
My Family Health Portrait

Evaluation Activities from Oct. 2006 – Sep. 2009

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Overview

This report describes evaluation activities on My Family Health Portrait (MFHP), a tool to assist people in recording their family health history. MFHP is a key element of the Surgeon General's National Family History Initiative which is now an annual event celebrated on Thanksgiving Day.

Since its inception, MFHP has undergone four major releases:

- Version 0: A client tool that ran on PCs using the Windows operating system launched in November 2004.
- Version 1: A web-based version launched in November 2005
- Version 1.5: A minor redesign of Version 1 launched in November 2006
- Version 2: A major redesign launched in January 2009.

A previous report summarized evaluation activities on Version 0 and Version 1. This report covers evaluation activities with Version 1.5 and Version 2. The table below shows the timeline of evaluation activities.

Time line of MFHP evaluation activities for this report		
Nov 2006	Version 1.5 launched	New visual treatment, new functionality, and improvements to the user interface were introduced.
Dec 2006 – Jan 2007	Round #1 Usability Testing	Usability testing focused on new functionality
Jan 2009	Version 2.0 launched	Major changes to the user interface
Jul 2009	Round #2 Usability testing	Usability testing with low social economic status and low web literacy participants.
Aug 2009	Version 2.0 revised	Changes made based on the results of usability testing in July 2009
Sep 2009	Round #3 Usability testing	Usability testing with low social economic status and very low web literacy participants.

This next section discusses findings that were consistent across all three evaluations. Following that are sections for each evaluation round shown in the table above. The methodology for the sessions is described in Appendix D.

General Observations Across Evaluations

Less web experience = more difficulty with MFHP

Participants with a higher degree of web literacy and general comfort with computers were more successful at entering and viewing their family health history information. Those participants were

used to meeting formatting requirements for data entry and interpreting error messages. They were also willing to explore and poke around; trying links to see happened. Participants with less experience were not accustomed to meeting formatting requirements for data entry, had difficulty interpreting error messages, were easily flummoxed, and cautious and uncomfortable trying things when they weren't sure what to do next. The participants for the second and third round of testing were screened to be low social economic status and low web literacy. Many of the participants from the second round and none from the third round were unable to use MFHP without assistance from the moderator. The participants from the third round also did not learn easily. Even after an area of confusion had been explained or they successfully used a feature after several attempts, they didn't retain that knowledge – they repeated mistakes.

Saving was often unsuccessful

The save process was consistently problematic for MFHP, no matter which version. Some participants completed the save process without any difficulty, but there were always some participants that failed to save correctly. Successful completion of the process depended on their familiarity with the download process for their particular operating system/browser combination. Relocating the file later depended on their familiarity with their computer's file system. Not surprisingly participants with less computer experience failed at this more often than those with more computer experience.

Problems using/revisiting saved files

Using file that was saved from MFHP was a persistent problem as well. In Version 1.5 the information was saved in an HTML file. This had the benefit that when it was clicked it behaved in a fairly intuitive way (it opened MFHP in a browser window, loaded the stored health information from the file, and left people on a web page in MFHP with only one obvious button to click in order to get to the MY FAMILY page where they could start making changes or doing other actions). There were however a couple of downsides to this approach. It was possible to have the file open in two separate browser windows and be making different edits in the two windows. A client-based application (such as Word) would catch this kind of problem (attempting to open/edit the same file from parallel sessions) but this was not possible for MFHP. The other downside of saving the file in HTML meant that it was not readable by other systems such as electronic or personal health record systems.

In Version 2.0, the current version, the file can be saved as an XML or as a PDF. The PDF of course can not be changed after it is saved but has other benefits. It is a file format many people are familiar with – they may not know what PDF stand for – but they recognize it as something they can look at and print. The XML file has the benefit that the information is in a standard format that can possibly be read by other systems. However usability testing showed that it has a major downside, which was that the process for updating the file was extremely unclear to participants. The intuitive and expected process for participants was to locate the file and then to open it (usually by double-clicking on it), which works for most files on a computer, but didn't work as expected for the saved XML files. When participants clicked on the XML file they were shown the raw XML in whatever application was linked to XML files on the computer, or asked what application they should use to view the XML file if the computer didn't know what to do with it. Either way clicking on the file led to unexpected behavior and didn't provide any information on the right way to handle the file. Once participants were directed to the home page of MFHP they were able to proceed on their own; they understood they should use the OPEN A SAVED HISTORY FILE button. However, they needed the critical information that the starting point for revisiting a saved XML history file was the home page of MFHP, not locating it on their computer and clicking on it. This paradigm is unusual and it is likely some people will never figure out

how to re-use and update saved XML history files from Version 2. If they can find the web site again via a bookmark or via a search engine, then it is likely they will succeed. But they may not think to look for the web site when clicking on the XML file doesn't give them the results they expect. And they may not find the web site again if they don't remember enough about it to enter good search terms – particularly if it is a long time between their initial use of MFHP to enter and save information and a later time when they want to re-visit and update their saved information.

The option to save a re-indexed health history (moving the focus person) has always had the same problems as the save process plus the additional challenge that is a concept that needs to be explained and visualized for people. Version 2 however did come with a label for this process (MAKE COPY FOR FAMILY MEMBER) that was more intuitive than previous versions of the tool.

Chart often missed

The chart has tended to get missed because participants get focused on the tree diagram in all versions. When they found the chart, they said it useful because it summarized their family's information in an easy-to-scan format. But in many cases they only found the chart because they were prompted by the moderator. It is likely that many of them would not have noticed or investigated the chart on their own; they would have only found and viewed the tree diagram, which implies that people in general may not be finding the chart.

Round #1 – Usability Testing with Version 1.5

This next section covers the highlights from usability testing on Version 2. Detailed findings and recommendations from this round are in Appendix A.

Background

In the fall of 2006 the NHGRI web team gave MFHP a new visual look and introduced new features. The new features increased the usefulness of the tool but also increased the complexity of some of the screens. Usability testing was done to ensure the people understood how to use the new features. The sessions distributed over several months. By distributing the sessions over several months, the web team was able to make incremental refinements which were tested in subsequent sessions. The new features incorporated into Version 1.5 were:

- A place to record the date or age of death for deceased relatives was added.
- Missing information was both highlighted and listed at the top of the HEALTH HISTORY page for relatives so people would know what still needed to be filled in.
- The ability to add familial diseases, diseases that ran in their family, to the pre-populated list of diseases provided by the tool (breast cancer, prostate cancer, ovarian cancer, heart disease, stroke, diabetes).
- A page SUGGESTIONS FOR ADDITIONAL DISEASES was added which provided help deciding which familial diseases to were important enough to add.
- A page DEFINITIONS FOR HEART DISEASE, STROKE, DIABETES, COLON CANCER, BREAST CANCER, AND OVARIAN CANCER HELPED provided help understanding oft-confused pre-populated diseases such as heart disease & stroke.
- The save pages provided more assistance.

- The save as pages provided more assistance including the ability to preview what the family tree would look like with someone else as the focal point.
- New visual treatment and navigational changes (renaming and re-positioning of buttons).

General Observations

The participants were a mix of age, gender, race, and computer/web experience. They displayed a wide variety of web habits. Some were careful and cautious; they tended to look around, read explanatory text, and check their information before clicking. Although that did not guarantee that they noticed everything on the page. Other participants churned ahead - scanning and clicking very quickly. So long as they were making progress forward, they tended not to stop and look closely at anything. Most participants were a mix – sometimes reading carefully, sometimes diving ahead without looking around.

All the participants were able to successfully enter their family health history using MFHP (this finding matches findings from previous rounds of usability testing). The MANAGE DISEASES page for entering family conditions was problematic but overall the flow worked well for participants. They understood the pages in the initial sequence for entering the health history of their immediate family (the bootstrap process) and how to keep moving forward. However after they progressed through the bootstrap process and reached the central decision nexus of MFHP, the MY FAMILY page, they were always uncertain what to do next. They proceeded but as they moved ahead they expressed uncertainty that they were proceeding correctly. In some cases they would have left the tool after entering their information and viewing the diagram (family tree) or printing it. Most but not all were successful in saving their health history information.

Highlights (positive)

- Participants liked the look of the splash page
- Entering their profile information and the health history for themselves and their immediate family members was easy.
- When they knew the information participants liked the ability to record the age and cause of death for deceased relatives – it made the information seem more complete to them.
- Marking missing information in the HEALTH HISTORY pages helped participants see what information they still needed to fill out
- Many participants used the SUGGESTIONS FOR ADDITIONAL DISEASES page and responded positively to it. They liked having guidance rather than guessing what sorts of conditions they should enter.
- Participants liked viewing their family tree.
- Participants liked the at-a-glance information provided by the CHART REPORT.
- The revised instructions for SAVE MY HEALTH INFORMATION TO MY COMPUTER and SAVE MY HEALTH INFORMATION AS ANOTHER RELATIVE instructions were better understood because the screen shots were more obviously screen shots due to visual changes, and not something to be clicked on.

Highlights (negative)

- Functionality for adding diseases specific to a person's family was not well-understood.
- The tool still needed more navigation support.
- Participants were not always clear what to do after the bootstrap process (entering their health history information for their family) or how to re-visit their family after viewing the diagram (their family tree).
- Not all participants were successful at saving. This is an on-going challenge for this tool.
- The SAVE MY HEALTH INFORMATION AS ANOTHER RELATIVE had the same difficulties as the save process with an additional complication. Because rotating a family tree to another focus is a concept that has to be explained, there is no single phrase or word that captures the concept, participants were often unsure what the outcome of the SAVE MY HEALTH INFORMATION AS ANOTHER RELATIVE process was supposed to be.
- Not all participants were able locate their saved file
- None of the participants understood that opening their saved file while having their original session open (i.e., one history file open in two separate browser windows) posed potential difficulties.

Findings and recommendations for specific pages and sections are in Appendix A: Details from Round #1

Round #2 – Usability Testing with Version 2

This next section covers the highlights from usability testing on Version 2. Detailed findings and recommendations from this round are in Appendix B.

Background

In 2008 MFHP was redesigned with several major changes in the overall approach. The initial bootstrap process where a series of screens asked for health information for the person's immediate family was removed. Instead people were asked just for their own health information – this had the benefit of reducing the amount time required on an initial use of MHFP and allowing people more flexibility in deciding which relatives to complete. Previous versions of the tool requested information on six core diseases for every relative. The redesigned version let people choose what diseases to enter for each relative. This redesigned version (Version 2) was launched in January 2009.

General Observations

Version 2 was first tested in July 2009. The recruitment was for people with low social economic status and low web literacy to see how easy, or not, MFHP was to use for that population. The gender and age mix of the participants was skewed towards middle-age women since that is the primary audience for MHFP as they tend to be the health managers within families. Most of the participants exhibited low web skills; they were captured by what was immediately visible - they didn't scroll reliably to see what else was on the page. They were less adventuresome – less likely to try an alternate route or way of doing something when what they were trying wasn't working, they were unaware of browser activity such as pages in the process of loading, they weren't aware of and didn't

manage new windows well. They were however familiar with standard web form widgets: links, buttons, dropdown menus, radio buttons, and check boxes. And they had the concept of saving- they noticed and thought they should use the SAVE FAMILY HISTORY button without prompting from the moderator. They had a low success rate for actually saving successfully but at least they recognized the need to save in order to keep information. Some of them read through all of the FAQs and were able to summarize some of the main points afterwards. It is unlikely they would have read all of the FAQs outside of the session since that is quite a bit of reading. In the session they were responding the moderator's initial question on what they thought the purpose of the web site was. The MY FAMILY page proved to be a serious stumbling block. They didn't know what the icons (+, pencil) stood for and the instructions at the top were too vague to help. They tried several ways to change information for a relative – they clicked on the cell where the relative's name would go, they clicked on the column header (the header had the words for what they wanted to do "Add Relative" or "Update Relative"). Because these attempts didn't work, they often tried the ADD ANOTHER FAMILY MEMBER and were highly frustrated when the relative wasn't listed. Later when they were adding family members outside their immediate family they didn't associate ADD ANOTHER FAMILY MEMBER with adding a cousin, niece, or nephew. Instead they thought of that activity as adding information to the parent. So they visited the parent (using the + or pencil) icon and looked for a place to add them there. Only after pursuing this a few times and not having any luck did they look around for an alternate means to accomplish adding nieces, nephews, and cousins.

Entering dates correctly was a major problem for these participants; few saw the formatting hint mm/dd/yyyy and used that format. The error message didn't help them diagnose the problem. Another common problem area was the DISEASE / CONDITION list. They knew how to make selections from the dropdown but often thought that was sufficient and didn't click the ADD TO LIST button. When they did use the ADD TO LIST button they didn't always get feedback because the list happened to be below the fold line of the browser (out of sight). They also weren't always clear on what to do with the secondary dropdown for DISEASE / CONDITION. Those that ignored the label PLEASE SPECIFY and just dove in to see what was in the dropdown - got it. But some read the label PLEASE SPECIFY and weren't sure what it meant and weren't comfortable exploring it. The problem with not clicking the ADD TO LIST button was exacerbated by the fact that there was no warning about it when they left the window. And they left the window thinking they had specified a DISEASE/CONDITION, but they hadn't.

On the VIEW DIAGRAM & CHART page there were a few stumbling blocks as well. Participants didn't always scroll down and find the tree and later the chart. If they did find the tree they had difficulty locating themselves in the diagram. Very few located the chart because it was further down and the tree was so visually arresting and seemed like a logical output of the information they had entered previously so they didn't have any reason to keep scrolling down the page. Those that did find the chart found it useful because was an easy-to-scan way of reviewing most of the information they had put in. The CHANGE REPORT OPTIONS button was problematic because participants thought it would give them a way to change information on their family. Once in there the instructions were high-level and assumed a more complete mental model of the previous page (VIEW DIAGRAM & CHART) than they had. Bottom line - for the most part they couldn't make heads or tails of the CHANGE REPORT OPTIONS page.

Only two of the participants used the tool with ease and they were both younger, less than 30 years old. The other participants ran into serious snags and required assistance from the moderator to move forward – they would not have been able to use the tool on their own. Some of the participants mentioned another person as their go-to person for web or computer help, usually a relative. It is

reasonable to assume that on their own, if they were sufficiently motivated, they would have sought assistance when they ran into difficulties using MFHP from those people. Because this group had less experience using the web they tested the usability envelope of MFHP and found areas where the interface and/or error messages were not clear and understandable.

Highlights (positive)

- Participants knew how to get started from the Home page.
- The sequence, what needed to be filled out, in the HEALTH HISTORY window was clear
- Participants understood the general flow through MFHP (enter information for relatives, save, view diagram & chart, maybe print)
- Participants understood the CHECK HERE IF YOUR PARENTS ARE RELATED TO EACH OTHER IN ANY OTHER WAY THAN MARRIAGE checkbox
- They understood how to use ADD IMMEDIATE FAMILY MEMBERS.

Highlights (negative)

- Hidden pop-up windows caused problems.
- Participants didn't always see the secondary dropdown for PLEASE SPECIFY when adding a disease, or they saw it, they didn't know what it was for.
- Participants often thought they had added a disease / condition because they had selected something in the DISEASE / CONDITION dropdown but really hadn't because they didn't click on the ADD TO LIST button.
- Participants did not immediately understand how to add to the disease list. Most of them eventually figured it out.
- The icons (+, pencil) on the MY FAMILY HISTORY page were non-intuitive. Participants didn't know what they stood for and the instructions at the top weren't accurate and didn't help.
- Some participants didn't know how to update a family member when they were on the VIEW DIAGRAM & CHART page – they didn't know to go back the MY FAMILY page.
- Participants had difficulty entering dates and ages because the formatting requirements were too stringent and the ensuing error messages weren't helpful.
- Participants either misunderstood CHANGE REPORT OPTIONS or had no idea what it was supposed to do.
- There wasn't an easy way to double-check information. Participants didn't always find the chart report and even when they did, it didn't list the all the information they entered. The only means of double-checking everything was to visit each relative one by one.
- Many participants did not complete the save process correctly.
- The process for switching to Spanish as not intuitive
- GET HELP didn't help participants. It described the steps for filling out that portion of the form but didn't address possible problems a person might run into or questions they might have.

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- Participants tried to enter 2nd and 3rd cousins using ADD ANOTHER FAMILY MEMBER. Tried because although they picked COUSIN from the list and entered their cousin's information, they were not able to associate the cousin with the correct parents since MFHP doesn't support beyond 1st cousins.
 - Participants incorrectly entered ½ siblings on the ADD IMMEDIATE FAMILY MEMBERS page because they thought of them as "brothers" or "sisters" and there were no instructions telling them that the page was only for entering full siblings.
 - Participants didn't understand how to make use of their saved file (revisit web site, use the OPEN A SAVED FAMILY HISTORY, etc.). They thought they could just click on the file.
 - Participants didn't notice COPY FOR A FAMILY MEMBER until prompted to look for that kind of possibility by the moderator.
 - When experimenting with COPY FOR A FAMILY MEMBER, participants wanted to print the re-indexed diagram and there wasn't an obvious way to do that.
 - They didn't understand the model of how COPY FOR A FAMILY MEMBER works (separate files, changes in one won't be reflected in the other, etc.)

Findings and recommendations for specific pages and sections are in

Appendix B: Details for Round #2

Round #3 - Usability Testing with Version 2

This next section covers the highlights from another round of usability testing on Version 2. Detailed findings and recommendations from this round are in Appendix C.

Background

After round #2, the testing done in July 2009 with low social economic status and low web literacy participants, the web team addressed as many of the issues as was possible in the limited time frame between round #2 and round #3. The changes were made on a staging server so the changes would be available for testing without disturbing the live public site. Several of the changes proved efficacious and were definite improvements. The list below highlights some of those improvements.

- Hidden pop-up windows, a persistent problem in prior rounds, was solved.
- The option for a Spanish version was more apparent.
- There was an option for ESTIMATED AGE for deceased relatives.
- Clearer instructions on the MY FAMILY page. Several participants read them when they weren't sure what to do and learned how to use the icons.
- Re-labeling of CHANGE REPORT OPTIONS (old label) to DIAGRAM & CHART OPTIONS (new label). Participants no longer expected that button would lead them back to a list of family members where they could make changes.
- The two save options were presented side-by-side .
- Re-labeling of the 2nd dropdown for DISEASE / CONDITION to MORE OPTIONS.
- The key was closer to the tree on VIEW DIAGRAM & CHART.
- The proband (self) on the tree was marked.
- The close window button was more prominent on pop-up windows.
- Siblings in ADD IMMEDIATE FAMILY were marked as (full) and the instructions also told people that they could enter ½ siblings later.
- The PREVIEW screen had a PRINT button.

General Observations

The inclusion criteria for these participants was low income, low education, and even less web experience than the recruitment for the previous round of testing in July 2009. **All of them ran into major stumbling blocks and were not able to use the tool without assistance.** Their struggles with MFHP mostly stemmed from inexperience navigating web applications and a lack of understanding of just how idiosyncratic web forms can be about data entry compared to paper forms. A common thread running through this group of participants was that they rely on others to help them with using their computer and the web.

"I call my son all the time, you know, he knows this stuff" - participant (when he got stuck)

"now this is where I would call my daughter down" – participant (when she got stuck)

These participants were somewhat surprisingly familiar with standard web form widgets. They knew how to type into boxes, click on radio buttons and check boxes, and select from dropdown menus. They knew how to close browser windows by clicking on the close X. Unfortunately many of them used the close X to leave the window for entering health history, not the NEXT/SAVE button. They were not facile in seeing and interpreting error messages. They got confused when the system took them back to a section they thought they were done with because of an error. If they did see the error message they couldn't figure out what the error message was telling them, proceeded to try several incorrect fixes, and became very frustrated in the process. This was a major stumbling block because date of birth was a required field and participants who couldn't figure it out - couldn't proceed.

The date and number formatting requirements were far too stringent given that these were type-in boxes. Some participants were tripped up by putting a space in front of a number. E.g., entering space zero (" 0") instead of just a zero or entering 04/ 15/1994 (zero four slash space one five slash one nine nine four). The idea that a space (which was invisible to them) would be the problem was outside their realm of experience.

One of the most common problems for these participants was selecting a DISEASE / CONDITION and not clicking the ADD button. And they were inconsistent about it. It wasn't the case that they didn't use it at first, then used it, saw what it did, and continued used it from then on. The few that used it did so one moment and not the next. They didn't associate their use of it with whether or not the disease/condition was retained. This difficulty also tied into another difficulty. These participants didn't always notice that information was missing because they didn't locate the chart (which has a summary) or notice missing information in the tree. If they did notice that diseases that they thought they had entered (but hadn't because they hadn't used the ADD button) were missing, they were puzzled but often thought the system had a reason for not retaining diseases they had entered or they simply thought the system had messed up.

Error messages weren't worded from the perspective of a user – they often reflected the error from a programmatic standpoint. A few participants tried GET HELP but it rarely told them what they needed. It didn't help them diagnose error messages they were facing by giving examples.

There was a surprisingly high understanding of the idea that in order to keep information around it had to be saved. So despite their general low level of web- and computer-savviness they had learned that basic concept. They noticed and tried the SAVE FAMILY HISTORY button but once on the SAVE FAMILY HISTORY page reactions and levels of success differed considerably. One participant thought she had saved because she had clicked on SAVE FAMILY HISTORY (from the MY FAMILY page) so she left the SAVE FAMILY HISTORY page without clicking any further. The SAVE FAMILY HISTORY page was not very inviting, it contained more text, more jargon, and warnings than any of the other pages. When participants read the paragraphs they were usually able to summarize one or two points (e.g., *"it says here that I have to be careful with it"*), but definitely didn't understand everything they were reading

Like participants in other rounds of testing, these participants did not know how to use or view a file they had saved. They located their saved file on the hard drive and clicked on it. When they clicked on the XML file the XML code appeared in a browser and they had no idea what had happened. Their expectation that they could use or see the file by clicking on it was not unreasonable since many computer files work that way. They definitely did not know that the sequence for using a saved file

involved going to the home page of the site, clicking OPEN A SAVED HISTORY FILE, and proceeding from there.

Overall these participants had frustrating experiences using MFHP. There were moments when they used a feature easily and correctly but the percentage of those moments was low compared to the time they spent struggling. It is unlikely these participants would have stuck with the tool if they had been on their own. This set of participants demonstrated that there is a line below which MFHP is not usable without assistance. That line is difficult to quantify but is certainly tied into low web literacy. On their own these participants would have given up, or, if they were sufficiently motivated, would have found someone to help them as they said they did on other occasions when they got stuck using the computer

Highlights (positive)

- Participants knew how to get started from the Home page.
- The option for En Espanol was highly visible.
- The first two instructions at the top of the MY FAMILY page worked well (for those that read them).
- After selecting a DISEASE / CONDITION participants saw the secondary dropdown for MORE OPTIONS and used it.
- Some participants thought this (collecting and entering family health history) was a good idea.
- They understood how to use the screen for ADD IMMEDIATE FAMILY MEMBERS.
- Participants used the Family History

Highlights (negative)

- Participants had difficulty entering dates and ages because the formatting requirements were too stringent and the ensuing error messages weren't helpful.
- Date of birth (DOB) was a required field and had extremely stringent formatting requirements. Many participants were not able to figure out the formatting requirements and were therefore unable to proceed.
- Participants didn't understand that for relatives they only needed to enter one of: date of birth, age, or estimated age.
- Participants often thought they had added a disease / condition because they had selected something in the DISEASE / CONDITION dropdown but really hadn't because they didn't click on the ADD button.
- The icons on the MY FAMILY page were not self-explanatory and not all participants read the instructions at the top.
- The 3rd bullet on the MY FAMILY instructions wasn't useful. The instructions simply repeated the label on the button – it didn't explain that this was the way to enter aunts, uncles, nieces, nephews, cousins, ½ siblings, etc.
- Participants didn't know how to add cousins, nieces, and nephews. They tried to add them by going to the parent. E.g., they went to their sister to add their sister's children (their nieces & nephews).

- Participants didn't understand the DIAGRAM & CHART OPTIONS page.
- There wasn't an easy way to double-check information. Participants didn't always find the chart report and even when they did, it didn't list the all the information they entered. The only means of double-checking everything was to visit each relative one by one.
- Most participants did not complete the save process correctly.
- Participants didn't understand much of the information on the save page.
- GET HELP didn't help participants. It described the steps for filling out that portion of the form but didn't address possible problems a person might run into or questions they might have.
- Participants didn't understand how to make use of their saved file (revisit web site, use the OPEN A SAVED HISTORY FILE, etc.). They thought they could just click on the file.

Findings and recommendations for specific pages and sections are in

Appendix C: Details for Round #3

Concluding Comments

MFHP has been through several major revisions – each one improving on the “pain points” of the previous version while sometimes inadvertently adding new ones. The benefit of the evaluation activities on MFHP has been to identify those pain points and provide direction for improvements. During the evaluation activities people carved a variety of paths through the tool depending on the specifics of their family and their web usage habits. The benefit of observing a wide range of people was seeing the different ways they thought about their family and interpreted information on the screen. Without the inclusion of the feedback from these participants the tool would be limited to situations and settings the developers and stakeholders – all very familiar with the tool – could enumerate. The feedback from the participants, not familiar with the tool and with less web experience than the developers and stakeholders provided a means of seeing the tool through their eyes.

Continued iterative usability testing of the tool with consumers is recommended in order to keep ironing out stumbling blocks. Iterative testing can be done on a low-cost basis if results are reported and discussed informally with stakeholders and developers as part of an iterative improvement effort.

If the goal is to have the tool usable by low literacy populations than an expert in writing for low-literacy should be brought on-board to review the writing (instructions, descriptions, error messages, help pages, etc.).

Appendix A: Details for Round #1

This section details the evaluation results from round #1 which were described earlier in this report. That evaluation was done with Version 1.5 (which has since been replaced by Version 2).

Specific Findings and Recommendations

Splash page

Positive

- The text on the splash page was short enough that participants read it.

Negative

- Links of potential interest to people such as PRIVACY, FAQs, and GLOSSARY were easy to miss. Some participants wanted to know more before proceeding with using the tool. They understood how to start, the button for CREATE A FAMILY HISTORY was prominent, but wanted more information. In some cases the splash page text wasn't sufficient to tell what the tool was for and they just wanted a better general understanding of the tool. In other cases they had specific questions such as what the government would be doing with their personal information.

Recommendation:

- List the footer links in the center of the page as well. Leave them in the footer so they are available in other pages, but on the home page, also list them under the buttons to give them higher visibility on this key page where people may be looking for them.

Re-using Pop-up Windows

Positive:

- Presenting help in a separate window allowed participants to view the help and the page they wanted help with at the same time.

Negative:

- Not all participants closed pop-up windows. As they continued working in the main window the secondary (pop-up) window remained open, but was buried under the main window. Later, when they clicked on a help/suggestion link it appeared to them that the link was broken because nothing happened on their screen that they could see. The link was working, but because the secondary window was buried, they didn't see the new information that was put into the secondary window.

Recommendation:

- Devise a strategy for handling secondary windows. There may be browser restrictions that don't allow these but some possibilities are:
 - Force secondary windows to the front when they are refreshed

- Use a new window every time. This has the disadvantage of proliferating new windows when users don't close the old windows but ensures users see the information they expect when they click on a help/suggestion/hint link.
- Close secondary windows after a certain length of time

Profile (self)

Positive:

- The form was straightforward and provided a reassuring entry into the tool.

Negative:

- Some participants asked about entering weight and height in metric
- Women, particularly overweight women, didn't want to enter their weight

Recommendation:

- Allow weight to be entered in English or metric
- Mark weight as optional

MANAGE DISEASES

Positive:

- Participants liked the ability to add to the disease list so it included diseases relevant to their family.

Negative:

- The process for adding diseases wasn't transparent to some participants.
- One participant added several diseases into the initial text entry box.
- A few participants entered conditions that applied to only one family member.
- Participants who found the GLOSSARY said it was extremely useful. And once they found it they often referred to it repeatedly. But it was two clicks every time they want to use it- because they were getting to it from the HELP FOR ADDITIONAL DISEASES; very few participants located the GLOSSARY link at the bottom of the page.
- Some participants were frustrated when they wanted to find the GLOSSARY again because they didn't remember how they got to it before.
- Participants often thought that they should only enter "big" diseases or cancers because that is what they see in the list of 6.
- Many participants wondered whether they should be tracking things like depression or alcoholism.

- Participants that used the SUGGESTIONS FOR DISEASES TO TRACK IN YOUR FAMILY found it very helpful; they liked having guidance on what they might or could add.
- Participants are the least sure about what is included under heart disease. One tester didn't list high cholesterol anywhere b/c he assumed it was under heart disease
- Participants were confused by the spell checker when their spelling was correct.
 - It didn't behave as expected. They were expecting it to tell them either "yes, this is correct", or "no, here's some possibilities..."
 - When the spelling was correct it said "no match" – followed by "this may be spelled correctly". Some participants stopped reading after the "no match found" text and didn't get to the "this may be spelled correctly".

Recommendations

- Change sentence at the top to specify "one by one"
- Clarify that diseases or conditions specific to just one or a few individuals can be entered later.
- Make the GLOSSARY link more prominent
- Add a hint after the GLOSSARY link about what it contains.
- Make the SUGGESTIONS FOR DISEASES TO TRACK IN YOUR FAMILY much more prominent.
- In the SUGGESTIONS FOR DISEASES TO TRACK IN YOUR FAMILY, clarify heart disease in laymen's terminology in both the SUGGESTIONS FOR DISEASES TO TRACK IN YOUR FAMILY.
- Modify the spell checker to say "Your spelling may be correct - the spell checker didn't find alternative spellings".

HEALTH HISTORY (self and relatives)

Positive:

- The process for entering health history was straightforward.

Negative:

- Missing information wasn't marked

Some testers understood that an incomplete green bar on the MY FAMILY page meant there was missing info for a relative. But – when they went to edit that relative they didn't always locate the problems. E.g., perhaps there was an AGE AT 1ST DIAGNOSIS that wasn't filled in – they would scan the page but it wouldn't notice that AGE AT 1ST DIAGNOSIS was the missing info.

- Many participants did not notice or fill-in the radio buttons for IS THIS RELATIVE STILL ALIVE?

This missing information is not highlighted as explicitly as the missing twin information. Only the green progress bars (on the MY FAMILY page) flag this missing information and not all participants correctly understood the meaning of the green bars, or went back to complete missing information.

The consequences of this are that the reports will not have correct information on whether relatives are deceased.

- NAME - Participants are universally just a bit unsure what to put into the Name box (just first name? full name?). But they made a decision and moved on, they didn't get stuck.
- AGE OF DEATH - Some participants put in something besides a number for AGE OF DEATH (such as "60's"). But others didn't know what to do when they didn't know the exact age of death.
- CAUSE OF DEATH - Participants weren't sure what to put when they didn't know. Add a hint after the box.
- PARENT dropdown (for cousins, nieces, nephews) – Some participants didn't see the PARENT dropdown
- IDENTICAL TWIN - Most participants did not notice or fill-in this radio buttons
- Self HEALTH HISTORY - Many participants were initially unclear that this page was about themselves because they had just come from a page that looked similar and was about diseases for the entire family. Sometimes participants started by filling it out "for the family". They eventually figured it out it was for one person, themselves, but was not immediately obvious.

Recommendation:

- For missing information:
 - Put a message at the top of the form that information is missing.
 - Mark missing information
- Make IS THIS RELATIVE STILL ALIVE? more visually prominent.
- Provide guidance on acceptable entries for AGE OF DEATH
List examples after the box: "Examples: 65, in her 70's, don't know"
- Lengthen the AGE OF DEATH box to allow for non-numerical answers.
- Provide guidance on acceptable entries for CAUSE OF DEATH
List examples after the box: "Examples: cancer, unknown, heart-related"
- Make the PARENT dropdown more prominent
- Make IDENTICAL TWIN question more prominent
- Accept weight and height in metric too.
- Brief text at the top of the HEALTH HISTORY for self to clarify that this is about the individual, not the family.
- Change HELP FOR ADDITIONAL DISEASES to "Suggestions for Additional Diseases."

Add Family

Positive:

- Most participants understood how to use this form.

- The descriptions were succinct enough that participants read them and found the information helpful. The text did a good job of answering the questions they had about which relatives they should enter.

Negative:

- Some participants added 2nd cousins

Recommendation:

- Add explanatory text that only 1st cousins should be included and why

Many participants did read the short blurb at the top. The text was sufficiently succinct and informative that they were willing to read it.

Congratulations page (following the boot strap process)

Positive:

- The page provided guidance for participants as they moved from the initial bootstrap process and the MY FAMILY page.

Negative:

- Many participants looked to the lower right corner after reading the instructions: "You may now proceed to the main MY FAMILY page, by clicking the GO TO MY FAMILY button in the right corner."

Recommendations:

- Specify that the GO TO MY FAMILY is in the upper right corner

MY FAMILY

Positive:

- Participants understood this page was showing the relatives they had entered.
- They understood how to edit a relative
- They understood, once they read the explanation, what the green progress bar indicated and often went back and completed incomplete histories based on what the green progress bar was telling them.

Negative:

- The green progress bar never showed less than half full, even when no information had been entered

- Participants were consistently puzzled by the DELETE option (this is a repeat finding from previous usability testing). It was rare that participants enter too many relatives and need to remove the extras so this possible use of the DELETE option did not occur to them. The explanation at the bottom about why there is not a DELETE option for the self-person, their parents, and grandparents was insufficient – it did not spell out the reason.

One participant misconstrued the reason for the DELETE option. She thought the DELETE option was a suggestion – that the relatives with a DELETE option were ones she should delete.

- Participants were consistently unsure what to do when the first landed on this page. They all expressed a desire for guidance on this page. Some thought they were done and would not have proceeded with any actions.

Recommendations:

- Adjust the calculation for progress bar so that is a true reflection of the ratio of complete/incomplete information.
- Explain the reason the DELETE option is available. “In case you accidentally enter too many relatives. E.g., you mistakenly enter 4 cousins when you really only have 3 – you can delete the extra cousin.”
- Provide guidance.

Insert brief explanatory text at the top that outlines the minimum suggested actions (VIEW and SAVE). Ideally people should save first (and some did after reading the suggestion to save on the VIEW REPORTS page), but since the save procedure is less than straight forward and people generally have no interest in saving until they understand what they are saving, suggest that people at least do (1) VIEW REPORT and (2) SAVE. And the other actions are optional.

General Navigation

Positive:

- Participants used the PREVIOUS button during the initial bootstrap process to revisit pages when they remembered information they wanted to add to relatives they had already completed
- Participants used the NEXT button to move to the next relative
- Some participants used the progress box on the right to move between relatives. Those that didn't were still able to navigate using the NEXT and PREVIOUS buttons.
- Some participants, but not all, quickly associated the BACK TO MY FAMILY HISTORY button with the page that provided a list of possible actions.

Negative:

- Some participants weren't sure what to do from the MY FAMILY page

During the bootstrap process of entering health history for themselves and relatives, participants didn't have difficulty knowing what to do next. But then they reached the MY FAMILY page, which

didn't direct them. In some cases they thought they were done, because they had entered all their family health history and weren't expecting that they needed to do anything else.

- Participants not sure how to proceed after viewing the diagram or saving

Once they left the MY FAMILY page and completed an activity such as viewing the diagram, or saving their information, they weren't sure what to do next. They didn't associate the BACK TO MY FAMILY button with "the page that lists things I can do".

Recommendations:

- Suggest follow-up actions at the bottom of the page.

Appendix B: Details for Round #2

This section details the evaluation results from round #2 which were described earlier in this report.

Specific Findings & Recommendations

Occasional slow response time

In some sessions the system response time was slow and that caused problems for a few participants.

One had 4 brothers he had accidentally added that he wanted to delete. The system got itself in a snarl trying to process his quick clicks (the page was not always completely refreshed before he clicked on the next trash can).

A few other participants got the system in a snarl because they were clicked on items multiple times when there wasn't a response to their first click.

The more web-savvy participants paid attention to the signals that the site was still refreshing and held off on further actions. They knew to do this based on experience with other site whereas the less web-savvy participants didn't know how to tell when the page was still refreshing...and that they should wait. In some ways a responsive system is more important when users are less experienced because they tend to over-click and are looking for instant feedback/ re-assurance on what their click did.

The problem with pop-up windows

Some participants left the pop-up window open and were not aware that this window was still open and covered by the main window. Later when they clicked on a link that replaced the content of the pop-up window it appeared to them that the link did not do anything. The link was in fact refreshing the pop-up window but since it was hidden they didn't know this.

Some participants maximized the pop-up window and didn't know how to get back. They tried the back button, but because it was a new window there was no back button. They didn't see the close window option – it not in an obvious place and obscured by surrounding text.

Some of the pop-ups aren't necessary. If there is no navigation on the page, (e.g., the FAQ page) then people tend to use the back button to return to where they were.

Recommendations:

- Review the pop-ups and determine which need to be in a pop-up because people need to see the screen the pop-up is referring to (Help screens are the usual cases). For information that doesn't need to be in a pop-up, take people to a new page instead of a pop-up. The new page can be a dead-end page (without navigation). This will allow them to use the back button - which what they have learned to use on other sites.
- For the pop-up windows that are kept, place a CLOSE WINDOW button in a very visible location, not in a header bar or footer. Don't obfuscate it with surrounding text

Splash page

Positive:

- Participants knew how to start
- Some visited the LEARN ABOUT MY FAMILY HEALTH PORTRAIT link

Negative:

- The information on the home page wasn't sufficient for them to understand what the web site was for. Some of the text was too generic. The 3rd bullet in particular wasn't informative

Recommendations:

- Consider alternate wording such as "Print reports of your family health history to share with family or health care worker."
- Consider alternate wording such as "Save the health history of your family so you can update it over time"

FAQs

Positive:

- Some participants went there on their own. It is not clear if they would have done so on their own, outside of the session where they were asked what the purpose of the web site was.
- These FAQs were the most helpful and easiest for people to understand
 - Why is family health history useful?
 - How long does it take to fill out the form? What do I do with it then
 - What are the key features of the Surgeon General's family health history tool?
 - What about my privacy? Does the government (or others, like my employer) have access to my information?
 - What if I need help in filling out the tool?
 - How can I encourage other family members to share their health information?
 - What if my knowledge about my family health history is incomplete or imprecise?
 - Will the family health history tool give me advice on actions I should take?

Negative:

- Less well-understood FAQs and of less immediate relevancy
 - How long does it take to fill out the form? What do I do with it then?
 - Note: Doesn't say how to share with health care practitioner
 - What security precautions should I take when I share information with relatives?
 - Why is it important that the tool "re-indexes" as different family members use it?

- Why is it important that the tool is "EHR- and PHR-ready"?
 - Participants got the idea that the information might be already at the emergency room or at the hospital if it was in an EHR but had no idea how that would actually happen.
 - What is "clinical decision support"? How does it apply to family health history?
 - Can doctors use information from the tool even if they don't have EHRs?
- Adoption section much more difficult to understand and uses the label "adoption" in a non-obvious way. Participants soldiered thru this section despite gleaning little from it.

Recommendations:

- Separate the FAQs relevant to immediate understanding and use of the tool.
- Separate the FAQs giving background & possible additional ways to use the tool (e.g., EHR, "clinical decision support") into a separate section
- If another word besides Adoption can be used, use it. In this context, with families, the word adoption already has a primary meaning.
- Consider putting the adoption FAQs on a separate page.
- Add text telling individuals that they don't need to read this section that it is meant for organizations.

Entering HEALTH HISTORY (self & relatives)

Dates (DOB, COD) & Age

Positive:

- Four participants initially said the home page was "busy," but some of them later said that it was fine after they had worked with it for a few minutes.

Negative:

- Participants a dates in a variety of invalid formats
 2/3/45 6/23/ 8/2/??
- Participants didn't always know the age of relatives. In some cases they wanted to be able to specify something general. E.g., 60's
- The error messages didn't help participants, they were too generic and didn't give enough information that participants could understand and fix the problem

***Gender:** ☐ Male ☒ Female
Living? ☒ Yes ☐ No ☐ Unknown
 Enter either the date of birth or current age.
Date of Birth: mm/dd/yyyy
Age:

"I got this one, this one I know, 4/17/66"

My Personal Information
Age: 1942
Height: 66 in
Weight: 130 lbs
BMI: 21.0

What the system recorded for that person's age

***Date of Birth:** 04/17/0066 mm/dd/yyyy

Even on a revisit, participants didn't notice an incorrect date, unless they were looking for it specifically.

***Gender:** ☐ Male ☒ Female
Living? ☒ Yes ☐ No ☐ Unknown
 Enter either the date of birth or current age.
Date of Birth: mm/dd/yyyy
Age:

"I'm not sure how old she is and I sure don't know her birthday, but I think she's in her 60's"

Recommendations:

- Accept 4/17/66 as 4/17/1966
- Allow non-numerical answers and provide examples
- Tell people how to correct the problem in the error message.
- Include an example of a correct date in the error message
- Tell them what to do if they don't know the date (since that was sometimes the reason for having an incorrectly formatted date)

Disease/Condition

Positive:

- Although participants made mistakes with the disease list (see below) initially, once they understood it, it worked well.

- Participants used the OTHER – ADD NEW to add diseases not on the list (although they commented on not knowing how to spell items)
- Most participants understood that (MORE OPTIONS) meant they would be able to pick a sub-category of the disease.

Negative:

- On their first use of the DISEASE/CONDITION section, not everyone clicked on ADD TO LIST. They made a selection for DISEASE OR CONDITION and AGE OF DIAGNOSIS and moved on without actually adding it.
- When they left the window with a disease selection that hadn't been saved, whether via the NEXT, SAVE, or the close X, they didn't receive a warning.
- The connection between (MORE OPTIONS) and the 2nd dropdown was not obvious to some participants. They didn't associate the 2nd dropdown box labeled PLEASE SPECIFY as the place to put in "more options".
- In some cases they repeatedly clicked on the (MORE OPTIONS) text in the 1st dropdown box, trying to get more options to show up.
- In the PLEASE SPECIFY dropdown participants wanted an UNKNOWN option. E.g., several participants didn't know what kind of diabetes or heart disease or psychological disorder a relative had and they wanted to specify unknown rather than picking the most generic item in the list.

The image shows two screenshots of a web form titled 'Disease or Condition'. The form has three main sections: 'Disease or Condition:', 'Please Specify:', and 'Age at Diagnosis:'. The first screenshot shows the 'Disease or Condition' dropdown set to 'Heart Disease (more options...)' and the 'Please Specify' dropdown set to '--Please Specify--'. A red callout box points to the 'more options...' text with the text: "Why won't it give me more options?" -- as she clicked several times on "more options". The second screenshot shows the 'Disease or Condition' dropdown set to 'Other - Add New' and the 'Please Specify' dropdown set to an empty text box. Two red callout boxes point to the 'Please Specify' text box with the text: "I don't know how to spell epilepsy?" and "Uh oh now you're going to make me spell sclerosis".

Recommendations:

- Give a warning when the window is closed and the settings in the DISEASE/CONDITION dropdowns haven't been added.
- Change the label on the second dropdown to include the text "More Options"
- Add UNKNOWN to the secondary disease list options.

Cause of Death

Positive:

- Participants understood how to fill this out
- Participants liked having UNKNOWN as an option because they didn't always know

Negative:

- They got an error message on what appeared to a valid choice

Name:

Relationship to me: Paternal Grandfather

*Gender: ☒ Male ☐ Female

Living? ☐ Yes ☒ No ☐ Unknown

Please specify Unknown Disease.

Cause of Death:

Age at Death:

This should be a valid combination.

Recommendations:

- Don't flag UNKNOWN and UNKNOWN as an error

PARENTS RELATED BY ANYTHING OTHER THAN MARRIAGE?

Positive:

- Despite the awkward sentence structure, participants understood this checkbox.

Check here if your parents are related to each other in any way other than marriage. ☐

"They want to know if I'm in-bred"

"That's like when you marry your cousin or something"

ADD IMMEDIATE FAMILY MEMBERS

Positive:

- Straightforward for most participants

Negative:

- Participants had questions that were not addressed in the explanation
 - Enter ½ brothers here (as brothers)?
 - Enter blood relatives or just household?

“Do you mean blood relatives? Or just my household? I’ve got ½ brothers I never see”

“What about step-kids? I gotta lot of [1/2] brothers, you know with my dad”

Recommendations:

- Clarify blood relatives, not just household
- Add that ½ siblings can be added later
- Add “(full)” in front of BROTHER and SISTER

MY FAMILY HISTORY

Positive:

- Participants read the explanation at the top
- They liked the separation of mother’s and father’s side of the family
- They understood the trashcan icon

Negative:

- Most participants did not understand how to add information for relatives or how to update their information.
- The icons were not self-evident
- The explanation at the top was too vague; it referred to the “update history image”, rather than the plus image or the pencil image
 - Text from web page: “Change your information by clicking on the "Update History" image next to your name in the list.”
- The explanation was incorrect for adding was incorrect; it referred to the wrong image, referred to the image too generically, and said it was “next to their name” (it is at the other end of the table)
 - Text from the web page: “Add information for a family member by clicking on the "Update History" image next to their name in the list.”

On this screen you can:

- Change your information by clicking on the "Update History" image next to your name in the list.
- Add information for a family member by clicking on the "Update History" image next to their name in the list.
- Add another family member to your history by clicking "Add Another Family Member."
- Remove a family member from your history by clicking the "Remove Relative" image next to their name in the list. (You cannot remove yourself, your parents, or grandparents.)

If you are finished filling out your family health history, click "Save Family History." Then you can view a drawing or chart of your family tree by clicking "View Diagram and Chart" at the top of this page. You can also copy this for a family member by clicking "Copy for Family Member" at the top of this page.

Name	Relationship to Me	Add History	Update History	Remove Relative
My Family				
	Father	+		
	Mother			
Sparticus	Self			
	Son			
	Daughter			
	Brother			
	Sister			

Participants tried very hard to enter information for a relative. They clicked on:

The cell for the name, the cell for the relative, the cell (but not the + or pencil icon), the column header “Add History”, and the column header “Update History”

They didn’t know what the “Update History” image referred to in the instructions meant.

Recommendations:

- Clean up the instructions
- Use text instead of icons. One link “Update History” would be sufficient although separate links for “Add History” and “Update History” would also be fine.

- If the icons are kept, refer to the icons by what they are, a plus sign and a pencil, not by generic descriptors

ADD ANOTHER FAMILY MEMBER

Positive:

- Participants found this button easily.
- Participants read the explanation

Negative:

- When they were trying to update information on their immediate family, and didn't understand what the + icon was for, they tried to add the relative using this button.
- They were confused and frustrated that relatives they wanted to enter, e.g., brother, weren't listed.
- One participant added a 2nd or 3rd cousin. There were no instructions not to enter 2nd and 3rd cousins and since she hadn't yet updated her maternal aunts, she just picked a "maternal aunt" from the dropdown list.
- One participant wanted to add her husband

Recommendations:

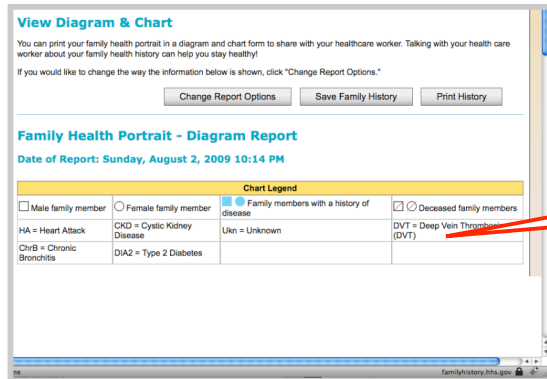
- Add more explanation at the bottom or on the side. Let them know that relatives in their immediate family that aren't listed here are probably on the previous page and can be reached by closing this window and clicking on the + for that relative.
- Also tell them that spouses and 2nd etc cousins are not listed because they don't impact their family health history
- Add "(1st only, no 2nd & 3rd)" to the COUSINS option

VIEW DIAGRAM & CHART**Positive:**

- Four participants initially said the home page was "busy," but some of them later said that it was fine after they had worked with it for a few minutes.

Negative:

- In some cases not even the top of the diagram was visible – participants had no cue to scroll. And since they didn't know what to expect they were just confused. Most eventually scrolled but some were stuck for several minutes.
- The chart doesn't provide a complete summary. The only way to check the information entered is to visit each relative one by one. Participants who entered DOB incorrectly never saw their error unless it happened to be for their DOB and they happened to see it at the top of the Chart.
- Most participants had already saved by the time they reached this page and thought the site was asking them to save again. What they really wanted was confirmation that their file had been saved, not a sense of being asked to save again.
- Viewing the tree was challenging because of the scrolling involved. In some cases people had trouble locating themselves in the diagram.
- After viewing the diagram or chart participants often wanted to make changes, adding additional information or fixing errors. They were rarely at the top of the screen where top navigation bar with MY FAMILY HISTORY is. Instead they were usually in the middle or at the bottom of the screen and the options available were: CHANGE REPORT OPTIONS, SAVE FAMILY HISTORY, PRINT HISTORY. Of those, CHANGE REPORT OPTIONS seemed like the best bet. When they went to the CHANGE REPORT OPTIONS – they were frustrated. It wasn't what they expected and they even after reading the explanation they didn't understand what it did.



"I see the diseases in my family but I don't see my family"

Recommendations:

- Include a hint to scroll in the instructions
- Move the diagram closer to the key so the top edge is more likely to show
- Have the space for the SAVE MY FAMILY HISTORY button differ depending on the save status. I.e., reflect the save status. Show the Save My Family History button when there are un-saved changes. Otherwise show a confirmation that there are no un-saved changes.
- Include more information in the chart.
- Color the proband. This will also help on the PREVIEW display for COPY FOR FAMILY MEMBER.
- Add a button navigation back to MY FAMILY HISTORY to the button list at the top & bottom of the page

Change Report Options

Positive:

- Participants thought it was important to save after they had entered their family's health history. This was true even of the less web-experienced participants.

Negative:

- Key point: Participants didn't think of **VIEW DIAGRAM & CHART** page as a "report".
- The text at the top isn't explanation or instructions – which is what people needed. The text is more appropriate to the top of the VIEW DIAGRAM & CHART.
- The only option participants sort of understood was the SHOW MY PERSONAL INFORMATION... and even with that one they didn't know exactly what it referred to because in their quick scroll of the diagram & chart page they didn't always notice the personal information section. They didn't understand the other options
- They made no association between highlighting and blue on the tree unless they experimented and poked around long enough to see the effect.
- Many ignored the dropdown for highlighting. Too many words and the words weren't meaningful.

- Because they didn't think of the VIEW DIAGRAM & CHART page as a report and hadn't internalized the two sections (tree and chart), they didn't understand the effect of the last two checkboxes. They weren't sure what was meant by the two terms or what checking/unchecking the boxes would do.
- Although these issues aren't critical it reduced people's confidence to encounter a page they couldn't decipher.

Recommendations:

- Rename this section to clarify that it is for modifying how information on the View Diagram & Chart page is presented, not modifying family history information for relatives.
- Change the text at the top; explain specifically what the options are and what effect they will have.
- Use Include instead of View for the checkbox options

SAVE FAMILY HISTORY

Positive:

- Participant thought it was important to save after they had entered their family's health history. This was true even of the less experienced participants.
- They associated saving with being able to change the information later on.

Negative:

- The explanation and instructions use jargon ("other media", ".xml") and vague terminology ("this system")
- Not all the participants completed the save process correctly.

The browser used for testing was FireFox. It asked participants whether to save or open the file. To complete the Save process correctly the participants had to click on SAVE 3 times and OK once.

SAVE FAMILY HISTORY – from the MY FAMILY HISTORY page

SAVE FAMILY HISTORY – from the SAVE FAMILY HISTORY File pop-up

OK – from the Firefox dialog box about whether to save or open the file

SAVE – from the OS dialog box about where to save the file.

Some of them may have completed the save process correctly had they been on their home machines, if their browsers were set to save to a particular folder rather than asking where to save the document to because that would have eliminated 2 of the 4 clicks these participants needed to do.

- No one read the browser-specific instructions before saving; the instructions were not visible without extensive scrolling. Some people read the browser-specific instructions after the fact but didn't understand what the instructions were for.
- Some participant concluded that the file would be saved as an excel file; they read ".XML" as ".XLS". An easy mistake to make, especially if you have never heard of XML.
- Some participants went to the Desktop to confirm the file had saved. Some of those went a step further and open it to double-check what it did. They were confused it opened in Dreamweaver. Dreamweaver happened to be the application on the test machine that opened .xml files.

On the participants own machine it would either open in one of their applications or ask which application should open it. Either way clicking on the file would not have expected results.

- Participants did not understand that to see what was in the file they would have to visit the familyhistory.hhs.gov web site and use the OPEN A SAVED FAMILY HISTORY button.
- The instructions "Please look below to see which set of instructions is applicable to your browser and operating system" seems like it refers to the next save option (SAVE PRINTABLE FAMILY HISTORY)
- A few participants didn't know what to do after saving. The button for SAVE FAMILY HISTORY (in the pop-up) was still visible. They were expecting it to go away once they had saved.
- The key difference between the two save options wasn't spelled out - SAVE FAMILY HISTORY (the only save option that allows you to change the information some other day) and SAVE PRINTABLE FAMILY HISTORY (allows you to print and see what it looks like right now)
- Participants wanted confirmation that their file had been saved.

Recommendations:

- Spell out the differences between the two save options.
- Change "this system" to "this web site" in the explanation.
- Change "or other media" to specific examples.
- Remove extraneous information such as "Some doctor's offices and electronic health record systems can also use this family history file"
- Although true, the number of offices that can do this is small and individuals will need much further instructions in order to hand the file off to their doctor's office.
- Change "Close" to "Done"
- Provide confirmation on the save status.

SAVE PRINTABLE VERSION

Positive:

- Some participants tried this option.
- They understood the diagram was a family tree

Note: The machine used for testing opened the PDF in a PDF reader automatically.

- Many recognized the concept of a PDF as something they could print.

Negative:

- Not all of them understood this was saving the information in a way that could only be printed

COPY FOR FAMILY MEMBER

Positive:

- They easily used the drop-down for selecting a family member and the PREVIEW button.
- Once they saw the PREVIEW page they understood the concept. Typically it was locating themselves in the re-index tree helped them understand.

Negative:

- Participants did not visit this functionality on their own. They checked out because of prompts from the moderator. If they had read the FAQ on re-indexing during their initial entrance into the tool, they had a better understanding of what the page was about. Otherwise they were much more unsure.
- They often wanted to print the PREVIEW page but there was no options provided for that. Since there were no controls on the screen they tried to return to the previous page via the back button. When that failed most used the close button on the window, but not all. Some were stuck.
- Participants who saved a copy did not understand how they would make use of the file. They expected to be able to click on it to see what was in it.

Recommendations:

- Provide a print button on the preview page
- Provide a CLOSE button on the page at the top and the bottom
- Color the proband.

Spanish Version

The two Spanish speaking participants were invited to try the Spanish version towards the end of their session. One said her family used English at home since the family was a mix of Ukrainian and Puerto Rican but that she could read it pretty well. The other was a non-native English speaker and happy to move into the Spanish version.

Positive:

- They liked that a Spanish version was available. Said for some members of their family it would make a big difference.
- Once they were guided into the Spanish version they liked it.

Negative:

- They had to be guided.
- The dialog box generated by clicking on the En Espanol button was very off-putting. It did not adequately explain the process.
- The required process was completely unexpected and unintuitive (Save, then click on En Espanol – which goes back to the home page, then click on Open Saved Family History)

Recommendations:

- Fix the instructions. The process is unusual so it requires a clear explanation. Something along the lines of:
 - To switch to the Spanish version you will need to:
 - Save Family History (if you made any changes since you last saved).
 - Click on the En Espanol tab (that will take you back the home page but in Spanish)
 - From the home page use the “Open a Saved Family History” to locate the file you just saved (it will retrieve your family information and display it in Spanish)
 - If you haven’t made any changes since the last time you saved your information, then click OK
 - If you have made changes, click the Cancel button, save your family history, and the try the En Espanol button again.
- The instructions should be repeated in Spanish.
- Also, the instructions that appear if someone is in the Spanish version will also need to be in reversed for someone switching from Spanish to English.

HELP

Positive:

- A few participants tried the HELP button when they got stuck

Negative:

- HELP tended to state the obvious and didn’t always provide trouble-shooting assistance. I.e., considering reasons why someone would be looking at the help section and addressing possible difficulties.

- One participant couldn't figure out how to add information for a relative on the MY FAMILY HISTORY page. The phrase "clicking on the symbol in the Add History column" on the HELP page was not helpful.
- Another participant was trying to add her husband and frustrated that it wasn't showing up in the ADD ANOTHER FAMILY MEMBER options. GET HELP didn't address that concern.

Appendix C: Details for Round #3

This section details the evaluation results from round #3 which were described earlier in this report.

Specific Findings & Recommendations

Splash page

Positive

- All but one participant knew how to start.
- The EN ESPANOL button was more easily noticed than in the previous testing (in July 09)
- Participants who wanted more information noticed, and used, the LEARN MORE ABOUT MY FAMILY HEALTH PORTRAIT link.

Negative

- After reading the text on the splash page not all the participants were able to describe what the web site was for. It is however possible that they were heavily influenced by pre-conceived notions since facility used for the sessions was at the National Cancer Institute and that in the recruitment process they had been asked questions about where they looked for health information online.

Recommendations:

- Keep the EN ESPANOL button in this location.
- Keep the LEARN MORE ABOUT MY FAMILY HEALTH Portrait link in it's current location.



These are in good, easily noticed positions

Your Personal Information

Positive

- This section was clear to participants. Entering basic information that everyone knew provided a gentle start to using MFHP.

Negative

- Some participants exited by using the close X. This was most likely to happen if they encountered errors they couldn't figure out how to fix, or were confused by what happened when they had an error (the screen shifted to the area with the error but if the participant didn't see the error message they were just confused by having the screen go back to someplace the participant thought they were done with). But some used it even if they didn't have an error – they were done entering information so they closed the window.
- Overweight women were not happy about being asked to put in their weight

Recommendations:

- Give a warning when participants have made changes and close the PROFILE /HEALTH HISTORY window instead of using SAVE /NEXT. Something along these lines:

You have unsaved information in this window. What would you like to do?

- Close this window without saving the changes
- Don't close this window

Entering Health Information

Positive

- Although several participants commented that there wasn't a NO checkbox for ADOPTED it wasn't an issue, they moved on.
- Participants had no difficulty with the RACE checkboxes though many skipped it or just entered one race even though in their commentary they mentioned other races in their family background.
- Participants were slightly puzzled why there were both RACE and ETHNICITY labels because it was all the same to them but this wasn't an issue.

Negative

- Overly stringent requirements on the entry of required date fields meant that some participants got completely stuck. See details in a later section.
- Most participants failed to use the ADD button when entering a disease and so the information wasn't retained. See details in a later section.
- Closing the window didn't generate a warning. Participants unintentionally lost changes when they left by closing the window instead of using the SAVE/NEXT button.
- Some participants did not see the error messages. They didn't understand why it was showing them a part of the page they had already filled out when they had just told the system they were done and ready to move on (by clicking NEXT or SAVE).

“but it’s going back to the same page” – participant

- Important instructions didn’t stand out; they blended in. They were the same font face and size as the rest of the text on the page. The field labels (bold) and field forms (shapes) were more visually noticeable.
- When participants had errors they were frustrated that some of the information they had entered had been cleared out.

In the list below, select a **Disease / Condition** (if any) from the dropdown box. Then select the **Age at Diagnosis** and click the **Add** button. You may repeat this process as necessary.

Disease / Condition	Age at Diagnosis	Action
Diabetes (more options...)		
Type 2 Diabetes	30-39 years	Add

Your Family Background Information (click to hide) [Get Help](#)

Check here if your parents are related to each other in any way other than marriage. ☐

Multiple races and ethnicities may be selected.

Race: ☒ American Indian or Alaska Native ☐ Asian ☒ Black or African-American
☐ Native Hawaiian or Other Pacific Islander ☐ White

Ethnicity: ☐ Hispanic or Latino ☐ Ashkenazi Jewish ☐ Not Hispanic or Latino

[Why are we asking about Ashkenazi Jewish heritage?](#)

[Next](#)

Date of Birth must be in date format (MM/DD/YYYY)

Date of Birth: 2/3/45
mm/dd/yyyy

Were you born a twin? ☒ No ☐ Yes - Identical (Same) ☐ Yes - Not Identical (Fraternal)

Were you adopted? ☐ Yes

Height: 5 Feet 7 Inches -OR- Centimeters

Weight: 200 lbs

Your Health Information (click to hide) [Get Help](#)

In the list below, select a **Disease / Condition** (if any) from the dropdown box. Then select the **Age at Diagnosis** and click the **Add** button. You may repeat this process as necessary.

Disease / Condition	Age at Diagnosis	Action
None		

Your Family Background Information (click to hide) [Get Help](#)

Check here if your parents are related to each other in any way other than marriage. ☐

Multiple races and ethnicities may be selected.

Race: ☐ American Indian or Alaska Native ☐ Asian ☒ Black or African-American
☐ Native Hawaiian or Other Pacific Islander ☐ White

- Participants didn’t understand that they had three different options for entering DOB for relatives. Many thought they had to enter both DOB and AGE. This was a reasonable assumption on their part since many medical offices ask for both DOB and age (even though age is redundant when DOB is given) so people are in the habit of filling out both of those. A few noticed the ESTIMATED

AGE dropdown and thought they had to enter all three fields. Even when they couldn't remember a relative's DOB, they didn't skip the DOB box, they made up an entry or tried to put in something general.

- One participant read the WHY ARE WE ASKING ABOUT ASHKENAZI JEWISH HERITAGE text but didn't check it off for his daughter because he didn't consider her an Ashkenazi Jew since he viewed her jewishness as passing through the female line, not the male (his) line.

Recommendations:

- Give an error message when participants leave the window and have un-added disease/conditions. (i.e., they made selections in DISEASE / CONDITION and AGE AT DIAGNOSIS but didn't use the ADD button).
- Add something visual such as an icon to attract attention to error messages.
- Don't clear information that has been entered when there is an error
- Make the instructions for DOB more prominent. People don't think they need instructions for filling out DOB because they know what date of birth means but in this case the instructions that there are other options is important so the instructions need to stand out more. In the current arrangement labels and fields rather than instructions is what stands out the most.

Entering Dates

Problems entering dates accounted for a large percentage of completion failures by this set of participants. When participants were unable to address the error after several tries the moderator wrote down an example of what was required, e.g., "05/03/1980, not 5/3/80". When they saw that kind of example, they understood. Though some forgot by the next time they had to enter a date.

Negative

- The date error message wasn't noticed in some cases. Participants weren't sure what to expect when they clicked NEXT/SAVE so they didn't realize that they should have moved on or gone back to the MY FAMILY page. They thought it was odd and confusing that MFHP was showing them information they had already filled in.
- The date formatting requirements were much too stringent for a text entry box. Some participants were not able to complete this form because they could not figure out the correct way to enter DOB. Because DOB was required they were not able to leave the page and many eventually chose to just close the window in frustration. Some examples:

11/12/98 followed by November 12, 1998	This was the most common way of entering dates. When participants saw the error message they understood there was a problem but not how to fix it; they didn't understand they needed to change /98 to /1998. A few participants attempted to fix the problem by writing out the date (November 11, 1998). When asked why they tried that fix they said that they had used slashes the first time and it (the system) hadn't liked it so they were trying another way to put in the date. Needless to say they were very frustrated when they got the same error message again.
04 14/97	One participant entered the date this way. When she got the error message she changed 97 to 1997, but left the space after 04. She didn't understand why she got the

followed by 04 14/1997	error message again. To her eye 04 14/1997 matched the requested requested “MM/DD/YYYY” format.
031078 followed by 03-10-78	<p>Another participant entered the date without any separators. When she got the error message she said</p> <p><i>“what do you want” – participant in an upset voice addressing the screen</i></p> <p>She then tried 03-10-78. She was very frustrated when she got the error message again.</p> <p><i>“I don’t know what they want” – participant, still upset</i></p> <p>She was not able to figure it out on her own and needed assistance from the moderator to proceed.</p>
2 5 48	Another participant entered the date this way. When she clicked on NEXT and the screen jumped back up to the top (where the error was) she just gave up because she didn’t understand why the system was showing her the information she had just filled out (she didn’t see the error message). For her it was so inexplicable that she just closed the window right away.

Recommendations:

- Use individual dropdown boxes for month, day, and year. Use words (January, February, etc.) for the month to remove the possibility of people inadvertently swapping the month and day (i.e., entering 03/05/1987 for May 3, 1987). . Individual dropdown boxes will remove the possibility of errors and this is critical for a required field.

Entering Numbers (age, number of relatives)

Negative

- One participant wrote out her daughter’s age as SIXTEEN. The error message told her she needed to use an integer. She had no idea what an integer was.
- Another participant entered “ 4” (space four). He had no idea what he done wrong. The space was invisible to him.

Recommendations:

- Remove leading and trailing spaces; don’t require people to do that.
- Don’t use jargon “integer” in error messages. Give examples.

Entering a relative's data of birth or age

Positive

- The few participants who used the ESTIMATED AGE dropdown liked it because they didn't know the exact age and this gave them a way to answer the question comfortably.

Negative

- Most participants didn't notice they had a choice on how to enter relatives' ages. Although what they needed was the ESTIMATED AGE, they didn't see it, or thought they needed the other options as well.

The screenshot shows a form for entering a relative's data. The form includes fields for Name, Relationship to me (Mother), Gender (Male/Female), and Living? (Yes/No/Unknown). Below these is the instruction: "Enter either the date of birth, current age, or estimated age." The form then presents three options: "Date of Birth:" (mm/dd/yyyy), "Age:" (mm/dd/yyyy), and "Estimated Age:" (a dropdown menu labeled "--Select Estimated Age--"). Each option is preceded by a yellow circle containing the text "-OR-". At the bottom, there are checkboxes for "Was this person born a twin?" (No/Yes - Identical (Same)/Yes - Not Identical (Fraternal)) and "Was this person adopted?" (Yes).

Annotations in red boxes with arrows pointing to specific elements:

- "The instructions weren't noticed; they blended in." (points to the instruction text)
- "Participants focused on these. The bold labels and the geometric shapes jumped out more than the instructions." (points to the bold labels "Date of Birth:", "Age:", and "Estimated Age:")
- "They didn't notice the -OR- visual elements." (points to the yellow circles containing "-OR-")
- "Most skipped this. They didn't see it or they had entered something in the AGE box so this seemed superfluous" (points to the "Estimated Age:" dropdown)

Recommendations:

- Guide people through the process of deciding which of the three (ESTIMATED AGE, AGE, DOB) to use.
 - Do you know this relative's date of birth? yes no
 - If yes, show the field for entering DOB
 - If no, show next question
 - Do you know this relative's age?
 - If yes, show the field for entering Age
 - If no, show the Estimated Age at Death dropdown

Entering Diseases

In the previous round of usability testing (July 2009) the layout had too much separation between the place where a disease was added and the disease list below where it ended up. Because of the visual effect, participants often stopped scrolling at the bottom of the add box (see the dashed lined below). This meant participants didn't always see the effect clicking on ADD TO LIST had. Participants in the previous round also did not always complete the final crucial step of clicking on the ADD TO LIST button although it was not a major a problem as it was in this round.

Select the diseases and conditions as well as what age the disease came. If a disease or condition is not on the list, select "Other - Add New" to add a new one to the list. (Any disease that you add will appear at the bottom the list so it can be selected for other relatives.) If this person does not have any diseases or conditions, this section may be skipped.

Disease or Condition: Diabetes (more options...)

Please Specify: Type 2 Diabetes

Age at Diagnosis: 30-39 years

Disease / Condition	Age at Diagnosis	Remove
Crohn's Disease	30-39 years	Remove

This screenshot is from the version tested in July 2009.

Diseases were added here (above the scroll line – represented by the dashed line)

After ADD TO LIST was clicked, the disease moved to here (often below the scroll line – and therefore out of sight)

In this round when participants used the ADD button they noticed it's effect because the disease stayed in the same place which worked better than the other layout. But they rarely clicked on the ADD button – even more so than the last round of testing so this presentation did not solve all the issues.

Your Mother's Health Information (click to hide)

In the list below, select a **Disease / Condition** (if any) from the dropdown box. Then select the **Age at Diagnosis** and click the **Add** button. You may repeat this process as necessary.

Disease / Condition	Age at Diagnosis	Action
Bipolar Disorder	20-29 years	<input type="button" value="Remove"/>
<input type="button" value="v"/> -Select Disease-	<input type="button" value="v"/> -Select Age at Diagnosis-	<input type="button" value="Add"/>

This screen shot is from the version tested in Sep. 09. When participants clicked on the ADD button, they saw the results in the same region of the screen.

Your Mother's Health Information (click to hide) Get Help

In the list below, select a **Disease / Condition** (if any) from the dropdown box. Then select the **Age at Diagnosis** and click the **Add** button. You may repeat this process as necessary.

Disease / Condition	Age at Diagnosis	Action
Lung Disease (more options...)		
Asthma	In Childhood	<input type="button" value="Add"/>

In this layout participants didn't associate the ADD button with the selections they had made to the left.

"Action? What does add have to do with action? - participant trying to figure out what the Add button was for"

Positive

- Participants understood how to use the dropdown to make a selection for DISEASE / CONDITION.
- They saw the dropdown for MORE OPTIONS when it appeared and knew what it was for
- Most participants found and used the OTHER ADD-NEW option to add diseases not on the list.

Negative

- All the participants made selections from the DISEASE / CONDITION dropdown and the AGE OF DIAGNOSIS but very few clicked ADD. As far as they were concerned by making the selections they had told the system about the disease. The few that used ADD didn't do it consistently.
- A few participants' interpretation of the instructions was that they could only add one disease so they picked the one they thought was most vital to list. And since as mentioned in the previous bullet, they didn't click on the ADD button, they never realized they could add more diseases.
- Participants received no warning when they selected a disease but didn't click the ADD button. Many left the form thinking they had added a disease but in fact had not. This happened frequently. Sometimes something else prompted them to revisit a relative later and at that time most of them noticed that the disease they thought they had entered wasn't listed. In some cases they came to the wrong conclusion such as thinking that the system didn't care about or didn't want to store information on that particular disease and that's why the disease they (thought they) had entered wasn't listed. Others never noticed the omission of the disease they thought they had entered because they never found the CHART at the bottom of the VIEW DIAGRAM AND CHART page.
- A few participants clicked on ADD twice and were confused by the error message they got - PLEASE SELECT AN AGE OF DIAGNOSIS. They didn't know it had processed their second click as a separate request to ADD a disease where the dropdowns hadn't been filled out yet. This was however a minor point of confusion and not a major stumbling block.
- Some participants commented on the column header for the ADD button. They were trying to figure out what ACTION had to do with adding. They didn't associate the ADD button with the two dropdowns (DISEASE / CONDITION, AGE AT DIAGNOSIS) on the same row.

- Most participants had a question about a disease. In some cases it was how to spell it. In other cases it was things like not being sure if hypertension was the same as high blood pressure. They would have liked hints or help in deciding what they should tell the system.

Recommendations:

- In the table for adding diseases:
 - Remove the vertical bars separating the cells in the row so the row looks like one unit
 - Move the button closer to the AGE AT DIAGNOSIS dropdown
 - Change the label on the ADD button to Record This Disease
- Give an error message when people leave the window (via the CLOSE X, SAVE, or NEXT) and there is a selection in DISEASE / CONDITION that has not been recorded. This recommendation is the most crucial one. The other ones may help but it is likely people will still make selections in the dropdown but not add it to the list.

Cause of Death (COD)

Positive:

- Participants noticed the COD field that appeared when they clicked the NO radio button for IS THIS RELATIVE STILL LIVING?

Negative:

- Participants did not understand that they could use just one of the three options (DOB, AGE, ESTIMATED AGE). See section above for more discussion of this topic.
- Participants were confused by the MORE OPTIONS type-in box that appeared when they selected OTHER – ADD NEW. The MORE OPTIONS label did not make sense in that context.
- The error message when the MORE OPTIONS box was left empty and the dropdown selection was OTHER – ADD NEW, was confusing. It didn't help the participants understand that they needed to type something into the MORE OPTIONS box.

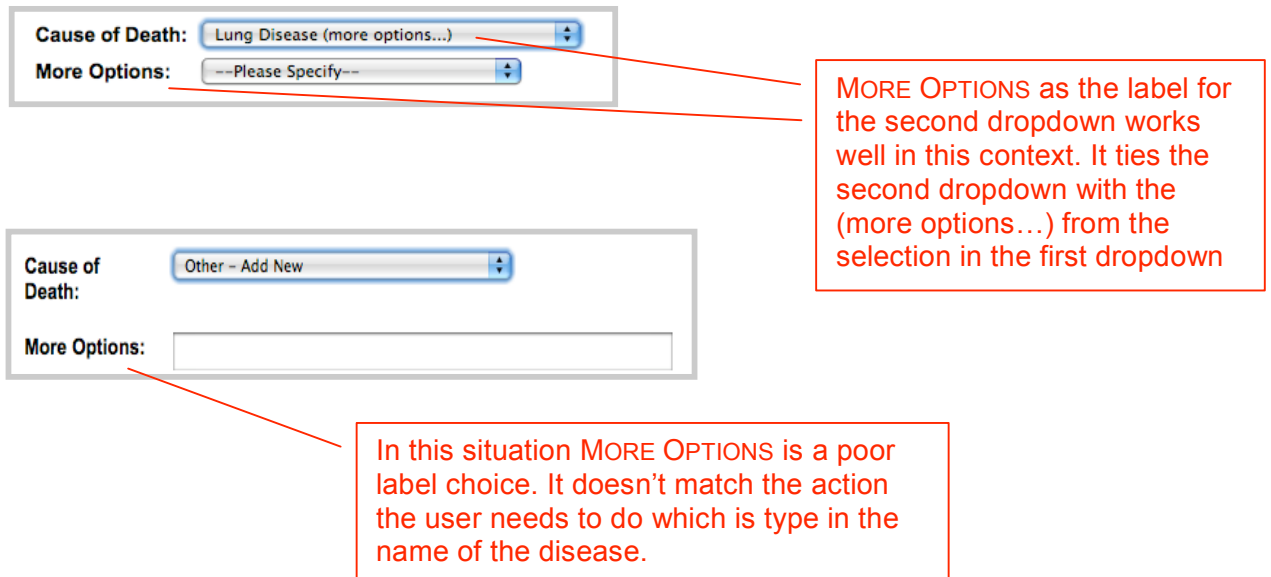


The screenshot shows a web form for 'Cause of Death'. At the top, there is a dropdown menu with 'Other - Add New' selected. Below the dropdown, a red error message reads 'Please specify Other - Add New.' Underneath the error message is a text input field labeled 'More Options:'. A red arrow points from the error message to a red-bordered box on the right.

Participants who got this error message had no idea what the problem was or how to fix it.

Recommendations:

- Tailor labels to the situation.



- Don't use one-size-fits-all error messages. Tailor error messages - consider the user's perspective and what the screen looks like when the user is trying to decipher the message.

My Family History




Positive

- The revised instructions (from the last round of usability testing) helped several participants.

Negative

- The icons are not self-explanatory and not everyone read the instructions. Some participants tried clicking in empty cells, where they could see the name should be, to enter information on a relative. Some participants tried clicking on the column headers.
- The 3rd bullet of instructions didn't help because it just repeated the button label. Didn't provide additional information such as a hint on what kind of relatives you could add with the ADD ANOTHER FAMILY MEMBER button.

On this screen you can:

- Change your information or a family member's information by clicking  (Update History) next to the name in the list.
- Add information for a family member by clicking  (Add History) next to the name in the list.
- Add another family member to your history by clicking "Add Another Family Member."
- Remove a family member from your history by clicking  (Remove) next to the name in the list. (You cannot remove yourself, your parents, or grandparents.)

The 3rd bullet didn't provide any useful information. It just repeated the text in the button.

Recommendations:

- Use text links instead of the icons. It will look busier but doesn't require people to read the instructions in order to learn what to do. Participants were clicking on the column headers because that had the text that represented what they wanted to do.
- Provide useful information in the 3rd bullet of instructions.

"Add more family members (aunts, uncles, cousins, ½ siblings, etc.) with the ADD ANOTHER FAMILY MEMBER button"

View Diagram & Chart

The major problem with this page that showed in both this round and the previous round of testing (July 2009) is that participants didn't stumble across the chart. This is an issue because the chart is the only place that provides an easy to scan summary. There were several reasons participants didn't find the chart. The tree grabbed their attention because it was a strong visual so they stopped scrolling to investigate it. They scrolled down far enough to see the key when they wanted to know what the symbols used in the tree meant, but didn't proceed beyond that. They didn't know the chart was on the page. It made sense to them that family information would be displayed in tree so they didn't have any reason to think there was something else, something they had missed on the page.

Positive

- Participants used the smaller internal scroll bars to move around in the diagram, including scrolling horizontally.
- Participants found the key for the tree.
- Participants found themselves [Self] in the tree easily (because it was marked).
- Participants found the CHART helpful because it showed them what they had entered.
- Participants found the MY FAMILY HISTORY button when they wanted to go back and make changes.

Negative

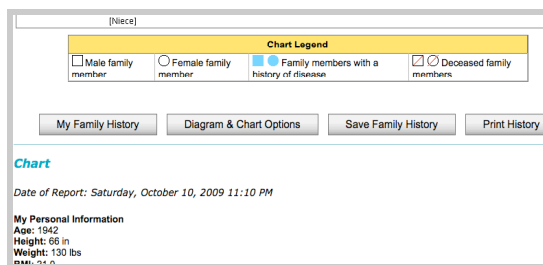
- Participants didn't always interpret the key correctly because it is laid out in a grid which to them implied relationships up and down. For example for participant the disease she had happened to line up under the key section for deceased icons so to her they looked connected. She was not the only participant to this there were up/down relationships implied by the grid layout of the key.

"Did I put down that I was deceased?" – participant [as she viewed the key]

- Very few participants found the chart. They simply never scrolled past the tree. Sometimes the top of the chart was showing for brief moments when they scrolled down to read the key, but they didn't notice it sufficiently to make them want to scroll further down the page. Because they were using the scroll bars for the diagram they seemed to forget to check the rest of the main page by scrolling. The tree was what they expected; they had found the tree, so they thought they were done with the page.
- The instructions at the top of the page got lost between the blue header and the strong visuals from the buttons and the tree.
- Nothing on the page helped participants locate the chart.

Recommendations:

- Make two legends for the tree. One for the tree symbols (circle, square, diagonal line). Another for the disease abbreviations. Put them side by side with a small amount of space between them.
- Get people to the chart. Some possibilities to be considered (note: not all of these should be done as some of them can't be done together, this list is
 - Close up the distance between the two reports and remove scroll stoppers (the line of buttons). Consider putting the profile information on one line.



These buttons made for a strong scroll-stopper (participants saw them and didn't scroll any further) and the area below them didn't hint at table to be found lower down.

- Option: Put the chart before the tree. Snug the tree right up under the chart, so the top of it is likely to show when people scroll down to the bottom of the chart. Remove the line of buttons between the tree and the diagram.
- Option: Use a similar presentation as the SAVE FAMILY HISTORY which presents two options side by side. In the presentation use thumbnails and a few bullets to describe the benefits of each. Each would click through to its own page rather than having both on the same page.

Diagram & Report Options

Neutral

- A few lucked out and happened to make changes that were visually evident when they left DIAGRAM & CHART OPTIONS.

Negative

- Very few participants didn't understand the purpose of this window. The explanation at the top was high-level – talking about the general purpose of the tool. The last sentence provided some guidance, but the biggest problem was that they tried one of the options they usually didn't see any effect so they concluded that DIAGRAM & CHART OPTIONS didn't really do anything. In most case there wasn't an effect to notice such as when they selected NONE (DON'T HIGHLIGHT A DISEASE) from the highlight dropdown. In other cases the effect was "out of sight" such as then they unchecked SHOW CHART and because they had never seen the CHART (because they didn't scroll down) they weren't aware it was no longer on the page. Likewise if they unchecked SHOW MY PERSONAL INFORMATION IN THE REPORT they didn't know anything had changed because that too was lower down on the page.
- Overall the problem with the DIAGRAM & CHART OPTIONS is that participants didn't have a solid mental model or picture of the page – they didn't think of it as a diagram and a chart. It was a page that had their family tree in a box they could scroll around in. They didn't think of it as something they could control the visual appearance of.

Recommendations:

- Remove the first 3 sentences – those belong on the VIEW DIAGRAM & REPORT page, not here. Remove the "please click on the options below...then click "Update Chart"". It is the only button on the page and people don't need instructions to click on it.
- Keep the explanation short and simple
 - This page allows you to control how your family health information is displayed.
- When a solution to the problem of people not finding the chart is determined, revisit this section to explore ways to address the problems identified above.

Add Another Family Member

Positive

- The explicit list at the top of what relatives they should, and should not, enter here helped participants

Negative

- Some participants didn't enter deceased relatives. In their mind they didn't have these relatives any more so they didn't put them in.

- One participant didn't know how many uncles he had on his father's side, so he entered a ? When he got an error message he changed it to a zero. But he had entered " 0" (a space then zero). That also caused an error message which he had no idea how to fix. To his eyes the box had a zero in it – the idea that an extra space would be a problem was foreign.

Recommendations:

- Accept leading and trailing spaces on otherwise acceptable numerical entries
- Add instructions to include deceased relatives.

SAVE FAMILY HISTORY

Positive

- Most participants said that they should save after entering all of their relatives.
- Participants quickly saw there were two options on the page. This was an improvement from the last round of testing in July 2009 when they often only noticed the first option on the page and didn't scroll down and find the second option.

Negative

- All of the participants had difficulty saving.
- The explanations were dense and full of unfamiliar terms. In some cases participants found the language off-putting.
- No one read the instructions before attempting to save.
- Participants didn't recognize the instructions as instructions. They often scrolled down to look at the instructions after they had tried one of the save options so they were viewing the instructions after the fact.
- Several participants thought they had saved before they were done with the process (the process required clicking on more than one Save button).
- Most participants didn't understand the difference between the two options.

"this one you can download [xml], this one lives on your computer [save printable version]" – participant



Dense, uninviting text. The second sentence had a lot of words but no useful information actually.

Also dense, uninviting text. The third sentence required people to remember a set of instructions and referred to items not currently visible.

Recommendations:

- Reduce and simplify the verbiage and make it more friendly. Speak to the user directly. The current language is information overload and not inviting to read. Work with a writer who specializes in clear language for low-literacy audiences. Adjusting the language and presentation in such a way will also benefit other audiences.

Examples of reducing the information to a few key points and using an easy to scan layout

Save your history as a computer file

- Save this way if you want to come back later and update the information
- **Not sure how to save on this computer?**
Scroll down to see instructions

Hint: Remember where the computer you save your file so you can find it again later.

Note: you can save both ways

- As a computer file so you can update it later
- As a printable family history file so you can print it now

Save a printable family history file

- Save this way if you just want to print the information you entered and don't plan to come back later and update it.
- Your information will be saved as a PDF file

Hint: A print-out will make it easy to share your information with your doctor's office or with your family members.

Note: you can save both ways:

- As a computer file so you can update it later
- As a printable family history file so you can print it now

Although it is true that the family history can be printed from other sections of MFHP the idea here is to give present the two options in as straightforward a manner as possible.

Using a Saved File

Positive

- A few participants wanted to check out the file they had saved

Negative

- They located their saved file and of course clicked on it. The XML appeared in a browser and they had no idea what had happened. Their expectation that they could use or see the file by clicking on it is not unreasonable since many computer files work that way. They definitely did not know that the sequence for using a saved file involved going to the home page of the site, clicking OPEN A SAVED HISTORY FILE, and proceeding from there.

Recommendations:

- Consider providing a third save method that produces a file that when clicked on starts the family history web site and uploads the data. Make this the primary way of saving.
- Make the xml save something doctors can ask patients to do in the event the doctor had a means for reading in the xml file.

Save Visual Family History File (PDF)

For many participants this was the first time they saw the diagram (because they saved before trying the VIEW DIAGRAM & CHART button).

Positive

- Participants recognized the print icon in the PDF viewer.

“I would do this before going to the hospital” – participant (as she hovered her mouse over the print icon in the PDF viewer)

Negative

- Some participants were confused by the PDF viewer.
- Several commented that they wouldn't print it because it was so small (not realizing that it's size on the screen didn't correlate to its size when printed)

Recommendations:

- Keep this option

Save For Later Use on This Website (XML File)**Positive**

- A few saved successfully but were very unsure of the sequence as they moved through it.

Negative

- A few understood this was the option to use the tool later but didn't know how they would use the file. I.e., didn't know the steps they would need to follow (go back to this web site, click the LOAD SAVED FAMILY HISTORY, locate the file)

Recommendations:

See recommendations under Using a Saved File (above)

Appendix D: Methodology

The goal was to observe participants using MFHP in as natural a manner as possible given that it a moderator was present. Each participant began by creating a family history for their immediate family using MFHP. As they worked they were asked to “think aloud” as a means of sharing their thoughts and reactions to the screens with the facilitator. When they reached the MY FAMILY page after entering their family health history, they, rather than the facilitator, determined their next steps. When a participant indicated that they were done using MFHP the facilitator asked them to complete additional tasks to ensure the participants used all the sections of MFHP.