional

_____ Service

_____ Administrative

_____ Researcher

_____ Not sure

_____ Non-employee

2. Did you complete your family history using the Surgeon General's "My Family Health Portrait"?

_____ Yes (***please circle one***: I completed it **on line** **on paper**)

_____ No **If no, please tell us why?**

_____ I still plan to do it

_____ Never had time to complete

_____ I was unaware of the project

_____ I was concerned about privacy

_____ I am separated from my family (e.g. adoption)

_____ Other, please explain _____

If you answered "no" to question #2 you may stop here (or go to <https://familyhistory.hhs.gov> to participate now). Thank you for completing this survey.

If you answered "yes" to question #2, please continue this survey.

3C1. Fall Participation Survey

3. If you previously returned a survey (e.g. our March 2006 survey) stating that you had not completed your "Family History", what changed since then? (check all that apply)
- Not Applicable
 - I have since learned more about the project
 - Friends or co-workers have described a positive experience
 - I was encouraged to participate by a family member
 - I am more trusting of the process now
 - New health concern
 - Other, please explain _____
4. **Rate the strength** of these **motivating factors** for you in completing your family health history using the Surgeon General's "My Family Health Portrait", with 0 being the least motivating factor and 5 being the most motivating factor:
- | | |
|-------------|---|
| 0 1 2 3 4 5 | I thought it would be interesting |
| 0 1 2 3 4 5 | I thought it would be fun |
| 0 1 2 3 4 5 | I thought it could be beneficial to my health |
| 0 1 2 3 4 5 | I did it for the sake of a family member |
| | if you had a family member in mind, was it |
| | <input type="checkbox"/> a parent |
| | <input type="checkbox"/> a brother or a sister |
| | <input type="checkbox"/> a child |
| | <input type="checkbox"/> other [relationship? _____] |
| 0 1 2 3 4 5 | I was encouraged by my co-workers or supervisors |
| | Other motivation, please explain _____ |
5. **How many times** have you returned to your family health history document to add or change information? [circle one]
- | | | | | |
|---|---|-----|-----|----|
| 0 | 1 | 2-3 | 4-5 | >5 |
|---|---|-----|-----|----|
6. **Rate the difficulty of each task** in completing your family health history, with 0 being the least difficult and 5 being the most difficult?
- | | |
|-------------|---|
| 0 1 2 3 4 5 | Discussing the subject with family members |
| 0 1 2 3 4 5 | Knowing what questions to ask my family members |
| 0 1 2 3 4 5 | Obtaining the health history information |
| 0 1 2 3 4 5 | Knowing where or how to enter information |
| 0 1 2 3 4 5 | Using the computer version of the history tool |
7. Would you encourage others to participate in the BWH Family History Project?
- Yes
 - No
8. Did you learn anything new about the health of your relatives in the process of completing your family health history?
- Yes
 - No
9. Did you share anything about your health with a relative in the process of completing/collecting your family health history?
- Yes
 - No

3C1. Fall Participation Survey

10. What did you do with the family health history portrait you created? (check all that apply)

- Kept it to myself
- Shared it with my health care provider
- Shared it with my family members
 - which family members did you share it with? [check all that apply]
 - a parent
 - a brother or a sister
 - a child
 - a cousin
 - other [relationship? _____]
- Other, please explain _____

11. How many relatives did you talk to in completing your family health history? (check one)

- None
- 1
- 2-3
- 4-5
- More than 5

12. As a result of your participation in the Family History Project, did you bring family history information to your healthcare provider?

- Yes
 - If yes, please estimate your provider's interest, with 0 being the least interested and 5 being the most interested: 0 1 2 3 4 5
- No
 - If no, please tell us why: _____

13. If you answered yes to #12, please check all of the following that occurred: (check all that apply)

- Discussion
- Recommendation of specific lifestyle changes
- Genetic testing
- Medical testing other than genetic testing
- Referral to a consultant [check all that apply]
 - Genetic Counselor
 - Medical Geneticist
 - Oncologist
 - Gastroenterologist
 - Cardiologist
 - Endocrinologist
 - Ophthalmologist
 - Other, please specify _____
- Nothing, we did not even discuss it

14. Are you interested in having a genetics professional (a genetic counselor or medical geneticist) review your family health history with you?

- Yes
 - If yes, please provide your contact information: _____
- No

3C1. Fall Participation Survey

15. May a BWH Family History Project staff member contact you to discuss further questions related to your participation in this project?

Yes

No

[If you answered "yes," please provide your contact information:

_____]

16. Have you heard of the Surgeon General's Family History Initiative?

Yes

No (Go to 19)

17. If you answered "yes" to question 16, when did you first hear about the Surgeon General's Family History Initiative?

Before I heard about the BWH Family History Project

After I heard about the BWH Family History Project

18. Where did you first hear about the importance of collecting your family's health history?

Television

Newspaper

Magazine

Health Professional

BWH Family History Project

Surgeon General's Family History Initiative

THANK YOU FOR COMPLETING THIS SURVEY!

If you have questions please contact us at 617-525-4777 or familyhistoryproject@partners.org or check out our websites at: www.brighamandwomens.org/FamilyHistory and www.bwhpikenotes.org/familyhistoryproject/introduction.asp

If you would like to return your completed survey by interoffice mail, please send it to:

Family History Project
BWH Genetics Division
NRB 466E

If you would like to return this by email, please attach it to an email and send to:

familyhistoryproject@partners.org



Appendix 4C. Website Visits and Page Views

The project's Senior Programmer worked with the NHGRI's Information Technology staff to generate a listing of the number of visitors to the different project websites.

[1] Listing of Hits to "My Family Health Portrait" from Partners computers

[2] Listing of Hits to Brigham and Women's Hospital Family History Project Internet Website

•
•
•
•
•
•
•
•

4C1. Listing of Hits to "My Family Health Portrait" from Partners Computers



**BRIGHAM AND
WOMEN'S HOSPITAL**

My Family Health Portrait

Logons from Partners Computers:
November 2005 - June 2007

<http://familyhistory.hhs.gov>

Month	PARTNERS		BIDMC	
	visits	views	visits	views
Nov 05	228	3,013	42	122
Dec 05	119	2,193	61	398
Jan 06	98	2,198	22	62
Feb 06	77	1,414	58	178
Mar 06	489	10,627	51	352
Apr 06	87	2,763	51	224
May 06	100	3,225	31	96
Jun 06	136	2,993	49	185
Jul 06	143	5,114	33	87
Aug 06	92	2,549	41	89
Sep 06	79	2,556	33	80
Oct 06	97	2,462	35	140
Nov 06	324	6,218	60	154
Dec 06	42	1,231	25	67
Jan 07	18	319	59	239
Feb 07	11	120	40	165
Mar 07	17	784	19	29
Apr 07	19	471	48	81
May 07	15	225	48	160
Totals:	2,191	50,475	806	2,908

Visit = A unique computer address

View = How many pages the computer address visited

BIDMC is a comparable academic medical center in Boston. BIDMC did not have any specific program to engage employees in the use of the US Surgeon General's web-based tool and is shown here as a control for the basal activity that could be expected for this time period at this kind of institution.

4C2. Listing of Hits to BWH FHP Internet Website



**BRIGHAM AND
WOMEN'S HOSPITAL**

BWH FHP Webpage

Vists to the Project Web Page
July 2006 - October 2006

www.brighamandwomens.org/familyhistory

Month	New Vistors	Total Visits
	<i>visits</i>	<i>visits</i>
Jul 06	25	36
Aug 06	106	229
Sep 06	115	175
Oct 06	155	226
Nov 06	530	774
Dec 06	396	719
Jan 07	367	731
Feb 07	362	727
Mar 07	415	733
Apr 07	295	311
May 07	288	300
Jun 07	316	343
Jul 07	230	414
Aug 07	298	659
Sept 07	361	660
Oct 07	288	487
Totals:	4,547	7,524



Appendix 5C. Feedback to “My Family Health Portrait” Site

Data collection for the BWH FHP included feedback on the usability of the U.S. Surgeon General’s “My Family Health Portrait” tool and the outcomes of bringing this information to health care providers. Throughout the project, feedback was continually generated on the usability of the U.S. Surgeon General’s “My Family Health Portrait” tool and the outcomes of bringing this information to health care providers.

This collection of data has not only allowed for continued improvement of the web-based tool, but it will also facilitate the understanding of what health care “consumers” and providers need to start building a robust system for patient data entry and health care provider-reviewed family health history information in an electronic format.

•
•
•
•
•
•
•
•

5C. Feedback to "My Family Health Portrait" Site

Feedback on "My Family Health Portrait" Web Based Tool

The employee users of the Surgeon General's Web tool have been encouraged to communicate with the project staff (via direct communication, email or telephone) with ideas regarding ways to improved the usability of the site.

Listed below are a series of communications between our project team member (Peter Zumphe) and the NHGRI usability group.

1). Add a primary key field

Category: Enhancement request

Rationale: Will be needed to facilitate bi-directional transferring and updating of data stored in the patient's electronic medical record should the patient chose to do so. It is also useful meta-data to indicate the number of problems that users encounter and the order in which relatives are entered and the number of times users need to delete and start again. This information can be used to enhance the intuition users have in entering data.

Comment: Can then also tell how often relatives have needed to be deleted and re-entered.

Resolution: Pending - discussed with Lynn Baumeister

2). Inclusion of an automated email option

Category: Enhancement request

Rationale: While there is reference to sending a file with the proband re-defined to another relative(s), some mention should be made as to how 'right-clicking' on the stored file can be used to email the file using the "send to" option, at least on the Microsoft platforms.

Comment: This is probably difficult to accomplish with html programs on differing platforms.

Resolution: Discussed with Lynn Baumeister

3). Inclusion of a Patient Current Questions Fields

Category: Enhancement request

Rationale: Since it is often recommended that patients bring a list of their questions with them to their provider, it would seem natural to attempt to use this as an additional incentive for patients to include this as part of their family history. The more incentives we can tag to the family history program the better

5C. Feedback to "My Family Health Portrait" Site

Comment: Can use the same field structure as the "other diseases field"

Synonyms:

- Problem list
- Chief complaint
- Past diseases and concerns
- Current anxieties about future health concerns

Outcome: Pending - proposed to Lynn Baumeister

4). Save_info Screen

Category: Enhancement request

Rationale: The process seems to not have any options so why not just have the script run.

Outcome: Discussed at length with Lynn Baumeister, will need to present again.

5C. Feedback to "My Family Health Portrait" Site

5). Eliminate Prominence of Delete Relative controls (1426)

Category: Enhancement request

Rationale:

- These controls are way too prominent - as though deleting is the most often used functionality
- Recommend replacing 'delete' with 'edit'

Resolution: pending

- Discussed with Lynn Baumeister
- In progress

The screenshot shows the "My Family Health Portrait" website interface. At the top left is the logo "My Family Health Portrait" with the tagline "A tool from the U.S. Surgeon General". To the right are two circular logos. A yellow horizontal bar spans the width of the page, with a "Help with this page" button on the right. Below the bar, on the left, is a vertical stack of family photos. The main content area is titled "My Family" and lists several family members with their names, relationships, and progress bars. The names and relationships are: Peter Zumpfe [Me], Peg [Mother], Margaret [Mother's Mother], Arthur [Mother's Father], Oscar [Father], Ida [Father's Mother], Oscar B. [Father's Father], Maniah [Daughter], Carl [Brother], and Paul [Brother]. Each name has a blue link to their profile. To the right of each name is a green progress bar of varying length, followed by an asterisk. Below the list, there is a note: "Note: The percent of green in the progress bars is a rough indicator of how much of the information has been entered for each relative." and a warning: "* You can't delete yourself, your parents or your grandparents." To the right of the family list is an "Actions:" section with several links: "View Reports (family tree drawing, health history chart)", "Add Family (aunts, uncles, etc.)", "Edit My Profile (age, height, weight, etc.)", "Save My Health Information to My Computer" (with a download icon), "Save My Health Information as Another Relative (for a parent, a child, or sibling, etc.)", and "Start Over (create a new history, or load a saved history)".

Name	Relationship	Progress Bar	Action
Peter Zumpfe	[Me]	██████████	*
Peg	[Mother]	██████████	*
Margaret	[Mother's Mother]	██████████	*
Arthur	[Mother's Father]	██████████	*
Oscar	[Father]	██████████	*
Ida	[Father's Mother]	██████████	*
Oscar B.	[Father's Father]	██████████	*
Maniah	[Daughter]	██████████	Delete
Carl	[Brother]	██████████	Delete
Paul	[Brother]	██████████	Delete

6). Apply HL7 field naming conventions

Category: Enhancement request

Rationale:

- Will enhance future interoperability and inclusion into electronic medical records
- Facilitate normalization of the data
- Easier integration into current and future data schema

Outcome: Not submitted

5C. Feedback to "My Family Health Portrait" Site

7). Inclusion of an Hypothetical Pedigree

Category: Enhancement request

Rationale:

- Sample pedigree displaying both common and uncommon entries.
- Model for participants to use
- Participants can call it up to see how to enter information
- Twins
- Known family genetic syndromes
- Half brother and sisters
- Other diseases
- How to make corrections section after initial submission to pcp

Resolution: Pending - discussed briefly with Lynn Baumeister

8). Inclusion of Patient Med list

Category: Enhancement request

Rationale

- Will confirm / suggest existence of other related conditions
- Another incentive for the patient to complete before visiting a clinician

Resolution: Pending - discussed briefly with Lynn Baumeister

9). Screen enhancements

Category: Enhancement request

Rationale:

- Non-Scrolling screens and frames - i.e. entire frame fits on screen
- Any control buttons in a frame should always be visible without scrolling
- Reduce the prominence of the 'Delete relative' button caption and/or change caption to 'Edit'

Resolution Pending - discussed with Lynn Baumeister

10). Last_update field

Category: Enhancement request

Rationale: Emphasize for the clinician that new or changed data is present.

Outcome: Initial proposal

5C. Feedback to "My Family Health Portrait" Site

11). Leaving edits to save family history

Category: Enhancement request

Rationale:

Currently need to page through each person unless you know to click on the bottom most person in the family.

Resolution: pending

- Discussed with Lynn Baumeister
- Already under discussion - in process

Comments: Add a finished editing button

12). Save File To: - Help Topic(1460)

Category: Enhancement request

Rationale:

- Adoption of more explicit recommendations for storing/retrieving the local file

Outcome: Pending - discussed with Lynn Baumeister

13). Expanded goal and functionality explanation

Category: Enhancement request

Rationale:

- Will help prompt /elicit critiques on topics particularly from users involved in health care.
- Brief references to more topics more likely to 'snag' someone's interest or 'hot button'

Resolution: Pending submission

14). Relaying other disease info on chart

Category: Enhancement request

Rationale: Currently it is possible to highlight one standard or non-standard disease within a pedigree chart. Would it be possible to add one or more non-standard diagnoses to the pedigree chart.

Resolution:

- Pending submission
- First mentioned on 2/21/2006

•
•
•
•
•
•
•
•

Appendix 6C. Single Question Survey

Since there was no direct measure of participation during this project, we elected to get a final estimate of participation based on a single question survey.

The question of “Have you spent time in the last year gathering and/or organizing any aspect of your Family Health History?” was widely distributed to 12,767 BWH employees via a single all user email on November 8, 2006.

Employees could respond by clicking “yes”, “no” or “*I will prior to November 30th*” and then hitting submit.

During the survey period [11-08 to 12-07-06] we received 1324 responses (10.5% response rate). Thirty six percent (N=482) said that they had performed Family History work during the project, and 61% (N=818) said that they had not. An additional 3% (N=43) said that they had not yet, but would prior to the end of the month. Those who responded in this manner had the option to then click immediately to the U.S. Surgeon General’s site if they wished. A follow up on this group in January 2007 showed that 39% went on to complete family history gathering as they planned in that time interval while 61% still had not participated.

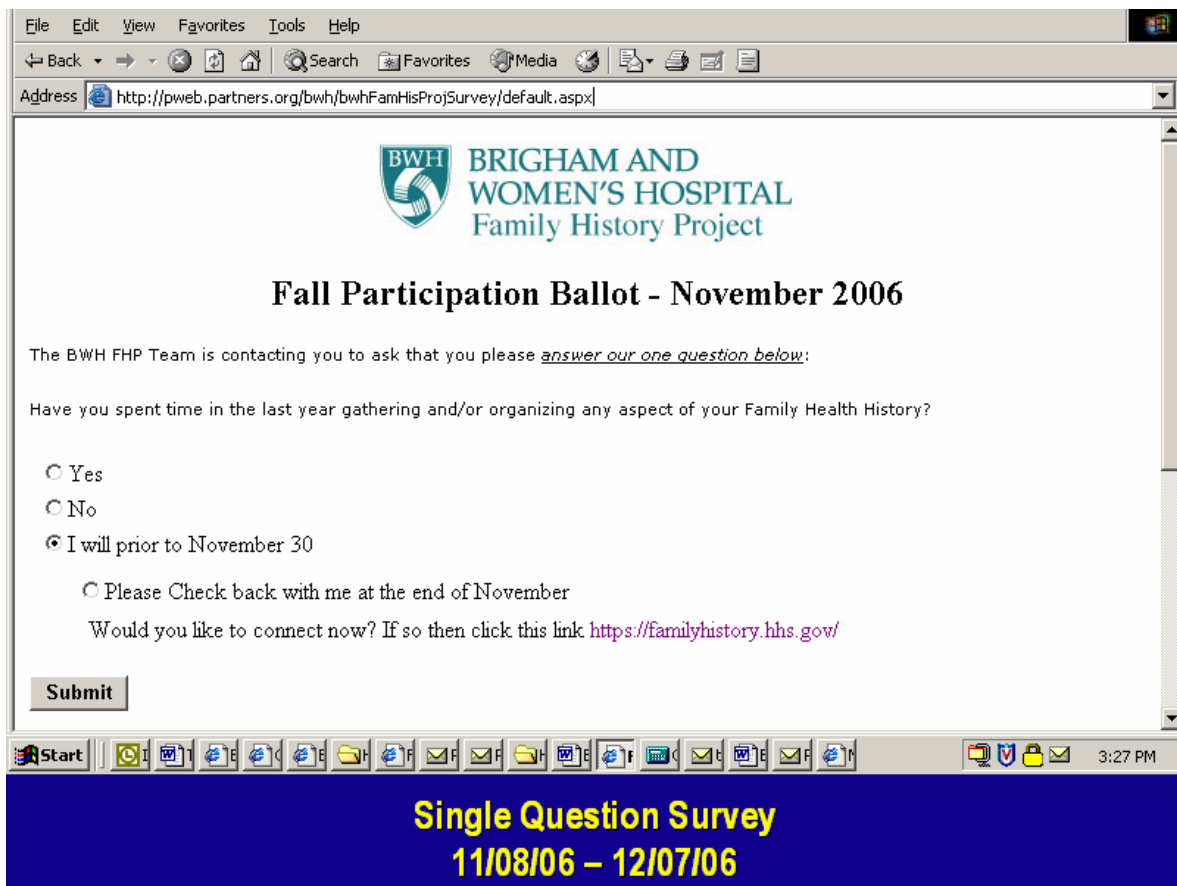
A paper version of this same ballot was distributed to approximately 100 employees who did not have email access as part of their jobs. In this sample 50% said that they had participated in family history gathering. This 50% participation, while reassuring that we had reached across the digital divide with these particular employees, was a likely overestimate of participation by non-email using employees since the 100 surveyed were in previously identified groups in whom there had been project outreach.

•
•
•
•
•
•
•
•

—————

—————

6C. Single Question Survey




The screenshot shows a web browser window with the following content:

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print Copy Paste

Address <http://pweb.partners.org/bwh/bwhFamHisProjSurvey/default.aspx>

 **BRIGHAM AND WOMEN'S HOSPITAL**
Family History Project

Fall Participation Ballot - November 2006

The BWH FHP Team is contacting you to ask that you please *answer our one question below*:

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

Yes

No

I will prior to November 30

Please Check back with me at the end of November

Would you like to connect now? If so then click this link <https://familyhistory.hhs.gov/>

Start | [Taskbar icons] | 3:27 PM

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

•
•
•
•
•
•
•
•
