

**OREGON HEALTH & SCIENCE UNIVERSITY
SCHOOL OF MEDICINE – GRADUATE STUDIES**

SCREENING MAMMOGRAPHY: A DECISION AID FOR WOMEN AGES 38 – 48:
TECHNICAL IMPLEMENTATION

By

Elizabeth P. Nelson

A CAPSTONE PROJECT

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CERTIFICATE OF APPROVAL

This is to certify that the Master's Capstone Project of

Elizabeth P. Nelson

“SCREENING MAMMOGRAPHY: A DECISION AID FOR WOMEN AGES 38 – 48:
TECHNICAL IMPLEMENTATION”

Has been approved

Capstone Advisor

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1 Introduction/Project Overview

For this capstone project, I worked with Paula Scariati to create a decision aid to help women younger than 50 decide whether to get a mammogram. The primary purpose of this capstone project was to develop the decision aid, “Screening Mammography: A Decision Aid for Women Ages 39-49”, and complete some user testing with it.

On November 16, 2009, the United States Preventive Services Task Force (USPSTF) updated its screening mammography guidelines transitioning from a call for routine screening on an annual basis starting at the age of 40 to routine screening every two years starting at the age of 50. It came with the following proviso for women aged 40-49: “The decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms”.¹ This tool is intended to provide women in this age group with information to help them decide if they should have a mammography or not.

I implemented the following technical aspects of the project, focusing on usability factors.

- Determine the appropriate technical architecture including:
 - Determine the database infrastructure,
 - Perform Logical and physical database design
 - Select the tool set for front end and processing
 - Address access and security concerns.
 - Determine the need for system administration and support
 - Implement technical aspects of the system, including the web front end, processing and storage of results.
- Conducted a usability review, including system navigation, screen layout and feedback on

content. Effort went into making good use of subjects in a light, iterative process.

In this paper I cover a summary of the software design and documentation of the usability testing process.

1.1 Intended audience

This web-based breast cancer screening tool was developed in response to the 2009 updated mammography screening guidelines from the US Preventive Task Force which stated that "The decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms".¹ The target audience is women aged 38-48 with an average risk for developing breast cancer. To use this tool properly, these women must be English speaking and have access to a computer with stable internet access.

2 Architecture

The Mammography Decision Aid (MDA) software was developed using the Ruby on Rails open source framework (<http://rubyonrails.org/>) linked to a SQLite3 (<http://www.sqlite.org/>) relational database. It runs on an Ubuntu (<http://www.ubuntu.com/>) server maintained at Oregon Health & Science University and located in their "DMZ" (or demilitarized zone) which is a network used to expose an organization's external services to a larger untrusted network such as the Internet. This server is used to run a number of other research projects.

The decision aid is made available to subjects over the World Wide Web to be accessed through web browsers such as Mozilla Firefox (<http://www.mozilla.org/en-US/firefox/features/>) or Microsoft Internet Explorer (<http://windows.microsoft.com/en-US/internet-explorer/products/ie/home>) on their own computers. Because of the heterogeneity of systems on the client end, the software has been

designed so that no specialized or additional software or hardware is needed beyond the ability to run HTML 4 and Javascript. Most existing browsers are supported.

Application security is implemented using SSL (Secure Sockets Layer) with the SSL Requirement plug-in, (http://agilewebdevelopment.com/plugins/ssl_requirement), the AuthLogic plug-in (<http://www.binarylogic.com/tag/authlogic/>) and application logic. Medical history data captured to determine eligibility will be deleted during the session: either immediately on being screened out or just before proceeding to the MDA. Data is not stored on the client computer.

An offsite server was used for code development, with regular updates of a test environment at the OHSU DMZ (Skynet). The development environment was built to mirror the test/deployment in most ways: primarily to preserve compatibility with an older version of Ruby/Rails.

Other software and tools include including Apache web server and Phusion Passenger. Gems was used for system software versioning, The JQuery (<http://jquery.com/>) javascript library was used for certain user interface objects.

We used an informal iterative development cycle, with multiple releases. This allowed us to prototype new concepts and get feedback quickly.

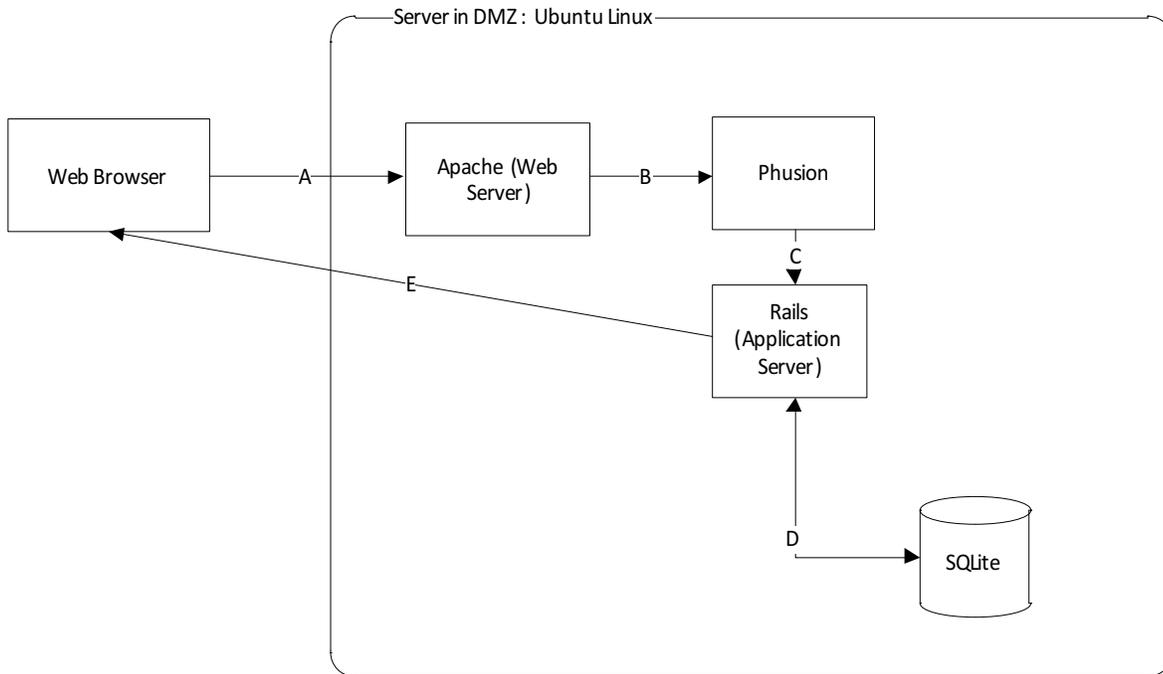


Illustration 1: Simplified Architectural Diagram

- A. Web browser (located anywhere) makes a requests to the web server
- B. Apache (within OHSU DMZ) receives the request, and forwards it to Phusion
- C. Phusion passes to request to Rails
- D. Rails reads and writes to the database, if needed.
- E. Rails returns the result (web page) to the user's browser

3 Application Flow and Page Design

The application flow is intentionally very straightforward. For each round of testing, a username (the email address of the user) and password are given to individuals who express interest in being a test subject. A link is provided to reach the web application. Once the user receives her credentials, she can log into the system. The subject proceeds through eligibility, and then through the MDA in

sequential order. The subject can log out at any time, and the system will let her return to where she left off.

Page layout and navigation options were kept simple to encourage users to proceed through the system without interruption. We chose a target resolution of 1024x768, and designed the application to have no horizontal scrolling and a bare minimum of vertical scrolling. Screen design broke down into a few key layouts, as describes below. We chose large font sizes because of the target age group.

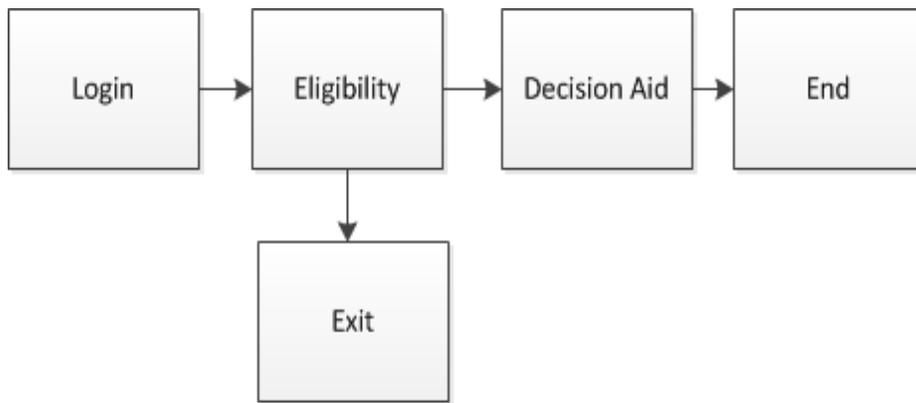


Illustration 2: High level flow

3.1 Login Page

Once the user navigates to the web site, she enters the username and password assigned to her. User login credentials are created using an administrative tool: only the email address (used as a login) and password are entered. The user and subject tables are populated with default values. When the user logs in, system data (login_count, current_login_id) is captured by Authlogic. Application use and status information (consented_date, first_login_date) is stored in the consent table. Each subject receives a unique user name and password to access the site. The password expires seven days after the

first use.

The username expires seven days after first use. User sessions are ended after 90 minutes, after which the user is required to log in again. The system will restore the user to the previously viewed page.

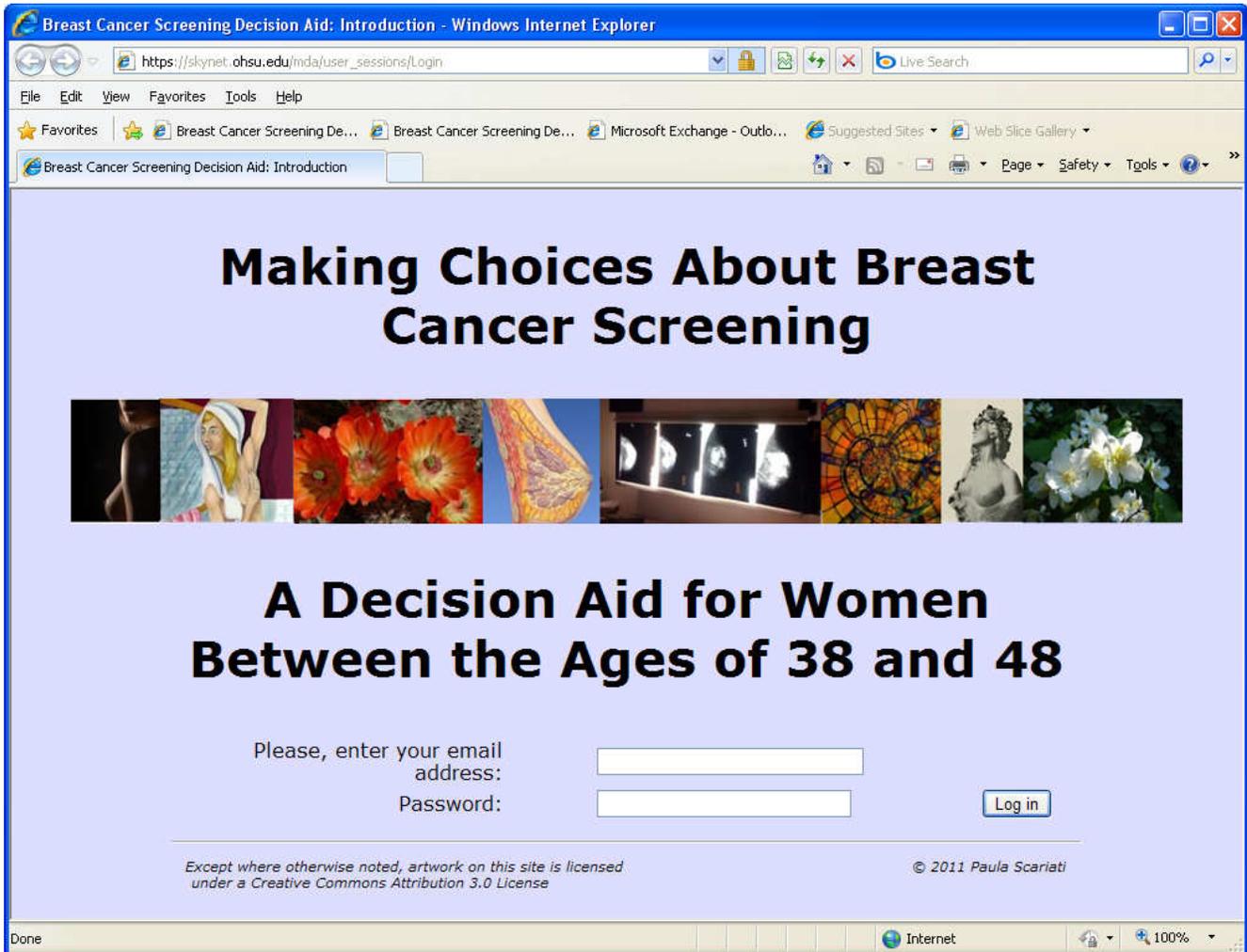


Illustration 3: Login Screen

3.2 Eligibility pages

The top and bottom of the page contain common content. On most pages users can go forward or back using the “back” and “next” buttons, or leave the system using the “Log out” button. Some pages

contain textual and graphical information about the study and others contain questions about personal and family history. There are 15 total pages in this section.

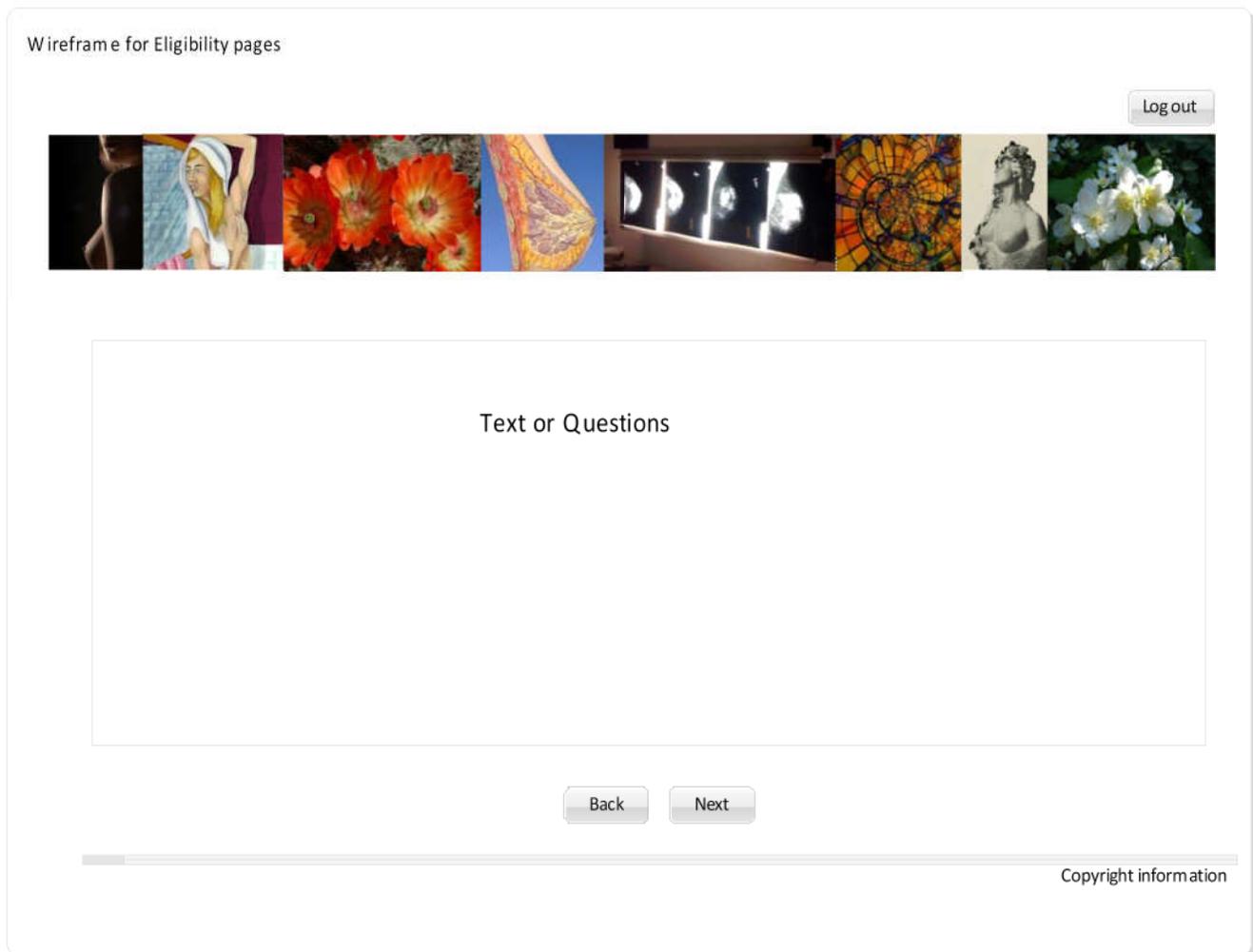


Illustration 4: Wireframe for Eligibility Pages

The user is presented with information about the study, and also a set of one or more questions (depending on her answers to the first set) to help determine whether the MDA is appropriate given her personal and family history.

These questions include: if the subject has a personal history of breast or ovarian cancer, a parent, brother, sister or child with a genetic marker for breast cancer, a mother, daughter, or sister who has or had breast cancer, an aunt, niece, or grandmother who has or had breast cancer, a father, brother, or son who has or had breast cancer, a blood relative who has or had breast cancer in *both* breasts, a blood relative who has or had ovarian cancer, a history of repeated radiation to the chest between the ages of 10 and 30, current signs or symptoms of breast disease or Ashkenazi Jewish heritage. Some risk is assessed on the basis of a combination of factors. The subject is presented with pages asking for details of her family history of breast or ovarian cancer only if she indicates the presence of such history.

If the subject's history shows her to be at higher risk, she does not proceed to the MDA, but instead receives a page with the following text:

Please Follow-up with Your Primary Care Provider

This decision aid tool is designed specifically for women in their 40s at average risk for developing breast cancer. Your responses to the personal and family history questions suggest that you might have a greater than average risk of developing breast cancer.

An email is being sent to you with information about risk factors for breast cancer and a list of select resources. Use these resources to learn more and then initiate a discussion with your healthcare provider!

Thank you for your interest in our study.

Subjects who are not screened out by the eligibility questions proceed to consent.

3.2.1 Consent

The consent page contains IRB approved text and allows the user to choose to participate in the study by selecting one button, or to exit the study by selecting the other. This page is formatted to look like a document, and does not share the graphical design of other pages. Subjects can also print the text. Once consent has been recorded, the subject may proceed to the MDA.

Consent Status

Subjects show one of five possible consented statuses:

0: default (no action has been taken)

1: consented (user consented on consent form)

2: ineligible (screening questions show higher risk)

3: declined (user declined on consent form)

4: left w/out finishing (from log out button, “not coming back”)

3.2.2 Decision Aid pages

The MDA pages add graphics for navigation and a progress bar. This section comprises the major portion of the application. Several types of pages within the MDA were different enough from the others to require different layouts. The application includes 39 pages containing information and graphic content, 38 pages containing survey questions and 6 transition pages, The question pages are interspersed with the information pages.

Log out



Text or Questions



Email the Research Team



Copyright information

Illustration 5: Wireframe for Decision Aid pages



Diagnosis or Screening

People often talk as if all mammograms are done for screening purposes only. This is not true! Mammograms are done for two very different reasons – diagnosis and screening. The distinction is important.

Diagnosis: If your healthcare provider orders a mammogram to investigate a complaint or finding such as pain, skin thickening or a nipple discharge -- this is diagnostic. Your age doesn't matter and it has nothing to do with routine screening.

Screening: This type of mammogram is done in healthy women to look for signs that breast cancer may be developing when there are no symptoms. In the United States, screening mammograms are usually offered to women starting at the age of 40 on a yearly or every 2 year cycle.



Illustration 6: Content Page

Content pages contain information to help subjects learn more about mammography.



Section Name
Section Name
Section Name

Section Name
Section Name
Section Name



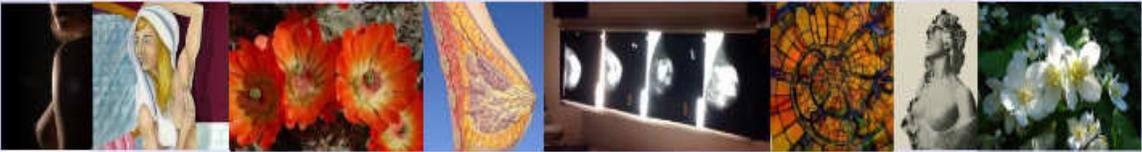
Email the Research Team

Copyright information

Illustration 7: Wireframe for Transition Pages

Transition pages give users context within the content, and slider controls were used in a number of questions.

[Log out](#)



Initial Questions

Have you had a mammogram?

- Yes, my last mammogram was in the last year
- Yes, my last mammogram was between 1 and 2 years ago
- Yes, my last mammogram was between 2 and 3 years ago
- Yes, my last mammogram was more than 3 years ago
- No, I have never had a mammogram

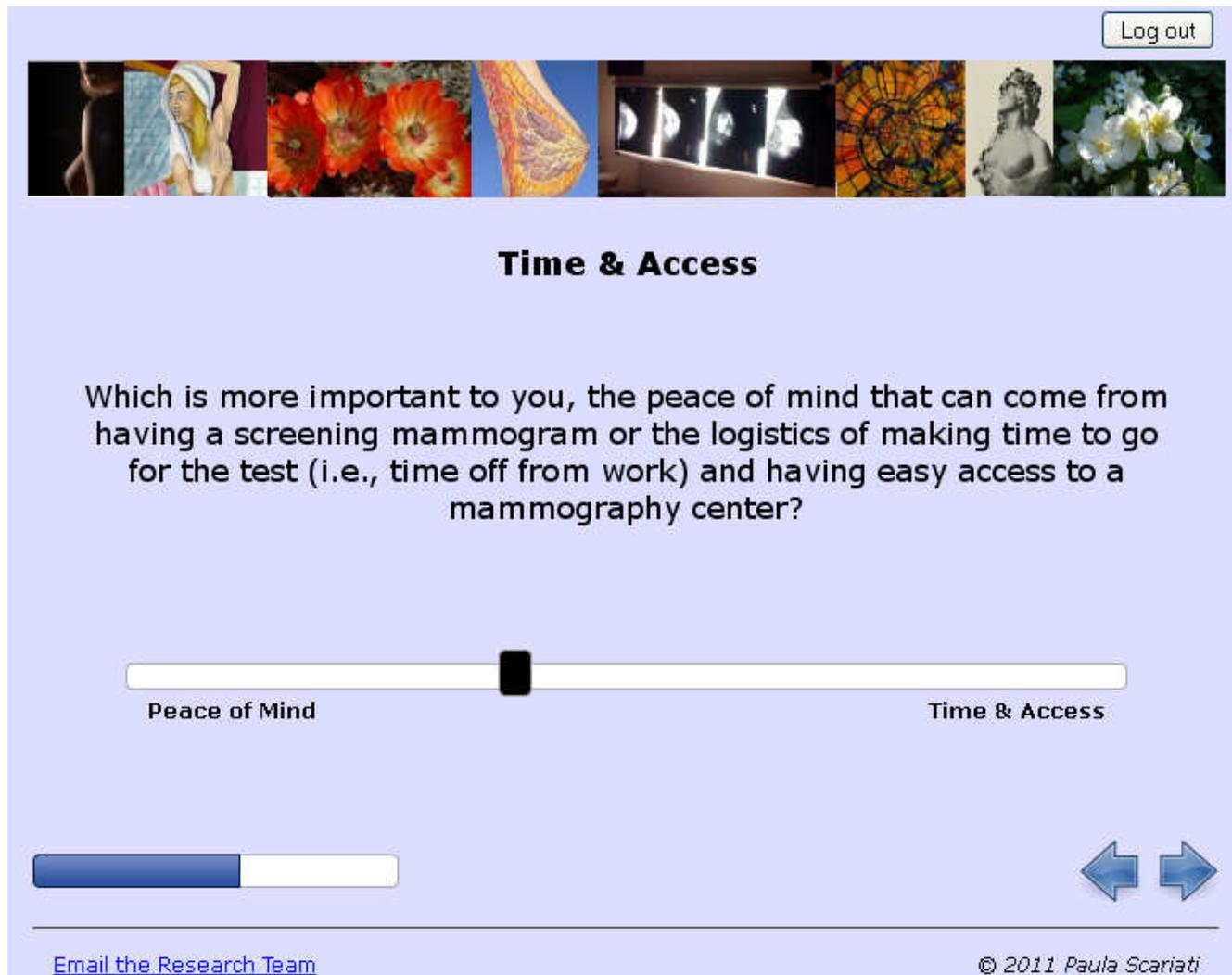
 

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Illustration 8: Page with Question

The data from the surveys is saved in the database for later analysis, and forms the basis of the related research study. A value reflecting the subject's response is saved when she clicks the "Back" or "Next" controls (left and right facing arrows). Each value is coded to correspond to a meaning as defined in the data dictionary. For instance, "No" is always coded as "0", "Yes" is "1" and "Unknown" is "2". Some questions use a custom scale, for instance the question "Have you had a mammogram?" has

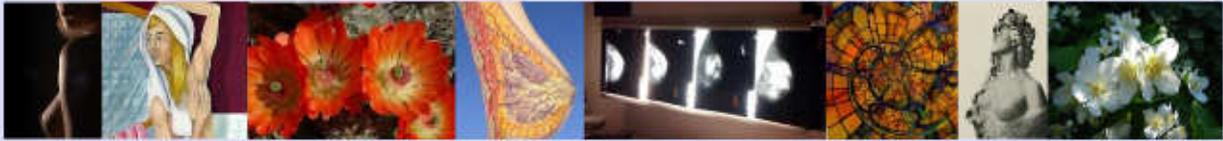
valid answers "Yes, my last mammogram was in the last year.", which stores a value of "1", "Yes, my last mammogram was between 1 and 2 years ago", which stores a value of "2", "Yes, my last mammogram was between 2 and 3 years ago", which stores a value of "3", "Yes, my last mammogram was more than 3 years ago", which stores a value of "4". and "No, I have never had a mammogram", which stores a value of "5".



The screenshot shows a survey interface with a light blue background. At the top right, there is a "Log out" button. Below it is a horizontal strip of eight small images: a person, a woman in a white top, red flowers, a breast diagram, a mammogram, a stained glass window, a classical statue, and white flowers. The main heading is "Time & Access". The question asks: "Which is more important to you, the peace of mind that can come from having a screening mammogram or the logistics of making time to go for the test (i.e., time off from work) and having easy access to a mammography center?". Below the question is a slider control. The slider has a white track with a black knob. The left end is labeled "Peace of Mind" and the right end is labeled "Time & Access". The knob is positioned approximately one-third of the way from the left. Below the slider is a blue progress bar that is about one-third full. At the bottom right, there are two blue arrows pointing left and right. At the bottom left, there is a link "Email the Research Team". At the bottom right, there is a copyright notice "© 2011 Paula Scariati".

Illustration 9: Example of page with slider control

Slider controls were used for questions with answers on a 1-100 or 1-10 scale.



Major Risk Factors

Age, First-Degree Relative & Prior Breast Biopsy



- Breast cancer risk increases with age. This is why routine breast cancer screening is recommended as you grow older.
- Having an immediate family member (mother, sister, daughter) with a history of breast or ovarian cancer is another major risk.
- Having a prior breast biopsy (the removal of breast tissue to check it for signs of cancer) that was *negative*, also increases the risk of developing breast cancer.



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Illustration 10: Graphics example

The content pages had varying graphic layouts. In some cases the graphics were purely illustrative.

Log out



So, How Does a Mammogram Work?

- You will be seated or standing in front of a machine used only for mammograms.
- The x-ray technologist will place your breast onto a plastic plate on the machine. A second plastic plate is lowered onto the breast applying pressure which will even out the breast tissue.
- This allows for a clearer image and reduced radiation dose.



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Illustration 11: Image example

In other cases the graphics helped explain the text.



Possible Outcomes of Breast Cancer Screening

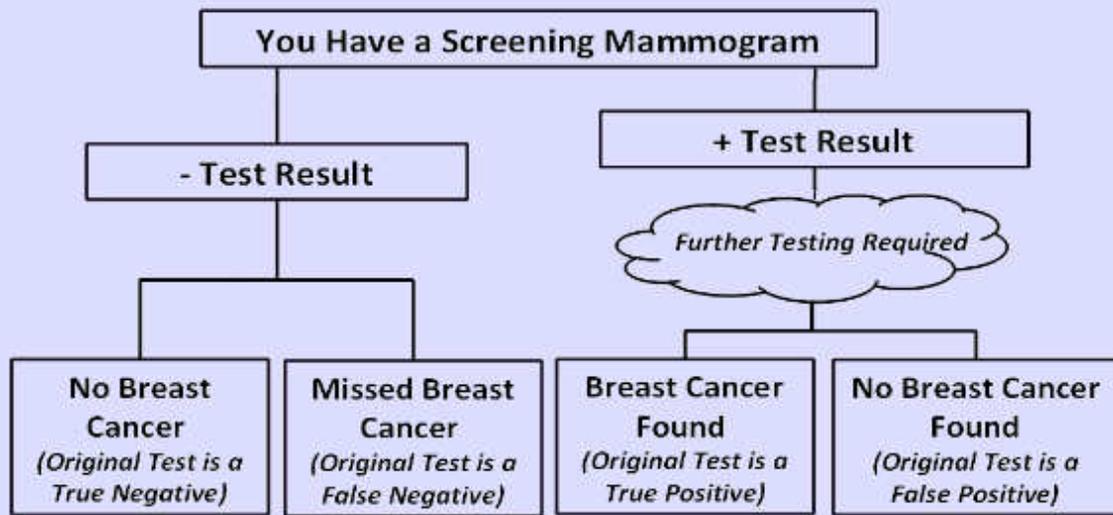
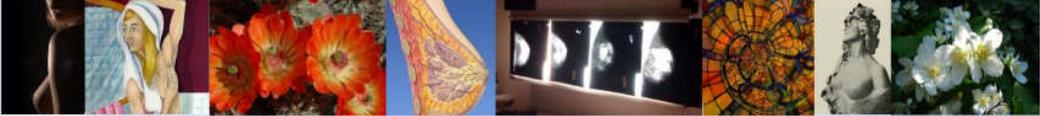


Illustration 12: Screening results

Some of the graphic pages were charts.

Log out



What Matters Most to Me?

Now please take these 10 areas that you just considered and sort them into most, least and middle importance. Drag the light gray items into the appropriate box.

Most Important

Moderate Importance

Least Important

Avoiding False Positives

Avoiding False Negatives

Catching Cancer Early

Cost

Embarrassment & Pain

Overdiagnosis

Peace of Mind

Stress & Fear

Time & Access

Radiation Exposure

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Illustration 13: A usability challenge

Some pages caused more design issues than others. The “What Matters Most to Me page inspired the most feedback in usability testing. On this page, the light gray text boxes are picked up with the mouse, and sorted into three categories (the darker gray boxes).

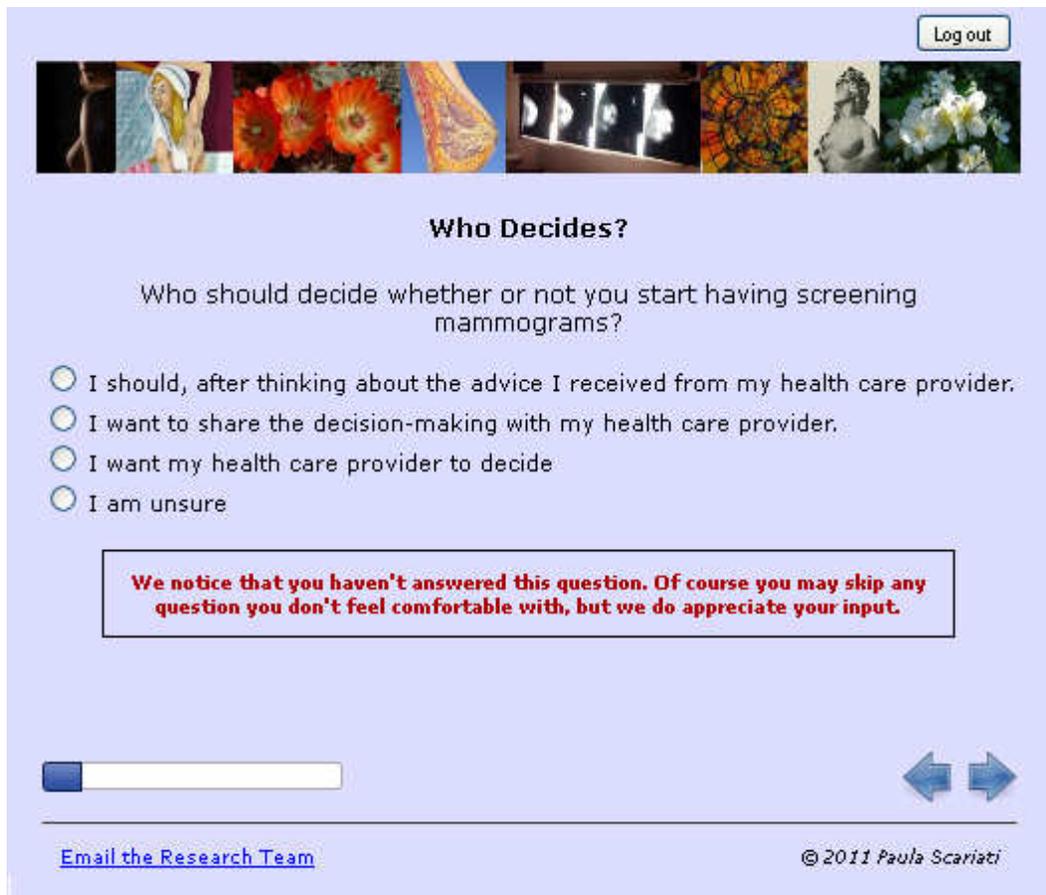


Illustration 14: Page with Unanswered Question

Subjects who attempted to go to the next page without answering a question on the page were prompted once to answer, and then were allowed to proceed. In this case, the text of the prompt reads “We notice that you haven't answered this question. Of course you may skip any question you don't feel comfortable with, but we do appreciate your input.” There are other variations. The system recorded the results differently depending on the reason a page was skipped.

Questions on a page never reached by the user had default answers of null. If an answer on one page prompts the application to skip the user over a page 997 is assigned, if a user skips of all questions on a page (after one prompt) 998 is assigned, if the user skips of one or more questions on a page when one or more were answered 996 is assigned.

3.3 User Resources

After the MDA has been completed, a PDF containing information is sent to the email address provided by the user.

3.4 Researchers review data.

An extract containing the responses to the survey questions is created from the data captured in the database. The extract is loaded into a statistical analysis tool and is then analyzed. Any data collected for eligibility are deleted before the user exits the application.

3.5 Database Design

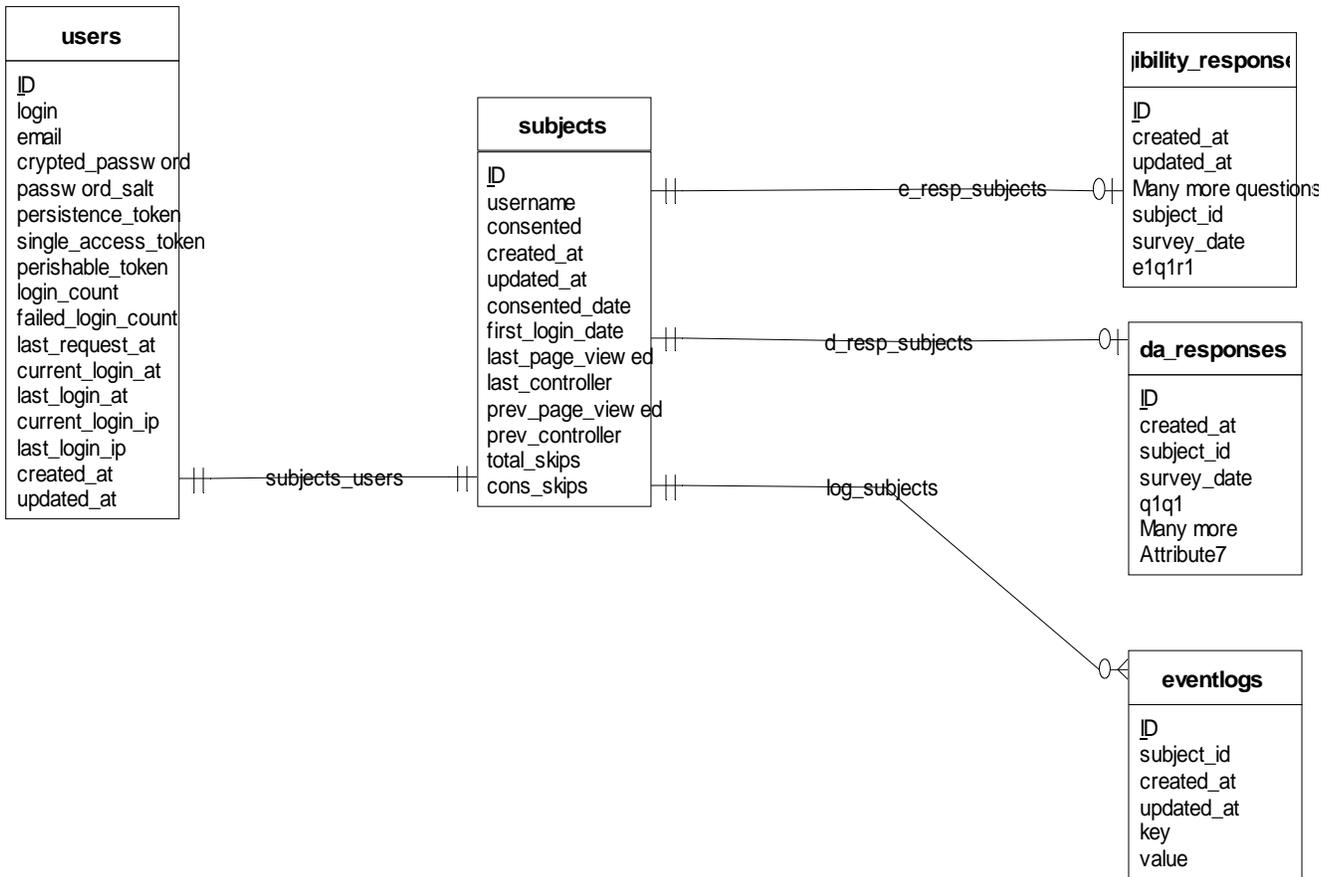


Illustration 15: Entity Relationship Diagram

A relatively flat design was adopted to facilitate screen design, and because the extract for the research team contains a single row per subject for analysis. The “users” table contains information relating mainly to login and security, and contains fields used by Authlogic. The “subjects” table contains mainly information related to the subject's use of the system. The “eligibility_responses” table contains information related to the subject's eligibility to participate in the study. There is one row per subject, and that row is always deleted, whether the patient continues with the study or not. The “da_responses” table contains the subjects responses to the questions asked in the MDA. There is one row per subject, and only the most recent responses are saved. The “event_logs” table contains

information about a user session such as what browser is used, ip address and page views. One or more events are generated when a user attempts to log in or when she views a page.

An extract is created on demand for the research team which contains data from the subjects and the da_responses tables. Only the subject's most recent responses are included.

3.6 Administrative functions

A simple interface allows an administrative user to perform several functions to manage user credentials. Administrators can list existing users, create new users, show a single subject's enrollment information and reset the user to default setting. When a subject logs in for the first time, the date is recorded,. The subject's account expires after seven days. The administrator can “unexpire” the account using the interface provided if the user requests access after this time period.

4 Usability

Usability testing was conducted throughout the development process. One of our initial platform considerations was ensuring that all team members had access to a working system prototype as quickly as possible. This prototype was updated with iterative deliveries as system components were made ready. Usability changes were made based on the comments of team members. When changes were made to the software, they were available to all users at the same time.

Several rounds of usability testing were also performed with a convenience sample of volunteers. We received feedback on content, wording, system design, system usability and technical glitches. Testing was performed on Internet Explorer, Firefox, Safari (www.apple.com/safari/) and Chrome (www.google.com/chrome).browsers, and various versions of Windows, Linux and iOS. Several Javascript controls we used did not work with the iPad 2.

4.1 Usability in patient populations

“Human factors engineering is a discipline that seeks to design devices, software, and systems to meet the needs, capabilities, and limitations of the users, rather than expecting users to adapt to the design.”³ Usability is goal oriented; the question is whether users can perform tasks in an efficient and enjoyable way. Approaches for testing usability can vary from highly theoretically based, requiring a deep understanding of information and cognitive models⁴ to pragmatic and simple discount usability tests. Discount usability techniques place a premium on ease and speed of administration. They are especially valuable early in the development process.⁵ Contact with real users can expose blind spots in development groups, who no longer view the system with new eyes. “Proper design of the user interface...can substantially increase the efficiency of the human-computer interaction in terms of increased task performance, user satisfaction, user's knowledge, retention and decreased training time and error rate.”⁴

Usability encompasses all the parts of the user experience with the system, including navigation, content, layout, efficiency, error handling and satisfaction. It can also identify barriers to use and work flow. As in any other form of testing, earlier feedback is far more effective.⁶ The earliest rounds of testing, even against very rough systems, can pick up major flaws in design at a time when the investment/cost is low. In a study of obese patients (Mackert et al⁷) found that some users needed more simple content than provided in the initial design.

There is great diversity within the patient population. Patients use a wide variety of technology. A system intended for patients needs to work in different locations of access, any number of operating systems and browsers - and which versions of each are supported. Different parts of the user experience may be captured depending on whether the test occurs in the field, a conference room or a usability lab. Software developers working in a large organization will not necessarily foresee the

issues faced by users in the field. Kaufman et al² found that older users struggled with telemedicine technology in their homes.

It is important to think through what constitutes a representative group of patients.⁷ Recruitment of usability test subjects is likely to skew toward people who are interested in software and software usability unless effort is made to seek input from a diverse group.³

4.2 Usability tests

The assessments discussed here were based on user populations likely to be subjects of the study. The goal was to have input from approximately five individuals in each round. Some of the usability tests we performed (not covered in this paper) included review by informatics graduate students, many of whom were trained in usability and software design.

In each case, users were contacted to assess their interest. If they agreed to participate credentials and directions were provided. Subjects could access the MDA from any computer with a web browser. Users viewed the system on their own computers, and were not observed during the testing. Most input was obtained through email or other messaging. No feedback was anonymous, and all subjects are acquainted to me personally – although most not well.

4.2.1 Email round (initial solicitation 3/29, final feedback 4/23)

For the first round, twelve members of a women's over40 soccer team were contacted via email and asked to review the software and give comments. [Reference to invitation text] Those who responded were given test user-id and a scenario and asked to complete the MDA with comments.

Demographics: Four women between 40 and 60 commented on the system. Female amateur athletes, upper middle class and white. Two of the four have held positions in high-tech companies. All have at least some college.

Summary of feedback. In general, the simplicity of the page design and system navigation was seen as a positive. Some technical glitches were identified and fixed. A couple of question screens were re-designed to accommodate feedback: these had been identified as problematic up front as well. Some pages with confusing wording were pointed out, as were questions that were missing applicable options.

Comment	Description	Disposition
"Do you know someone with cancer? – multiple choices apply. Friend and relative"	This question was initially implemented as a radio button, which allows only one choice to be made.	The control was changed to a series of check boxes, so that multiple selections could be made.
"Logging Out" – the log out button is "hard to find", recommend putting it at the bottom right of the screen	The log out button was located in the upper right corner, near graphical content	We did not make this change because other screen controls were in the suggested location.
"Education – most surveys offer a choice of "some college" so I don't feel quite so uneducated"	The question initially offered choices of ...	A choice of "some college" was added.
"As far as the content: I found it difficult to rate the 10 parameters about choices about getting a mammogram--early detection, cost, pain and embarrassment etc. It's almost like there are too many to reasonably rank them all."	The "What Matters Most o Me" page asks users to rate the importance of the Decisional Support questions. A version that asked users to sort in priority 1-10 was confusing.	Users were asked to sort ten parameters in to three priorities, low medium and high, instead of ranking them 1-10.

Other Feedback

"Very informative, Easy to read, particularly because there was no scrolling required. Nice graphics, fonts, etc."

"A little confusion in the questions about my knowledge of what screening is available. I know that digital imaging is available, but I don't know if it's available currently to me through my doctor, my hospital."

"People often confuse "positive" and "negative" when it comes to medical diagnosis – may want to change it to "positive for cancer."

"I think it's a very pleasant interface--colors and pictures. It's easy enough to use. The information is useful in providing basic statistics about breast cancer. As far as usability, I think the tool is very usable as is."

4.2.2 Facebook round (April 21 - May 2)

The second group was recruited through a Facebook (<https://www.facebook.com/>) Event.

Demographics: Six women between 49 and 54 participated. All are upper middle class and white. All have at least some college. All grew up in either Lincoln or Sudbury MA, and attended high school together.

Results: 20 women were invited to participate. In total, sixteen received credentials because they had volunteered in some way. Some of the 16 were on the initial invite list of 20, and others joined when they saw their friends responding. If input for a larger group is needed, asking people to forward the invitation, is an instance of snowball recruiting which uses social networks to broaden the base of potential subjects.⁸

Of the sixteen subjects receiving credentials, four successfully used the application and provided feedback. Two reported problems logging in and did not return to the system. The system was down for two days following the invitation. Several apologies were received from people who never found the time. Some people tried to log in using their personal email addresses. This seems to be a recurring source of confusion when we issue test credentials.

Users communicated a number of different things:

- they asked questions about the test
- they reported problems logging in
- they gave feedback on the MDA

The communications came in several forms. Most people used more than one form of communication:

- Comments on main thread

- Facebook messages to the group in response to directions
- Facebook messages directly to me
- Emails directly to me

One interesting dynamic was that several people started commenting on a public message thread and reinforced each other's points.

Summary of feedback. In general, people reacted to the content of the tool and to any barriers the system presented. Some typographical errors were found, the wording in the eligibility logic needed to be revisited, some of the terminology, especially “false positives” and “false negatives”, was found to be confusing.

We found formatting issues that showed up on some computers and not on others and performance was identified as an issue.

All of these issues were addressed in code changes.

Timing: The users who reported the time it took to complete the MDA showed a range from 35 to 75 minutes.

Comment	Description	Disposition
On the first section, family screening, I represented that I was in a high risk group for breast cancer and that all my relatives seem to have it. I was thanked for my time and kicked out after about 30 seconds. I feel unloved and I can see that I can't be saved! This may be a turn off for people who really have this kind of profile.	Content is presented to subjects in the higher risk group when they are informed that the information in the decision aid is not appropriate for them.	The language used for subjects who were flagged as above average risk was changed.
I would agree with your clinician that people with risk factors should work with their provider but I also think that there should be some suggestion of doing that instead of just ending the session. Maybe some language that says "given your level of risk we recommend	Content is presented to subjects in the higher risk group when they are informed that the information in the decision aid is not	The language used for subjects who were flagged as above average risk was changed.

consulting your physician to discuss an appropriate screening plan"?	appropriate for them.	
I answered "none of these" for the and it said I have an average risk?	Content is presented to subjects in the average risk group when they are informed that the information in the decision aid is appropriate for them.	The language used for subjects who were flagged as average risk was changed.
I chose the answer that no one in my family had had cancer and I can't remember the exact wording, but it sounded like they'd pegged me as a "risk"? Would be good for them to check this part out -- particularly since it's at the beginning of the form	Content is presented to subjects in the average risk group when they are informed that the information in the decision aid is appropriate for them.	The language used for subjects who were flagged as average risk was changed.
Why is thermography not an option? (I know it's not generally an option as far as health insurance is concerned, I just wondered as it's less invasive than a mammogram and this seems to be about mammograms)	Comment is pertinent to pages in which mammography options are discussed.	Not addressed.
Do you know what mammography screening options are available -- TO have one or to NOT have one? I don't really understand what the options are and this is why I wanted to go back into the system to see what I missed.	Comment is pertinent to pages in which mammography options are discussed.	Not understanding all options is a valid state.
I was a little confused/irritated on ... "Who Should Be Screened?" because in my opinion, how can you answer the question simply based on a woman's age? You have to factor in other things. So I just checked ALL the boxes. HA!	Zero, one or many age groups can be selected on a question page.	Selecting all is a valid choice.
False negatives...I read this through twice...found it difficult to understand, or process...but I don't know how you would actually explain it any more clearly than you have it stated here. It's a difficult thing to explain!	The content has several pages of information about the results of screening tests.	Text describing both false negatives and false positives was refined more than once.
I assume the questions you ask at the end (age, household income and cup size) are for demographic data. It wasn't clear when answering those questions why they were being asked. You may want to add some sort of statement explaining why, whether they're used in the summary or are simply demographic info.	Demographic questions	Cup size question was removed. Age and household income were kept.
You're absolutely right, the "What Matters Most to Me" page sucks.	We knew this was coming	We kept working on it...

Praise

"I can't even begin to tell you how much I appreciate the work that folks like you do to help educate people about breast cancer screening tools. Had I chosen not to have a mammogram in 2008, I wouldn't be here now to participate in your project. Rather than leave education to the news media and knee-jerk reactions to study results, having a tool like this to provide the bare facts to help make this decision is invaluable in my book."

"It was EXTREMELY helpful to me, doing this. I did learn a lot, especially about the little amounts of radiation- I had thought that there was a lot more radiation in the mammogram than what it actually is. That made it well worth it, just learning that tidbit!"

"I thought it was quite easy to maneuver. Instructions were clear. As someone who knows quite a bit about the subject, it's a bit of a challenge to "dumb myself down" to feel as though the information would make a difference in my decision. That being said, I thought the information provided was quite clear and educational. I did not get the sense that I was being pushed in one direction or another."

"Anything you like? option to log out on each page and knowing the system saves your work is really good! Status bar artwork/photos at top of pg, lavender color, Summary - laying out "what we've learned".

5 Limitations

5.1 System Implementation

The MDA took longer than anticipated to build, and is not quite ready for production. The database should be migrated from SQLite to a more full featured database such as MySQL before deployment to patients. A secure and more automated credential distribution system needs to be developed. Reporting functionality is needed to make information more accessible to researchers.

5.2 Usability Testing

The usability testers were, in general, well educated and technologically astute. No testing has been done with low-literacy groups or with subjects who are unfamiliar with the use of a computer. Further testing should include a wider range of test subjects, especially in terms of familiarity with computers. Formal usability lab testing with a small group would be helpful in finding gauging user reaction to the system.

6 Summary

In general the design and content for the MDA was well received. By making the software available over the web, we opened up opportunities to recruit subjects remotely. There is a trade-off in that a system open to the internet requires additional effort to ensure security and reliability. User data needs to be secured, and in our experience, subjects do not return when the system they are testing is unavailable. The usability testing was, by intent, informal, and allowed users to comment freely. The comments were useful and pointed out both positives and negatives in the design of the user interface and in the content.

Following the usability testing described here, the MDA is being made available to a wider range of subjects for research rather than usability purposes.

7 References

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8 Appendix 1 Email User Testing

8.1 Recruitment Materials - email

Folks,

I'm looking for a few volunteer to look at a decision aid I'm working on as part of my master's program.

The tool is intended to help women in their 40's decide whether or not to get a screening mammogram.

It's aimed at women of "average" risk, but your actual age, and personal & family history does not

matter for the usability test. (You don't need to answer questions truthfully - it's actually better if you don't.)

If you can set aside 30 to 60 minutes or so next week to help out, please let me know.

I'll send login credentials and a short list of questions to anyone who volunteers. And a beer.

Thanks,

LNN

8.2 Directions

Thanks for offering to help with the usability test of the project!

This may become part of an AHRQ grant on preventive medicine (really exciting news!) - so we're trying hard to get it right. PLEASE DO NOT HESITATE TO OFFER CRITIQUE - I'd MUCH rather hear about problems from you than from users after release.

The tool is intended to help women in their 40's decide whether or not to get a screening mammogram. It's aimed at women of "average" risk, but **your** actual age, and personal & family history does not matter for the usability test. We hope for it to take about a half hour. Please do not enter information you would want to keep private - and it's fine to enter bogus information.

If you have a comment about a page, you can identify it from the title or just copy the address. A couple of pages are not fully developed yet. Fine to flag them. Also, there is a question up front about family history - leave it blank if you have trouble getting past it.

The type of information that we're looking for: (don't answer all questions, just those for which you have something you want to say.)

- Is anything confusing?
- Is anything ugly?

- Is anything annoying?
- Anything you like?
- Anything you don't like?
- Is the information useful?
- Is it easy or hard to figure out what to do? Any place you get stuck?
- Was the amount of explanation about right?
- Did you feel pushed in one direction or another?
- Who do you think sponsored this?
- How long did it take?

Login Credentials

Please go to: <http://skynet.ohsu.edu/mda> to log in.

≤< username list elided >>

Password for all ids: ***** (you'll be asked to change it on login)

If I could have feedback by April 16th, that would be really helpful. (Later is fine too.)

Thanks,

LNN

8.3 Raw Feedback

Positive

Excellent job. It looks great. Read my comments as hyper-critical because that's what they are. Overall the survey could easily stand on its own as is. I was completely overanalyzing it, as I ask my kids to do when I make changes to my website. I wrote comments as I went on separate digital "Post-It" notes bumping along on the way home from NH, so they aren't necessarily in order.

Very informative

Easy to read, particularly because there was no scrolling required. Nice graphics, fonts, etc.

I believe one of the series of answers carried through to the next set of relevant questions, so you didn't have to choose again. "Unsure" about options, etc.

My connection dropped because I was using PdaNet on my phone and I got a call. I was easily able to resume after I re-connected.

I like the slide bars.

Proofreading

On the consent form, there's an extra comma at the end of someone's contact info. Same page says it's secure, but there's no "s" in http//: and no browser lock. I'm guessing that's because it's just a test survey, you know that, and when the official survey is done, it'll be secure.

Dates out of range for survey, but again, I'm guessing you know that.

Possible Changes

Toward the end: Do you know someone with cancer? – multiple choices apply. Friend *and* relative

Education – most surveys offer a choice of "some college" so I don't feel quite so uneducated.

Income – most surveys offer to let you opt out. I almost always do and it would be a very rare survey where I'd answer that question honestly, which isn't true for other questions. If you have to have it, maybe include a pop-up that explains why it's important to the survey. Sometimes I can be talked into it.

A little confusion in the questions about my knowledge of what screening is available. I know that digital imaging is available, but I don't know if it's available currently *to me* through my doctor, my hospital.

What matters most on a scale of 1-10 is tough and time consuming because some answers have the same approximate weight. Maybe each question could be on a scale of importance 1-5.

It took me longer than the average person will because I had a slow connections and I was scrutinizing every bit of it. It is a bit long. Maybe some time could be saved by not having to click through header pages.

I felt that the survey was leaning toward encouraging screening probably by someone in the medical industry, but then again, I know you.

Best of luck!

Comments on what I could get to (can't seem to get past the second screen any longer due to the last thing on this list). Let me know if you think it is fixed and I can try again...

"Logging Out" – the log out button is "hard to find", recommend putting it at the bottom right of the screen.

"Log out" button is missing from the "Welcome" Screen.

Page 6 – people often confuse "positive" and "negative" when it comes to medical diagnosis – may want to change it to "positive for cancer".

I answered a question, moved forward to page 7, and then immediately hit the back button – it should not give me the “notice” about not answering the current question (I would think this would only happen on forward movement).

In the middle of trying to use the backward and forward arrow, I suddenly got a “you must be logged in to access this page” and got put back to the login screen – is there some type of time out? I ended up having to start over (didn’t retain anything). After a few pages got a message, “something went wrong”.

Tried logging in again, and it did recognize that I had started, but it fails with the same error after the second screen.

I went through the breast cancer decision tool even though I am too old and have a higher than average risk of breast cancer.

I think it's a very pleasant interface--colors and pictures. It's easy enough to use. The information is useful in providing basic statistics about breast cancer. As far as usability, I think the tool is very usable as is.

As far as the content: I found it difficult to rate the 10 parameters about choices about getting a mammogram--early detection, cost, pain and embarrassment etc. It's almost like there are too many to reasonably rank them all.

The summary at the end is good--it's what you should be doing to help cement info in peoples' brains. I'm not sure why the question was asked as to whether or not the participant was aware of the changes in the recommendations etc. The tool is just supposed to help you decide if you want a mammogram, no?

I'm not sure you can tell who would be sponsoring the development and use of such a tool. Maybe if you are really trying to just help women decide, you don't need quite so many questions and additional statistics. I'm sure there are other reasons to ask for this info, though.

One verbal “it was fine. I liked it. No, I wouldn't like to write that down.”

9 Appendix 2: Facebook User Testing

9.1 Recruitment Materials

Instructions to create event

Join Facebook..

Create event. I started with a week, and extended it a bit. The event only shows for people if it is in the future or current.

Set Openness: The event can be open (anyone can RSVP) or closed (invite list only can see &

respond). I chose “open”.

Invite text: (shown below)

Responses: Subjects respond by replying “Yes” to invite, leaving a message in the main thread or personal message/email.

Propagation: For open events, friends who are not specifically invited can RSVP, and anyone can invite others to join.

Credentials: User Ids and passwords for all volunteers were created using tools in the MDA application

Directions: (Shown below) A message was sent to those who responded that included directions and credentials

Testing: Monitor event, respond to messages and emails.



Illustration 16: MDA Usability event in Facebook

Initial Invite.

Looking for usability testers

You are Attending · Share · Public Event

Time Thursday, April 21 at 9:00pm - May 2 at 12:00pm

Location Anywhere!

Created By LNN

I'm looking for a few volunteer to look at a decision aid I'm working on as part of my master's program.

The tool is intended to help women in their 40's decide whether or not to get a screening

mammogram.

It's aimed at women of "average" risk, but your actual age, gender and personal & family history does not matter for the usability test. You don't need to answer questions truthfully - it's actually better if you don't. You also don't need to be an expert with computers or testing.

If you can set aside 40 to 60 minutes or so in the next week to help out, please let me know. Please say you'll attend, and I'll send login credentials and a short list of questions to you.

Thanks!

LNN

9.2 Directions

Thanks for offering to help with the usability test of the project!

This is an early version of an application that will be deployed to a large number of women, so we're trying hard to get it right. PLEASE DO NOT HESITATE TO OFFER CRITIQUE - I'd MUCH rather hear about problems from you than from users after release.

The tool is intended to help women in their 40's decide whether or not to get a screening mammogram. It's aimed at women of "average" risk, but your actual age, and personal & family history does not matter for the usability test. We hope for it to take about 40 minutes. Please do not enter information you would want to keep private - and it's fine to enter bogus information.

If you have a comment about a page, you can identify it from the title or just copy the address.

We'll be continuing to make changes as we go. A couple of pages are not fully developed yet. It is fine to flag them. There is a question up front about family history – answer “none of these” if you have trouble getting past it. There is also a page titled “What Matters Most to Me?”-- It hasn't actually been implemented yet. It is just a stub. We know it sucks.

The type of information that we're looking for: (don't answer all these questions, just those for

which you have something you want to say.)

Is anything confusing?

Is anything ugly?

Is anything annoying?

Anything you like?

Anything you don't like?

Is the information useful?

Is it easy or hard to figure out what to do? Any place you get stuck?

Was the amount of explanation about right?

Did you feel pushed in one direction or another?

Who do you think sponsored this?

How long did it take?

Login Credentials

Please go to: <https://skynet.ohsu.edu/mda> to log in & use the fake email address below as your login.

<list elided>

Password for all ids: ***** (you'll be asked to change it on login)

If I could have feedback by April 30th, that would be really helpful.

Thanks,

LNN

9.3 Raw Feedback

User A

Went through this the other day and was going to go back through it again to make this more clear, but I can't get in -- It's OK, as I'm a perfectionist and would most likely spend 2-3 hours getting all the details "right."

Thanks, I enjoyed this and hope it helps you and your colleagues.

Let me know if you have any questions,

General Q:

- When put cursor on “Email the Research team” (bottom left of page) it always refers to “Decision Aid Eligibility Question” (no matter what page I’m on) Is that meant to change with each page or depending on which section of the Test I’m in?

Answering your questions:

Is anything confusing?

- 1st Question: I answered “none of these” for the and it said I have an avg risk?

- Why is thermography not an option? (I know it’s not generally an option as far as health insurance is concerned, I just wondered as it’s less invasive than a mammogram and this seems to be about mammograms).

TYPO: The Issue of Overdiagnosis . . .”-- that would never haved progressed. . .”

In Summary: “Screening 1000 women in their 40s for THE next 10 years results in:

“- 0.5 fewer deaths”.

False Negatives

Screening mammograms can miss a cancer. While this happens infrequently, it is important to remember that a negative mammogram does not guarantee that you don’t have breast cancer.

Which is more important to you, the peace of mind that comes from a negative screening mammogram or the small chance that a cancer may have been missed? HUH??

Think you already know that the page labeled “What Matters Most to Me?” isn’t working --

Related to above: “3. Your Priorities” - didn’t work because I was allowed to choose #2 for multiple answers.

“What you consider when making a choice about Mammography” Do you know what mammography screening options are available -- TO have one or to NOT have one? I don’t really understand what the options are and this is why I wanted to go back into the system to see what I missed.

Do you know the benefits of each option ?? I saw all the stats, etc. if that’s what you’re referring to?

How do you rate your overall health Add option? - I am in excellent health

Preventive measures - gauge (lower left moves to left instead of to the right)

General Life Outlook - gauge (lower left has gone backwards -- too much to left (this page only -- returns to normal on the following page)

Is anything annoying? - sometimes have to click 2x on the arrow for next pg, changing pages

slow

Anything you like?

option to log out on each page and knowing the system saves your work is really good! Status bar, artwork/photos at top of pg - lavender color, Summary - laying out "what we've learned"

Is the information useful? yes

Any place you get stuck? yes, see above

Did you feel pushed in one direction or another? yes, pushed to have a mammogram

Who do you think sponsored this? - OREGON HEALTH & SCIENCE UNIVERSITY - Dept of Med Informatics & clinical Epidemiology, Nat'l Lib of Medicine

How long did it take? 1-1/4 hours on test + 1/2 = 1-3/4 hrs

User B

Just finished...took me about 35 minutes.

It was EXTREMELY helpful to me, doing this. I did learn a lot, especially about the little amounts of radiation- I had thought that there was a lot more radiation in the mammogram than what it actually is. That made it well worth it, just learning that tidbit!

Here's some feedback

I was a little confused/irritated on datool/question4 "Who Should Be Screened?" because in my opinion, how can you answer the question simply based on a woman's age? You have to factor in other things. So I just checked ALL the boxes. HA!

datool/benefits10 False negatives...I read this through twice...found it difficult to understand, or process...but I don't know how you would actually explain it any more clearly than you have it stated here. Its a difficult thing to explain!

datool/41 Your Priorities.

This confused the HECK out of me. And maybe this is that stub you were talking about, "what matters most to me?" - it appeared on screen as though the answers I gave (according to priority for me) were listed in the exact OPPOSITE order of how I had listed them. (I even scrolled back to make sure I had done it correctly.) If this is the same stub you said hasn't been implemented yet, then please ignore my comments. If this is, however, supposed to work, please know it didn't.

I did not feel pushed in one direction or another, other than to feel as though I should be better about getting mammograms (which is actually good, because before this I would have probably just blown it off.) So I don't think I am actually being PUSHED, more just being better INFORMED.

I have NO IDEA who sponsored this tool!!!! Cannot imagine!!!

Thanks for letting me participate.

April 25 - LNN

Thanks User B! This is really helpful - your input on the content is really helpful. We've

actually been told that even asking the question is likely to bias people *against* getting mammograms, so a lot of work has gone into the content (mostly not mine) it's really gratifying to hear your views!

Yes, the datoo41 page is being completely re-written. Hoping to get a new version up tonight or tomorrow morning that matches the page that asks you what's important. Did you have any trouble with the page that asks you to sort priorities? (It's new & not quite done...)

Thanks!

April 25 - User B

Is that the one with the boxes that you moved into different categories, based on most important to less important? The only feedback I have on that is that the boxes kind of disappear after you move the items in, because they stack on top of each other, so you can't read them all...there isn't room to. But that wasn't that hard to figure out. Isn't that supposed to correspond to your priorities on the other (latter) page? Because it didn't, for me. Hope this helps?

April 25 - LNN

Yeah, the "snap" attribute doesn't really do what I had hoped. Keeps me busy.

If you're interested, I have the datool41 page at least working with data, if not exactly pretty. If you log in, and then copy <http://skynet.ohsu.edu/mda/datool/datool41> to your address bar you should be able to see it with your saved data. (to save you navigating through...)

It's always hard to balance wanting to show something nice with not waiting too long for input (and also having deadlines...)

April 25 - User B

Much better! Thanks!

Shared thread: including feedback between participants.

April 29 - User C

I completed the usability test. I thought it was quite easy to maneuver. Instructions were clear. As someone who knows quite a bit about the subject, it's a bit of a challenge to "dumb myself down" to feel as though the information would make a difference in my decision. That being said, I thought the information provided was quite clear and educational. I did not get the sense that I was being pushed in one direction or another.

You're absolutely right, the "What Matters Most to Me" page sucks.

Does the summary that gets emailed look the same as the summarized information on the screen? If yes, I would make a more clear suggestion in the emailed information to bring a copy with you to discuss with your doctor.

Also, I assume the questions you ask at the end (age, household income and cup size) are for demographic data. It wasn't clear when answering those questions why they were being asked. You may want to add some sort of statement explaining why, whether they're used in the summary or are simply demographic info.

I hope this helps with development! I can't even begin to tell you how much I appreciate the work that folks like you do to help educate people about breast cancer screening tools. Had I chosen not to have a mammogram in 2008, I wouldn't be here now to participate in your project. Rather than leave education to the news media and knee-jerk reactions to study results, having a tool like this to provide the bare facts to help make this decision is invaluable in my book.

Let me know if you need anything else!

April 29 - User B

Good point, User C! There should be a printout available to take to the doctor! Hadn't thought of that.

April 29 - LNN

Thanks User C! The content that's sent out hasn't been written yet, and won't be written by me, so I'm not sure what it will say exactly. (I'll just worry about writing the code to send it...)

It's been really exciting getting a chance to work on this project: it's a great group of people and I love being involved in something that hopefully can make a difference in people's lives. And I'm glad you're still here!

April 29 - User D

I finally went into your questionnaire. On the first section, family screening, I represented that I was in a high risk group for breast cancer and that all my relatives seem to have it. I was thanked for my time and kicked out after about 30 seconds. I feel unloved and I can see that I can't be saved! This may be a turn off for people who really have this kind of profile.

April 29 - User C

I would tend to agree with User D. The first time I tried the tool, I was honest about my history and was booted out before even getting to the first question. I would recommend something that says to someone in that position "your risk is higher than the general population and a mammogram is recommended".

April 30 - LNN

User D @ User C,

You are right about the language and setting expectations. I think we need to do a better job up front explaining who this tool can help, and what your next steps could be if the content doesn't fit your profile. The clinician in the group is adamant that people with risk factors should work with their provider to figure out what their individual's risk level is and determine an appropriate screening plan.

April 30 - User A

I chose the answer that no one in my family had had cancer and I can't remember the exact wording, but it sounded like they'd pegged me as a "risk"? Would be good for them to check this part out -- particularly since it's at the beginning of the form

April 30 - User C

Happy to help!

I would agree with your clinician that people with risk factors should work with their

provider but I also think that there should be some suggestion of doing that instead of just ending the session. Maybe some language that says "given your level of risk we recommend consulting your physician to discuss an appropriate screening plan"?

Best of luck to you and your team!