

***Making Choices About Breast Cancer
Screening: A Decision Aid for Women
Between the Ages of 38 and 48***

By

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CERTIFICATE OF APPROVAL

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ABSTRACT

Background: In November 2009 the United States Preventive Services Task Force updated its 2002 national guidelines for screening mammography. They transitioned from advising women to obtain a routine screening mammogram annually starting at the age of 40 to recommending a routine screening mammogram every two years starting at the age of 50. Although this change ignited a national debate, there was consensus on the need for a decision making resource to help women in their 40s understand the issues so they could make an informed choice in the matter. In response, we designed, built and tested a web-based breast cancer screening decision aid tool for women ages 38 to 48 with an average risk of developing breast cancer. The tool gave these women the resources they needed to work with their healthcare providers to make choices about screening mammography that were *right for them*. Engineered and developed in accordance with the International Patient Decision Aid Standards criteria, the tool was refined through three rounds of usability testing and ongoing feedback from select stakeholders.

Methods: Pilot testing was conducted in a convenience sample of 51 age, risk-appropriate women to provide a preliminary assessment of the impact of the decision aid on screening choice and decisional conflict. The decision aid was also presented to five subject matter and five clinical experts for their critical review. Feedback on user interface, content, environment and adoption was obtained through semi-structured interviews.

Results: A Wilcoxon signed-rank test was used to compare a woman's plans for screening mammography before and after using the decision aid tool. No significant change was seen ($Z = -1.5$, $p = 0.132$). Pre-post tool analysis of decisional conflict scores was undertaken using the same approach. A significant reduction in overall decisional conflict scores was observed ($Z = -5.3$, $p < 0.001$). In addition, a significant reduction in each of the decisional conflict subscores was seen: uncertainty ($Z = -4.7$, $p < 0.001$), feeling informed ($Z = -5.2$, $p < 0.001$), clarity ($Z = -5.0$, $p < 0.001$), and support ($Z = -4.0$, $p < 0.001$). The experts provided detailed feedback in response to the questions asked on content, user interface, methods of access and stakeholder adoption. They also provided spontaneous comments on language, controversy, values clarification and layout.

Conclusions: A predominantly upper socioeconomic cohort of women participated in our web-based breast cancer screening decision aid pilot study. These women did not change their intention to have a screening mammogram in the next 1 to 2 years. They did, on-the-other-hand, experience a significantly decreased amount of decisional conflict in making that choice. In fact, they felt more certain, better

informed, better supported and demonstrated increased clarity in their decision making process. These findings lead us to believe that, in this cohort, the breast cancer screening decision aid tool brings value to patient care not by impacting *what* a woman chooses but by impacting *why* or *how* she chooses it.

Soliciting feedback from subject matter and clinical experts was an unusual but valuable step in shaping this decision aid tool. It was key in honing tool content as well as raising and exploring unforeseen issues. Furthermore, it allowed for a better understanding of how to handle the epidemiologic divide that prevents the experts from agreeing on a single breast cancer screening recommendation.

INTRODUCTION

BACKGROUND

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^{1,2}. It came with the following proviso for women ages 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.

Despite similar recommendations made by the American College of Physicians in 2007^{3,4} and the National Institutes of Health in 1997⁵ a national debate ensued⁶⁻¹⁰. Was this quality evidence? Was this the first overt example of President Obama's administration rationing healthcare? Many talk show hosts, commentators and politicians showcased stories about women in their 30s or 40s with breast cancer who were saved through screening. The confusion¹¹ escalated further when the American Cancer Society issued a concurrent statement that their experts had reviewed the same data, and more, and were continuing to recommend annual screening starting at age 40¹². What was going on? Two well-respected organizations were making significantly different recommendations about screening mammography based on what they said was the same high quality data. How was that possible?

That question, which remains contentious, highlights the variability involved in defining and interpreting the evidence base. In this case the burden of proof lay with the USPSTF, an independent panel of experts funded through a governmental agency, to defend the merits of its recommendation. The average woman, already indoctrinated by years of successful public health campaigns championing the value of screening mammography on an annual basis starting at the age of 40, was not easily converted¹³. The issue was somewhat nullified by the Patient Protection & Affordable Care Act which was signed into law on March 23, 2010¹⁴. This act guaranteed annual screening mammography for women starting at the age of 40 with no co-pay or deductible. Unfortunately, the legislation was largely a response to public sentiment, not the merits of robust science.

To understand how one arrives at this point of dueling recommendations and legislative mandates it is important to understand the history of screening and why, over 20 years ago, systematic mammography screening was initiated in the United States. Screening is the detection of pre-clinical disease in otherwise healthy individuals. Performing a mammogram in a woman with a breast-related complaint of some kind is not screening. For example, if a woman presents with a lump in her breast, a

nipple discharge, or even the 'vague feeling that something is wrong', performing a mammogram is not screening, it is diagnostic. The inability to distinguish between screening and diagnostic mammography creates much of the confusion that electrifies the debate about mammography leading to erroneous, emotionally charged statements like 'I know a 30 year old woman whose life was saved because her breast cancer was detected through screening'. In fact, a 30 year old average-risk women would never be eligible for a screening mammogram and must have had a mammogram performed with some diagnostic intention.

A brief look at the history of mammography¹⁵ reveals that the first attempts to use radiography for the diagnosis of breast abnormalities were made in the late 1920's. But mammography as we understand it today, using dedicated x-ray units, was developed in the 1960's. The arrival of formalized breast cancer screening didn't occur until much later in the 20th century. And then, advances were rapidly made to the use of ultrasound, magnetic resonance imaging and, of course, digital mammography¹⁵. But the rationale for choosing breast cancer as a disease to screen for is thought to come from a 1968 landmark paper from the World Health Organization that outlined the criteria one should ideally meet before initiating a screening program for a given disease¹⁶.

- The condition sought should be an important health problem.
- There should be an accepted treatment for patients with recognized disease.
- Facilities for diagnosis and treatment should be available.
- There should be a recognizable latent or early symptomatic stage.
- There should be a suitable test or examination.
- The test should be acceptable to the population.
- The natural history of the condition, including development from latent to declared disease, should be adequately understood.
- There should be an agreed policy on whom to treat as patients.
- The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
- Case-finding should be a continuing process and not a 'once and for all' project.

With these criteria in mind, breast cancer appeared to be a good candidate for screening. The logic was simple. If breast cancer could be detected early, it could be prevented from advancing and death from breast cancer would be reduced. This philosophic approach was reflected in several successful public health campaigns on breast cancer screening that educated generations of women to believe that 'early detection is prevention' and that if you don't have a screening mammogram, 'you need more than your

breasts examined'¹⁷. By the early 1990s, annual screening mammography beginning at the age of 40 was a widely embraced recommendation. But this was based more on experience and common sense than scientific evidence.

In 1997, an expert panel convened by the National Institutes of Health conducted a critical appraisal of the evidence base and concluded 'that the data currently available do not warrant a universal recommendation for mammography for all women in their forties. Each woman should decide for herself whether to undergo a mammography'¹⁵. The public response to this recommendation was intense. In fact, the outrage was so great that the issue was taken up by the 105th Congress which, in a rare act of bipartisanship, passed a resolution in favor of routine screening mammography for women in their 40s¹⁸. Under continued political pressure, the National Cancer Institute rescinded its original recommendation in favor of one similar to that enacted by Congress. In 2007, the American College of Physicians, the largest medical specialty society in the United States, also championed decision making for women ages 40-49 considering screening mammography^{3,4}.

SELECT CONTEMPORARY CITATIONS

Although the evidence base on breast cancer screening is large, a number of elegant articles, recently published in close proximity, merit special mention. On October 8, 2009, over a month before the USPSTF screening mammography guidelines were published, the Cochrane Collaboration published *Screening for Breast Cancer with Mammography*¹⁹. This systematic review of the peer-reviewed literature concluded that:

Screening is likely to reduce breast cancer mortality. As the effect was lowest in the adequately randomised trials, a reasonable estimate is a 15% reduction corresponding to an absolute risk reduction of 0.05%. Screening led to 30% overdiagnosis and overtreatment, or an absolute risk increase of 0.5%. This means that for every 2000 women invited for screening throughout 10 years, one will have her life prolonged and 10 healthy women, who would not have been diagnosed if there had not been screening, will be treated unnecessarily. Furthermore, more than 200 women will experience important psychological distress for many months because of false positive findings. It is thus not clear whether screening does more good than harm.

On October 21, 2009, the *Journal of the American Medical Association* published a landmark article by Dr. Laura Esserman and her colleagues at the University of California, San Francisco and the University of Texas Health Science Center²⁰. The article drew three main conclusions: (1) The incidence of breast cancer increased after the introduction of screening but has never returned to prescreening levels. (2) This has resulted in an increased proportion of early stage breast cancers, but

(3) the incidence of regional and metastatic cancers has not decreased. Together, these findings suggest that screening mammography may be increasing the burden of low-risk cancers without significantly reducing the burden of more aggressively growing cancers and therefore not resulting in the anticipated reduction in cancer mortality. The final conclusion was that some new form of testing will be required (likely genetic) to identify the more aggressive forms of breast cancer.

Finally, on November 16, 2009, the *Annals of Internal Medicine* published a risk-benefit analysis by Dr. Jeanne Mandelblatt and colleagues²¹. In this study, the authors modeled 20 screening strategies with varying initiation and cessation ages applied annually or biennially. Their perspective was societal and they looked at lifetime impact. They found that biennial screening achieved most of the benefit of annual screening with less harm. The take home message was that a woman, optimally, should have 10 screening mammograms in her lifetime. That would equate to one every 2 years starting at age 50 and continuing into her early 70s.

HOW DOES DECISION MAKING FIT IN?

In its 2001 landmark report, *Crossing the Quality Chasm*, the Institute of Medicine reported that it takes 17 years to translate evidence into clinical practice²². Why so long? Why wouldn't new, promising treatment methods be rapidly adopted and utilized? The answer lies in the fact that evidence doesn't make decisions, people do (Figure 1). This means that evidence is not the only factor that needs to be considered when making a choice. Other factors such as provider acceptance, patient acceptance, health policy issues, political constraints, funding, oversight, insurance policies, time, money, access, treatment guidelines, insurance coverage and even public health needs, need to be considered²³⁻³³. In fact, evidence-based medicine must often negotiate a long and arduous path before being accepted and adopted into clinical care. Decision making resources can help facilitate this transition.

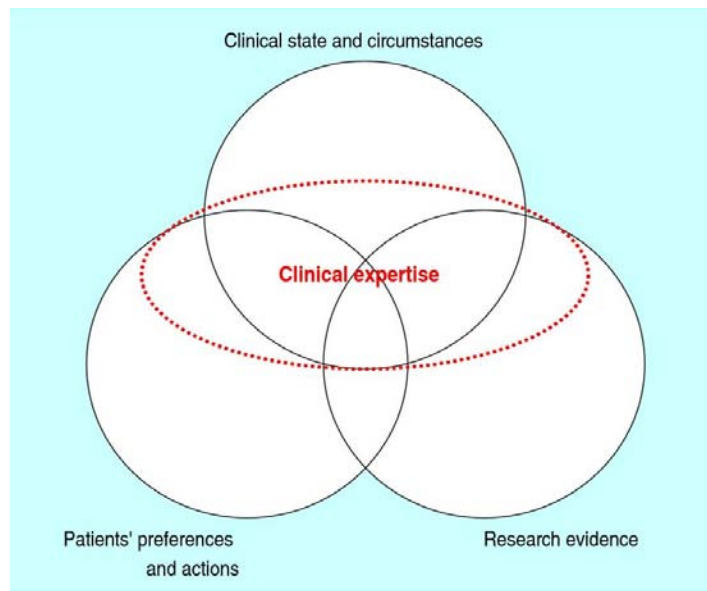


Figure 1: The relationship between key components of shared decision making.

The application of decision making is ideal when the tradeoff between benefits and harms is either unclear or unknown (Table 1)³⁴. Within this process the patient and clinician share information with each other, assess evidence and values, and mutually agree upon a course of action. The goal is to create the activated patient - a patient who is well-informed about the risks and benefits of a particular issue and feels comfortable that her choice reflects the appropriate combination of clinical input, evidence and personal values^{35, 36}.

Intervention	Description
Beneficial	For which effectiveness has been demonstrated by clear evidence from RCTs and for which expectation of harms is small compared with the benefits.
Likely to be beneficial	For which effectiveness is less well established than for those listed as beneficial.
Trade off between benefits and harms	For which clinicians and patients should weigh up the beneficial and harmful effects according to individual circumstances and priorities.
Unknown Effectiveness	For which there are currently insufficient data or data of inadequate quality.
Unlikely to be beneficial	For which lack of effectiveness is less well established than those listed under “likely to be ineffective or harmful.”
Likely to be ineffective or harmful	For which ineffectiveness or associated harm has been demonstrated by clear evidence.

Table 1: Description of intervention types. Decision making is most useful when an intervention has unknown effectiveness or there is a trade-off between benefits and harms (shown in red).

A recently updated Cochrane review on decision making³⁷ concluded that decision aids are better than usual care interventions in providing patients with knowledge, reducing conflict about making a decision, clarifying personal values and activating undecided or passive patients to make a decision. Exposure to these tools also resulted in patients choosing more conservative surgery options, lower use of menopausal hormones and reduced prostate specific antigen (PSA) screening.

There are a wide variety of decision making resources that can be used to facilitate a shared decision making process. At one end of the spectrum, a decision aid tool can be a simple, patient-focused brochure that explains the risks and benefits of a specific procedure. On the other end of the spectrum, it can be a web-based, interactive tool that engages the patient to respond to specific questions while providing targeted information and feedback based on probabilistic models³⁸⁻⁴⁰.

In this project we engineered, built, tested and piloted a web-based, interactive decision aid tool focused on giving women ages 38 - 48 resources to work with their healthcare providers to make a decision about screening mammography that was *right for them*.

PROJECT AIMS

This project had three aims. The first was to engineer, build and test a web-based breast cancer screening decision aid for average-risk women near or in their 40s who were making a choice about screening mammography.

The second was to pilot the tool in a convenience sample of 50 age, risk-appropriate women with the following key questions in mind⁴¹:

- (1) *Primary Question:* Do women ages 38 - 48 who participate in this breast cancer screening decision aid report a change in their intention to undergo screening mammography?

Hypothesis: Women between the ages of 38 and 48 who participate in this breast cancer screening decision aid are more likely to choose to delay screening mammography.

- (2) *Secondary Question:* Do women ages 38 - 48 who participate in this breast cancer screening decision aid experience less decisional conflict regarding their screening mammography choice than they did prior to the decision aid?

Hypothesis: Women between the ages of 38 and 48 who participate in this breast cancer screening decision aid are less likely to experience decisional conflict about their screening mammography choice than they did prior to using the decision aid.

The final aim was to obtain semi-structured feedback on the tool from subject matter experts who interpret the evidence-base and write the breast cancer screening guidelines, as well as clinician-experts who are passionate about sharing the decision making process their patients. In exploring the opinions of these key stakeholders we sought to understand unmet needs and further refine the tool to optimize it for future use.

MATERIALS & METHODS

INSTITUTIONAL REVIEW BOARD APPROVAL

The protocol for subject recruitment, data collection and data analysis was reviewed and approved by the Institutional Review Board of the Oregon Health & Science University (#7118).

ENGINEERING & PROGRAMMING THE TOOL

The most time and labor-intensive part of this undertaking was engineering and programming the decision aid tool. This began with considering a system architecture for the process envisioned. A context model was drawn to depict the relationship between the breast cancer screening tool and the external environment (Figure 2). The decision aid proper was grouped together with the database and the authentication logic. These sat together on a server within another layer of security (i.e., firewall, virus check). Women participating in the study accessed the tool through a unique user name and password provided to them by the research team. All information entered was captured directly in a database. Designated system administrators had access to all aspects of the decision aid and the database. This included the programmer, principle investigator and co-investigators.

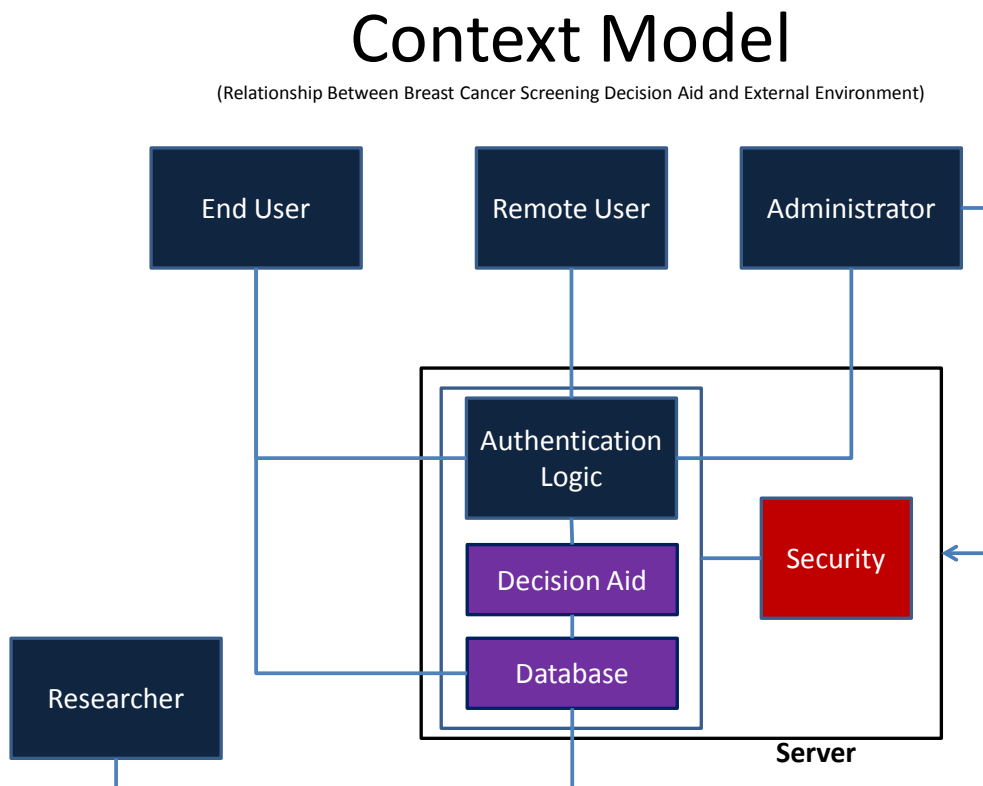


Figure 2: Context model depicting the relationship between the breast cancer screening decision aid, other hardware and software features, and the external environment.

The breast cancer screening decision aid was designed with a classic model-view-controller architecture (Figure 3). Access to the tool occurred through a secure URL address

(<https://skynet.ohsu.edu/mda>). Information was displayed; events were mapped; and changes were confirmed.

Model-View-Controller Architecture

(Breast Cancer Screening Decision Aid)

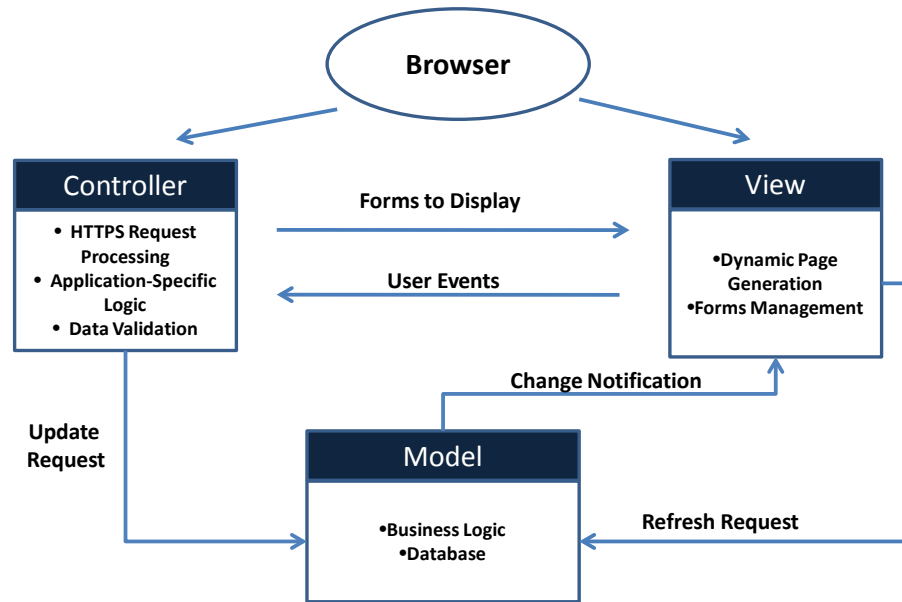


Figure 3: The breast cancer screening decision aid was designed with a classic model-view-controller architecture.

A class diagram was used to conceptualize the basic flow of data collection for the decision aid (Figure 4). We started with the user class which had the unique attributes of an email and password. The methods for this class were that the user could be authenticated (which allowed for a Boolean state of yes or no) and allowed to enter into the program (a Boolean state of yes, or no). Both of these determined the state of the user and whether she could continue on in the decision aid.

The user had a number of possible relationships. The first one was meeting the eligibility criteria. The attributes for this class included personal history, family history, and genetic risk. All users had to meet the eligibility criteria. The user also had a relationship with the consent class. Attributes of consent included purpose, risk, benefits and confidentiality.

Finally the user had a relationship with the questions. The questions class was part of a hierarchical relationship with two types: (1) single best answer questions, and (2) multiple answer questions. The attributes of the questions were listed under their respective types. Possible methods within this class included whether a question was answered or skipped (each of these was a Boolean state that prompt either continuation or a reminder message). A user answered many questions.

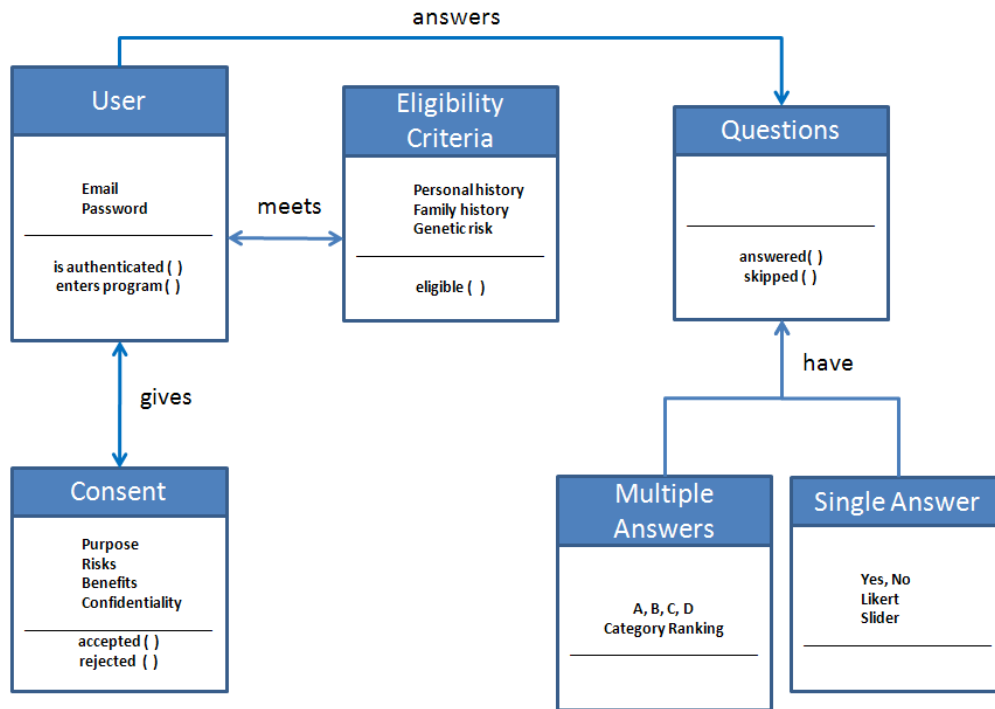


Figure 4: Class model of basic data collection in the breast cancer screening decision aid.

Before code writing began a list of requirement specifications was generated. These were separated into system specifications and user specifications. System requirements included:

1. Authentication logic being used to verify logins, logouts and re-entries.
2. System being able to execute skip logic as appropriate within the decision aid.
3. System being able to use information entered in one part of the decision aid to populate another (pre-defined) part of the decision aid.
4. System being hosted on a secure server.
5. System being ready for testing by June 15, 2011.
6. System having less than one hour of down time per month.

The decision aid was made available over the World Wide Web and because of the anticipated heterogeneity of user’s systems the software was designed so that no specialized or additional

software or hardware was needed beyond the ability to run HTML 4 and Javascript. User requirements included:

1. Being able to hover over complex terms in the decision aid and view an explanation or definition.
2. Being able to email the research team for support at any point in the decision aid.
3. Being prompted to answer a question that was not answered.
4. Being able to complete the decision aid in 40 minutes.
5. Having a secure user name and password
6. Being able to view the decision aid on any computer operating system using the most common web browsers (Mozilla, Firefox, or Microsoft Internet Explorer).

The software was developed using a Ruby on Rails open source framework⁴² linked to a MySQL⁴³ relational database. It ran on an Ubuntu⁴⁴ server maintained at Oregon Health & Science University (OHSU) in their DMZ or demilitarized zone. The DMZ is a network used to expose an organization's external services to a larger untrusted network such as the Internet⁴⁵. Application security was implemented using SSL, AuthLogic⁴⁶ and application logic. Each subject received a unique user name and password to access the site. The password was set to expire seven days after the first use. Data was not stored on the client computer.

A bottom-up approach to integration testing was used. Infrastructure components were created first and then higher level functioning components were added. This approach worked well because we were a small team with a small project and a single programmer responsible for writing code. Although code checking tools were used and select code was reviewed by another programmer as required, black box testing was the primary focus. Erroneous and valid data were entered into the system to ensure proper data processing, error generation and mapping. Most, if not all algorithm paths and skip logic patterns were tested. Scenarios were created to check specific aspects of tool functionality:

A woman with a history of breast cancer logs into the decision aid. Because of her history she has an above-average risk of developing breast cancer. Since the decision aid is only appropriate for women with an average risk of developing breast cancer, the tool should identify her and prevent her from continuing. Three system tests (requirements) that must be met in this situation are.

- ✓ *Test the eligibility algorithm and make sure that it appropriately identifies the subject as high risk.*
- ✓ *Test the path functionality and make sure that it exits this subject from the decision aid.*

- ✓ *Test the 'no return' function that makes sure this subject's username and password are invalidated when she is exited from the decision aid so that she cannot reenter the decision aid or allow someone else to use her username and password.*

The user interface of the tool received thoughtful consideration and was carefully orchestrated (Figure 5). Color choices were specific. For example, nowhere in the breast cancer screening decision aid will you find the color pink since that color is strongly associated with breast cancer and breast cancer screening. The choice to go with a more artistic look versus a clinical look was also purposeful and intended to emphasize the fact that women are women long before and after they are patients or users of a decision aid tool. Discussions about the art used in the tool were lively. Was showing a breast offensive? A statue was okay but a picture of a live person had to be artistic or clinical. Font type (sans serif), color, size and how much information could comfortably be conveyed on a screen were negotiated at length to best accommodate the tool and the multiple browsers being supported. A dozen background colors were tested before the current web-safe color was chosen. Again, it was tested across multiple browsers (which do strange things to colors, fonts and functionality). Finally, the font colors for the main part of the tool, for error message, and mouseovers were carefully coordinated with the main colors used in the graphics and background. The goal was to keep the palate consistent, feminine and balanced.

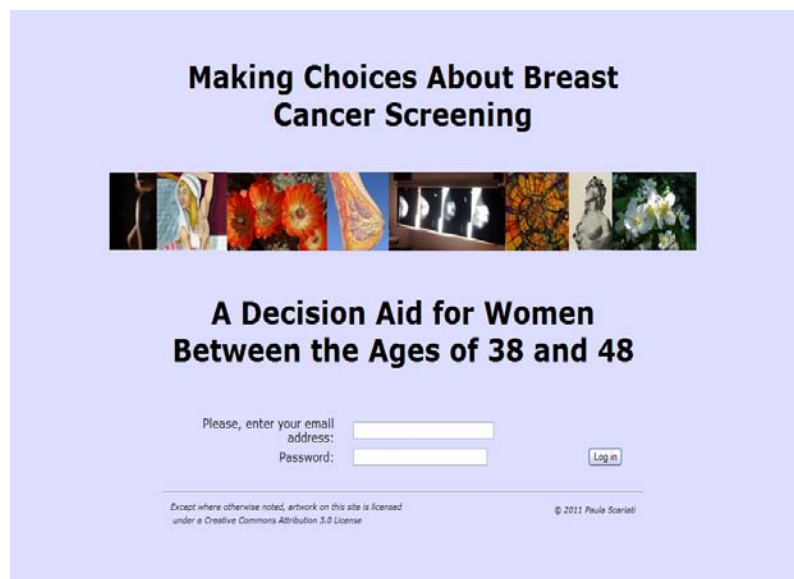


Figure 5: Login page for breast cancer screening decision aid. An example of the user interface.

One final consideration was developing and optimizing the key quality attributes of usability, reliability and portability. Usability is how easy it is to use the system. This depends upon the technical system components, its operators and its operating environment. The desired objectives with this tool were

ease of access, insightful content and rapid response time. To optimize these outcomes we specifically assessed several of these issues during testing and removed any unnecessary code and libraries to help optimize tool responsiveness. Reliability is the probability of failure-free operation of a computer program in a specified environment for a specified time. This was optimized by testing the different functions as they were programmed (i.e., authentication logic, eligibility algorithm) and the system as a whole when it was finished. Portability is the ability of the tool to run well on different types of computers (PC, Mac), different operating systems (Window XP, Mac OS, Linux) using different browsers (Internet Explorer, Firefox). The user interface must be compatible across these different platforms. This was facilitated by a developing the tool in a test environment that allowed for a variety of platforms to be checked. Certain interfaces, such as smart phones and iPads, were not supported. Usability was also conducted on a wide variety of system combinations to, again, check for real-world portability.

DECISION AID ORGANIZATION & CONTENT

The decision aid was developed in accordance with the International Patient Decision Aid Standards (IPDAS), considered the gold standard in the field. These internationally approved criteria were developed in 2006 by a group of 100 researchers, practitioners and stakeholders from 14 countries around the world⁴⁷. Examples of IPDAS criteria for decision aids include:

- disclosing the specific chances of all positive and negative outcomes from a proposed medical test or treatment (Figure 6),
- using event rates in a defined group of patients for a specific time (Figure 7),
- conveying the probability of a patient receiving a true positive, true negative, false positive and false negative test result (Figure 8), and
- describing the chance of various outcomes in the treated (or screened) group and the untreated (or unscreened) group using the same denominator over the same period of time (Figure 9).

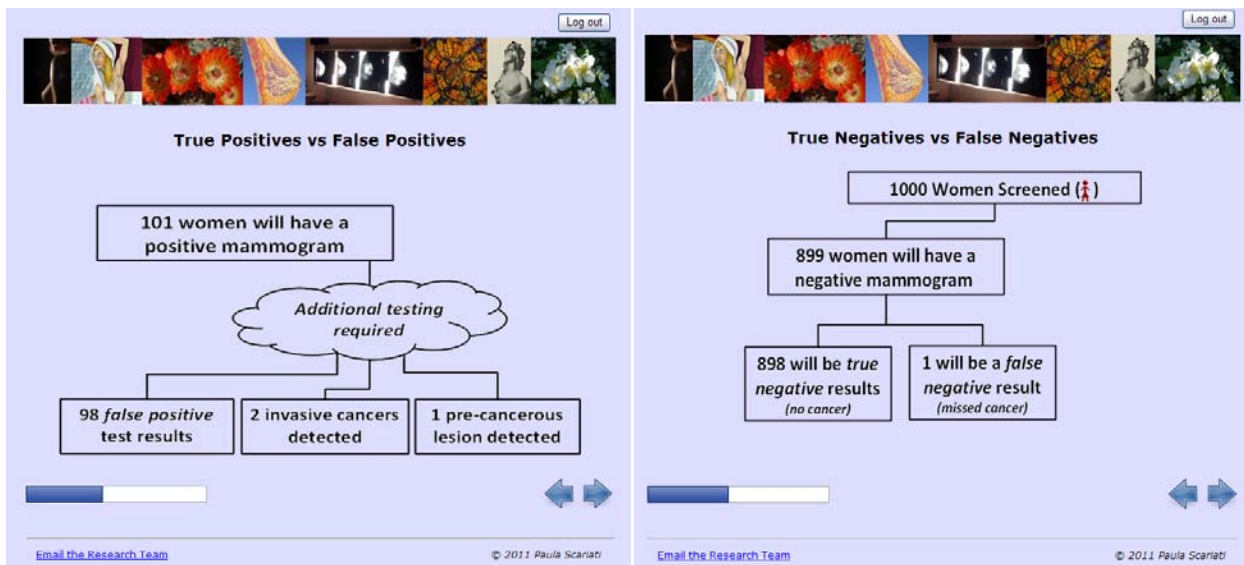


Figure 6: Chance of all positive and negative outcomes for a cohort of 1000 women in their 40s participating in breast cancer screening.



Figure 7: Conveying event rates in a defined group of patients over a specific time period.

Log out



In Summary

Screening 1000 women in their 40s for next 10 years results in:


- 0.5 less deaths from breast cancer
- 2 women diagnosed with invasive breast cancer
- 1 woman diagnosed with a pre-cancerous breast lesion
- 98 women undergoing additional testing to find that their mammogram detected something that was not cancer
- 898 women being correctly reassured they do not have breast cancer
- 1 woman with breast cancer that was missed



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Figure 8: One example of how the breast cancer screening decision aid conveyed probabilities about abstract concepts such a false positive and false negative test results.

Log out



Screening vs No Screening

- Of 1000 women in their 40s who have a screening mammogram, 3 will die from breast cancer over the next 10 years (997 will not).
- Of 1000 women in their 40s who *do not* have a screening mammogram 3.5 will die of breast cancer over the next 10 years (996.5 will not)
- Overall, of every 1000 women in their 40s, 0.5 avoid death from breast cancer as a benefit of screening mammography.
- Another way of saying this is that a total of 1904 women in their 40s need to be invited for screening mammography to prevent 1 breast cancer death in this age group.



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Figure 9: Comparison of outcomes in women who obtain screening mammograms and those who don't.

These criteria came together to define the spirit of the decision aid as an ‘intervention designed to help people make specific and deliberative choices among options by providing information about the options and outcomes that are relevant to a person's health status’⁴⁸. The goal was to deliver the appropriate amount and combination of information to users so they felt empowered and knowledgeable to make an informed choice. This is particularly important with a topic like breast cancer screening which evokes emotion, debate, and disagreement. Should the issues of overdiagnosis and Ductal Carcinoma in Situ (DCIS) be included^{49, 50}? How should abstract concepts such as false negatives and false positives be conveyed? The team struggled with these and many other such questions⁵¹⁻⁵⁴. In the end, it was agreed that giving women as much information as reasonably possible in as simple a format as possible was the right thing to do. Unfortunately, it was not the easy thing to do. The result was a longer tool with greater breadth and depth than originally envisioned.

Theories have been developed to help explain how people make choices. Prescriptive theories explain how people *should* make decisions while descriptive theories focus on how people *actually* make decisions. This dichotomous way of thinking is now giving way to newer mixed-models that consider emotional, cognitive, environmental, and time constraints that people face when confronted with difficult decisions⁵⁵. The foundational theory supporting the development of this decision aid was decisional conflict⁵⁶. Decisional conflict is a state of uncertainty about the course of action to take⁵⁷. This occurs with value-laden choices when a decision cannot be judged as right or wrong and values clarification or tradeoffs are required. To measure this, the Decisional Conflict Scale, 10 questions, 3 response low literacy format (Figure 10), was administered before and after the educational portion of the breast cancer screening decision aid^{58, 59}. This scale, which has been translated into 7 languages and used in over 30 studies⁶⁰ was adapted to measure the overall amount of conflict experienced when considering a decision about screening mammography. Scale subscores provided additional information on knowledge, values clarity, support and certainty. Psychometric testing using this scale show an internal consistency (or alpha score) of 0.86⁶⁰.

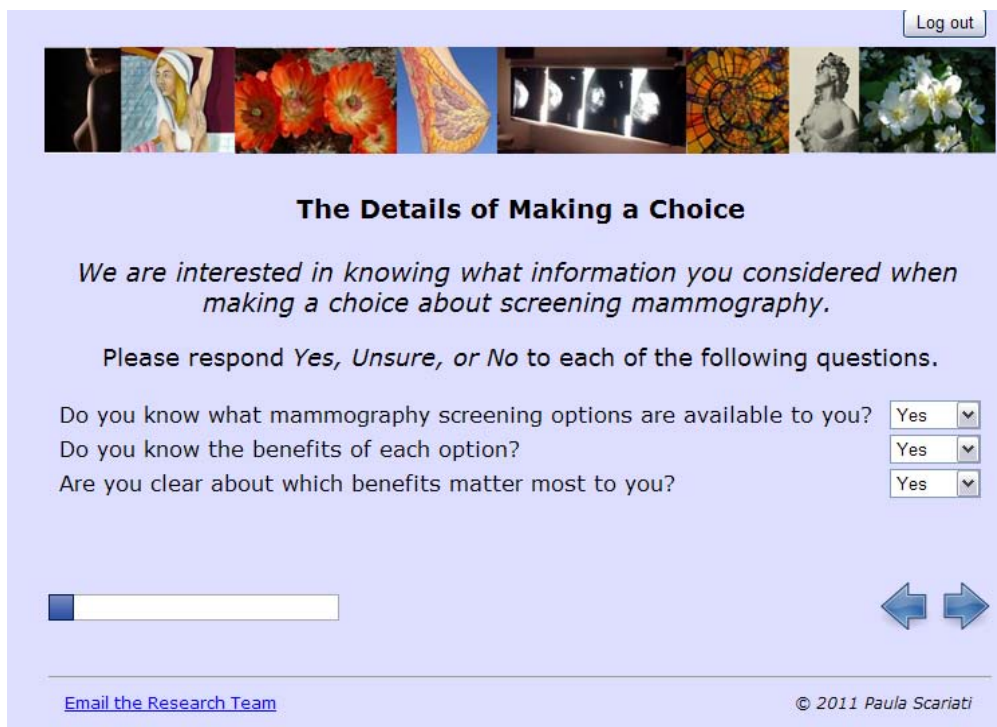


Figure 10: A screen shot of three of the ten questions comprising the Decisional Conflict Scale. This tool was administered before and after the main educational / informational portion of the breast cancer screening decision aid tool.

Information development and risk communication were guided by the tenets of Prospect Theory⁵⁵. According to prospect theory, decision making is divided into an early *editing* phase (preliminary analysis, framing and perception of options) and a subsequent *evaluation* phase where the option with the highest perceived value is chosen. The theory notes how individuals perceive consequences in terms of *change* from perceived reference points or anchors. Having different anchors leads to different decisions. Decision making is therefore influenced by 1) framing of information (gains versus losses) and by 2) the certainty effect - that individuals are generally more risk-averse when facing losses versus gains⁵⁵. With this perspective in mind, foundational concepts were defined first to create a frame of reference (i.e., What is breast cancer? What is mammography?) and then complex, abstract and even controversial issues were introduced and explored (i.e., overdiagnosis, false positive tests).

Subjects interested in participating in the pilot study of the breast cancer screening decision aid tool were required to meet the following eligibility criteria:

1. Female.
2. English speaking.

3. Between the ages of 38 and 48 years of age.
4. Average risk of developing breast cancer.
5. Access to a safe computer with internet access.
6. Comfortable using a computer and the internet to participate in the study.

A woman was considered above average risk for developing breast cancer, and thus ineligible for the study, if she had any of the following personal or family risk factors⁶¹:

1. A history of breast or ovarian cancer.
2. A history of a genetic marker for breast cancer (for example, BRCA1 or BRCA 2).
3. A history of repeated radiation to the chest between the ages of 10 and 30 (such as that required to treat Hodgkin's Disease or monitor tuberculosis).
4. Current signs or symptoms of breast disease (such as pain, skin thickening, nipple discharge, or a change in breast size or shape).
5. Having 2 first degree (mother, daughter or sister) relatives who have or had breast cancer – one of them before the age of 50.
6. Having 3 or more first or second degree (grandmother, aunt, cousin) relatives who have or had breast cancer at any age.
7. Having a first or second degree relative who has or had breast cancer in both breasts.
8. Having 2 or more first or second degree relatives who have or had ovarian cancer at any age.
9. Having a male relative (father, brother or son) who has had breast cancer.
10. Being of Ashkenazi Jewish heritage and having 1 first degree or 2 second degree relatives who have or had either breast or ovarian cancer.

The algorithm used to distinguish between women who were appropriate for this decision aid tool, and thus eligible, and those that were not, is shown in Figure 11.

Data Driven Model

(Simplified Data Flow for Eligibility Criteria in Breast Cancer Screening Decision Aid)

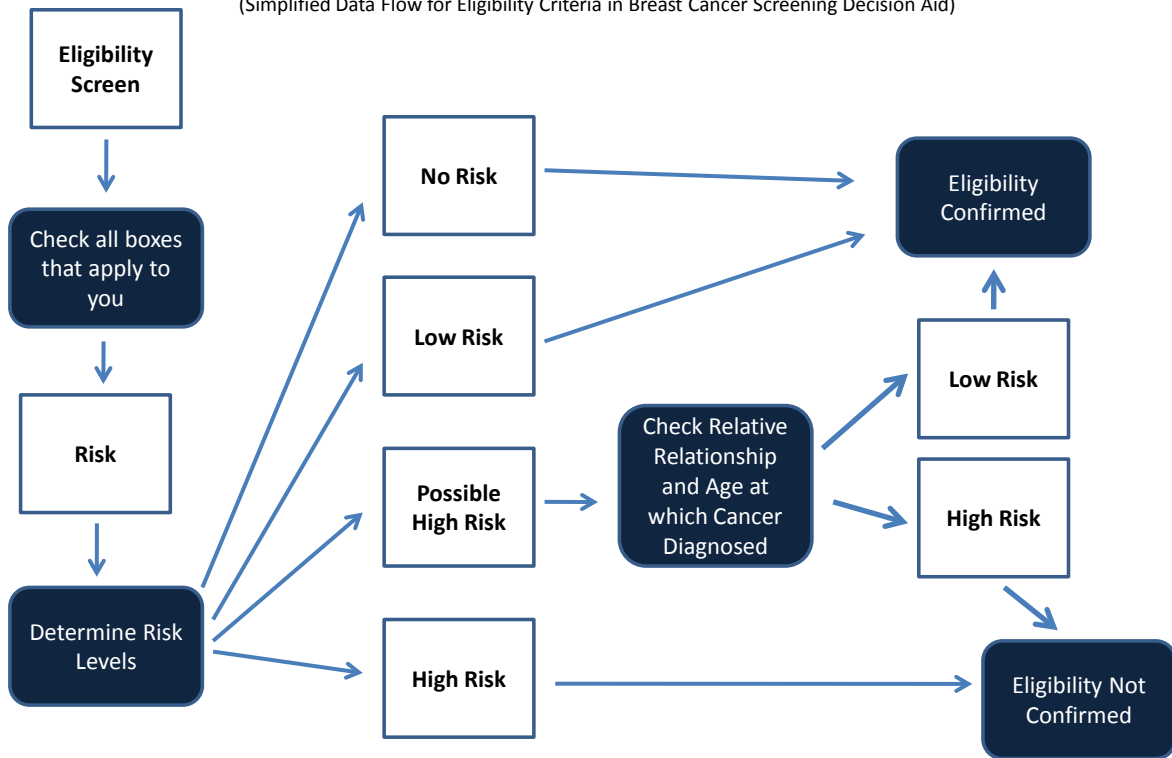


Figure 11: Eligibility criteria algorithm for the breast cancer screening decision aid.

After completing the informed consent process, eligible women received basic instructions on how to navigate the decision aid and were directed to continue on to the main part of the tool. The decision aid was divided into 6 sections: (1) Welcome, (2) Risk Factors, (3) Mammography, (4) Values Clarification, (5) Summary and (6) Final Questions, and took, on average, 35 to 40 minutes to complete. Screen shots of the complete tool are located in Appendix C.


Because a woman's choice to have or not have a screening mammogram in her 40s is a value-laden decision^{32, 33}, a considerable portion of the decision aid tool was devoted to values clarification and ranking of the key issues a woman might consider when making a choice about screening. Eight interactive sliders were developed (Figure 12) that assessed a woman's preferences around ten key issues:

- Time & Access
- Embarrassment & Pain
- True Positive Tests
- False Positive Tests
- True Negative Tests
- False Negative Tests
- Overdiagnosis
- Radiation Exposure
- Stress & Fear, and
- Cost

The intent of the sliders was to have women clarify their values regarding these common factors that can impact a decision about breast cancer screening. This laid the foundation for the ranking page exercise that followed (Figure 13).

For example, Figure 12 depicts the slider in which a woman is asked to consider the amount of time it takes to get a mammogram and the ease of access to a mammography facility, and contrast that with the peace of mind it provides. As shown, these two choices were placed on either end of the slider bar. The woman then moved the black box along the slider bar to a position that indicated her perspective regarding these two factors.

[Log out](#)



Time & Access

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?

Peace of Mind Time & Access

[Email the Research Team](#)

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Figure 12: An example of the slider feature used to elicit values clarification.

After she did this for each of the ten areas listed above, she went to a ranking page (Figure 12) where she sorted each issue into one of three buckets: (1) Most Important, (2) Moderately Important or (3) Least Important. In this way, she prioritized her key values in making a choice about screening mammography.

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
<div style="border: 1px solid gray; padding: 2px; margin-bottom: 5px;">Catching Cancer Early</div> <div style="border: 1px solid gray; padding: 2px;">Avoiding False Positives</div>	<div style="border: 1px solid gray; padding: 2px; margin-bottom: 5px;">Overdiagnosis</div> <div style="border: 1px solid gray; padding: 2px;">Avoiding False Negatives</div>	<div style="border: 1px solid gray; padding: 2px;">Embarrassment & Pain</div>

Cost

Peace of Mind

Stress & Fear

Time & Access

Radiation Exposure

Figure 13: The ranking page in the breast cancer screening decision aid tool.

The ultimate goal of the breast cancer screening decision aid was to facilitate a shared decision making process between a woman and her primary care provider. To encourage this process a summary page was provided at the end of the tool (Figure 14) which provided the following information:

- Risks and benefits of screening,
- The woman’s stated priorities regarding screening mammography (Figure 13),
- Any modifiable risk factors that the woman elected to address, and
- Other issues that the woman wrote-in to discuss with her primary care provider.

The woman was advised to print this page and share it with her clinician as they discussed the best possible breast cancer screening decision for her. In addition, the woman was sent an email with select references and resources to guide her search should she desire more in-depth information (Appendix C).



Your Summary Page – Please Print [Print this Page](#)

Risks & Benefits of Screening

As you now know, screening mammography can not accurately detect breast cancer 100% of the time. There are trade-offs.

In fact, for every 1000 average risk women in their 40s (like you) that have a screening mammogram we expect:

- 0.5 less deaths from breast cancer
- 2 women diagnosed with invasive breast cancer
- 1 woman diagnosed with a pre-cancerous breast lesion
- 98 women undergoing additional testing to find that their mammogram detected something that was not cancer
- 898 women being correctly reassured they do not have breast cancer
- 1 woman with breast cancer that was missed

Your Priorities Regarding Screening Mammography

Most Important	<ul style="list-style-type: none"> ◆ Avoiding False Positives ◆ Catching Cancer Early ◆ Cost
Moderate Importance	<ul style="list-style-type: none"> ◆ Avoiding False Negatives ◆ Overdiagnosis ◆ Peace of Mind
Least Important	<ul style="list-style-type: none"> ◆ Embarrassment & Pain ◆ Stress & Fear

Modifiable Risk Factors you Chose to Address

- Manage my stress with something like meditation.

Other Issues You Want to Discuss with Your Healthcare Provider




[Email the Research Team](#)

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Figure 14: Example summary page provided to each woman at the end of the breast cancer screening decision aid. Content varied according to the information provided by the woman while using the tool.

USABILITY TESTING OF THE TOOL

Although informal feedback was utilized by the programmer while developing the tool, three rounds of formal usability testing were conducted once the build was nearing completion. Round one was launched on April 19, 2011. Feedback was provided by OHSU biomedical informatics graduate

students and faculty advisors in the Spring 2011 BMI 605/505 class. Although some feedback was given in a written format, the majority was provided verbally during a one-hour group session.

- Tool functionality (i.e., sliders, ranking page) was not compatible with iPad
- Tool timed out erroneously in Google Chrome
- Several questions showed pre-populated answers
- Too long
- Too slow (sluggish responsiveness between screens)
- Inconsistencies in the use of font sizes, layout and italics
- Typographical errors
- Suggestions for simpler wording of complex concepts (i.e., false positives)
- Mismatches in choices made and the answers listed on subsequent screens
- Specific suggestions for making the ranking page more user-friendly

One user who provided comments after the group session made the following observation:

Good job. I thought the explanation of the probabilities was very clear (particularly with the stick figure illustrations, and the decision tree). But still, this is not an easy thing. I tried to put myself in the mindset of an overall healthy woman who is a little skeptical of the medical establishment (worried about over-treatment, etc.) And the difference (or lack thereof) between 3 and 3.5... Well, I think I would still be unsure of the best thing to do.

Round two of usability testing was conducted with Karen Eden's Managerial Decision Making Class. The class was comprised of students pursuing a Healthcare Masters of Business Administration who received extra credit for providing a semi-structured written critique of the tool. Their responses, which were timely, detailed, and voluminous, are located in Appendix E. Their comments centered around the following 12 themes:

- Repetition in content
- Health as a personal responsibility
- Wordsmithing / Language usage
- Reading level
- Concerns about approach to values clarification sliders
- Too long
- Clarify why there was a change in screening recommendations

- Create better context to other health-related issues
- Easier tool navigation
- Secure web-based email interaction
- Overwhelming amount of information
- Sample questions for patient to take to doctor

Several weeks later the third and final round of usability testing was launched. The target audience was 21 friends and colleagues who had volunteered to test the tool. Although only 3 (21%) responded, the feedback provided was detailed and thoughtful. Concerns were raised about the language level of the tool and specific consumer-centric recommendations were made for a number of the slides. This is best exemplified through one person's comments:

Please, take my feedback from the perspective of someone who works mostly with lower socioeconomic class patients.

Here they are noted as I was going through the tool, so, it may help to go through them as you are advancing on the questions:

LOVE the bar that tells you where you are in the tool.

Really long, time wise, none of my patients could sit for this long.

Do you need to distinguish between digital and regular mammogram? For the lay person it can be confusing and not really helpful.

False positive / negative is an abstract concept.

Slides after FP/FN are too detailed and complicated (cumulative risk, etc)

Overdiagnosis slides too complicated.

Summary?

GREAT points with the slider bar, is really intuitive and easy.

Can the subjects understand "avoiding false negatives"? It's a double negative statement.

I find it hard to understand the slide on false negatives.

I find that "which matters to you" question is confusing.

GREAT 3 squares with click and slide 10 points.

Wrap-up points are really good and tighter but still complicated.

The slider on "what I have learned" was not sliding smoothly on my computer.

Got stuck on the print page, could not go on, no choice to log off.

Overall is a really nice tool, very well designed, it just needs in my opinion to be taken down a few notches in the education/time-consuming/patience level to be completed.

I will be very happy to help further.

Following this last round of testing significant adjustments were made to the tool while it underwent database testing to track mapping of the data into and out of the database.

DATA COLLECTION

On August 10, 2011 the breast cancer screening decision aid got its own Facebook page (Figure 15)⁶². The goal was to leverage this platform in addition to routine networking (i.e., friend-to-friend) to recruit a convenience sample of 50 age, risk-appropriate women to use the tool.

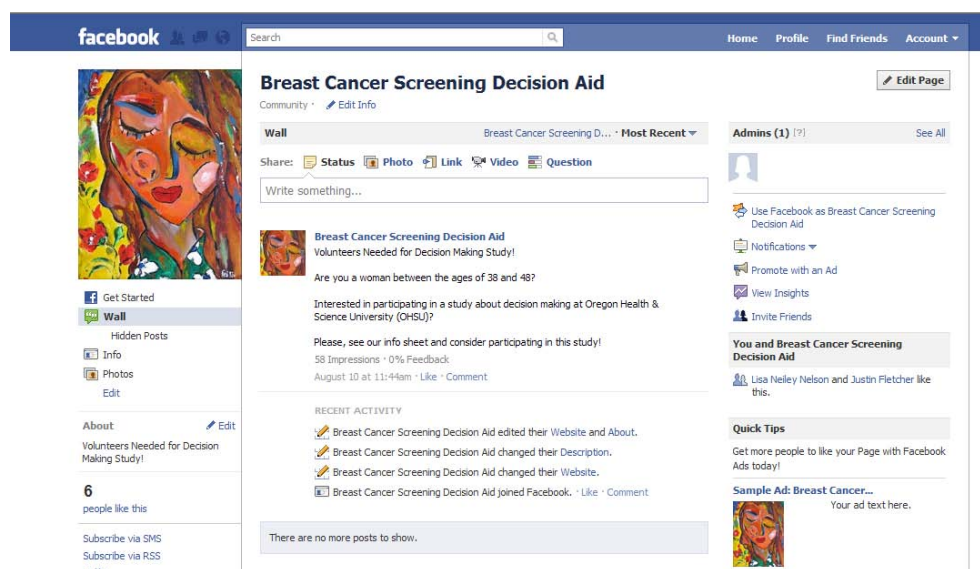


Figure 15: Screenshot of breast cancer screening decision aid's facebook page.

Women indicated their desire to participate in the study by sending an email to the research team at mammographyda@ohsu.edu. In response, each women was provided with a username, password and detailed instructions for accessing the decision aid (Appendix G). Eligible women who completed the study received a \$15.00 Starbuck's Card eGift by email as a token of appreciation⁶³.

The same day, seven subject matter experts and seven clinicians were contacted by email and asked to volunteer between 60 and 70 minutes of their time to critique and provide feedback on the breast cancer screening decision aid (Appendix F). Specifically, they were asked to spend approximately 35 minutes assessing the ineligible and eligible pathways within the breast cancer screening tool and then, as soon as possible thereafter, discuss their feedback by phone with the author.

Prior to their first access of the decision aid tool each interviewee was provided with 12 questions (Figure 16) that established the overarching framework for the interview. These questions were developed by the research team in response to issues raised during usability testing and concerns about the scalability of the decision aid tool in a larger, diverse population of women. Five of the questions were open-ended; the remaining 7 requested specific responses with the option to provide further clarification. The a priori areas of focus were:

1. User interface (Questions 5, 8)
2. Content (Questions 1, 2, 3, 4, 6, 11, 12)
 - Comprehensive
 - Correct
 - Balanced
3. Environment (Questions 8, 9)
 - Access
 - Platform
4. Adoption Factors (Questions 7, 10)

Interviewees were also encouraged to provide additional comments on issues unrelated to the 12 question framework. Snowball interviewing was used. That is, if a new issues was raised in the course of an interview with one interviewee, that same issue might be raised by the interviewer in an impromptu manner, with the next interviewee, thereby eliciting several perspectives on the matter.

All interviews were recorded and professionally transcribed.

Mammography Decision Aid Feedback

1. Did you find the exit path for ineligible women to be sensitive and supportive of further follow-up?
 - No
 - Yes
2. How did the decision aid challenge your existing notions about screening mammography for average risk women between the ages of 38 and 48?
3. What part(s) of the decision aid would you have excluded?
4. What *additional* information would you like to have seen in the decision aid?
5. Was any part of the decision aid offensive or distasteful?
 - No
 - Yes (Please Explain)
6. Was the information in the decision aid presented in a *biased or unbalanced* fashion?
 - No
 - Yes (Please Explain)
7. One goal of this decision aid is to give a woman something to take back and discuss with her healthcare provider during a brief visit. How can the content and output of this tool be altered to best achieve that goal?
8. Would you recommend this decision aid to a friend?
 - No
 - Yes

Why?
9. What would be the ideal way for a woman to access this decision aid?
 - Through her personal health record.
 - Through a web-based interface independent of her personal or medical record.
 - Through a computer system in her doctor's waiting room.
 - Other (Please explain)
10. How can we get the best buy-in from multiple stakeholders to use a decision aid program like this in appropriate outpatient settings?
11. Are there questions in the decision aid that you think a woman won't answer honestly if she knows that her healthcare provider will see her responses?
 - No
 - Yes (Please Explain)
12. Did you feel that the decision aid pushed you to have or not have a mammogram?
 - Yes, I felt pushed *to have* a mammogram.
 - Yes, I felt pushed *not to have* a mammogram.
 - No, I did not feel pushed in one direction or the other.

Figure 16: Twelve interview questions provided a priori to subject matter and clinical experts.

ANALYSIS

Statistical analyses were carried out using IBM SPSS Statistics 19 (IBM Corporation, Somers, NY, USA). Descriptive statistics were calculated for all variables of interest. Continuous measures were summarized using means and standard deviations. Categorical measures were summarized using counts and percentages. The two main outcomes of interest, intention to obtain a screening mammogram and decisional conflict, were measured in a pre-post fashion. Because the outcome variables were not normally distributed, a Wilcoxon signed-rank test was used to assess significance. A significance level of 0.05 was used unless multiple comparisons were indicated. In the latter case a significance level of 0.01 or appropriate correction (i.e., Bonferroni) was used.

RESULTS

PILOT STUDY

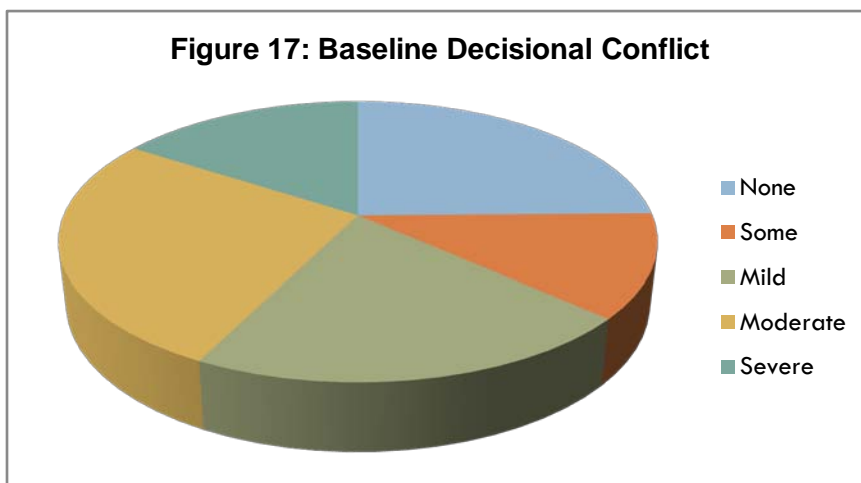
A convenience sample of 51 women ages 38 - 48 with no known risk factors for developing breast cancer participated in the pilot study. This cohort was predominantly white (84%), well-educated (78% with at least a college degree), insured (98% had health insurance) and financially comfortable (45% with an annual household income of at least \$100,000) (Table 2). Thirty-eight women (74%) reported having at least one prior mammogram with 19 of them (50%) experiencing a false positive test result at some point in time (Table 2).

Characteristic	n (%)
Race	
White	42 (83)
Asian	6 (12)
Black	2 (4)
More than 1*	1 (2)
Education Level	
HS Diploma	1 (2)
Some College	10 (20)
College Degree	21 (41)
Some Graduate	7 (14)
Graduate Degree	12 (23)
Income	
10K - <25K	1 (2)
25K - < 50K	6 (12)
50K - < 100K	19 (37)
100K or more	23 (45)
No Response	2 (4)
Health Insurance	
Yes	50 (98)
No	1 (2)
Prior Mammogram	
Yes	38 (74)
No	13 (26)
Prior False Positive Screen	
Yes	19 (37)
No	19 (37)
Not Applicable	13 (26)

Table 2: Demographic characteristics of pilot study subjects (n = 51)

*One subject self-identified as both White and Native American.

Prior to engaging with the decision tool proper, women were asked a series of questions to establish their baseline perspective regarding screening mammography. For example, when asked whether they planned to have a mammogram in the next 1-2 years, 42 women (82%) said yes, 4 (8%) were undecided and 5 (10%) said no. The amount of conflict experienced when deciding whether to have screening was assessed using the Decisional Conflict Scale described earlier^{58, 59}. Scoring of this tool yielded values between 0 and 100, with 0 indicating no decisional conflict and 100 indicating high decisional conflict. At baseline, 13 women (25%) experienced no decisional conflict; 6 (12%) had some decisional conflict with scores between 1 and 25; 10 (21%) had mild decisional conflict with scores between 26 and 50; 14 (27%) had moderate decisional conflict with scores between 51 and 75; and 8 (16%) had severe decisional conflict with scores above 75 (Figure 17).



Also at baseline, 45 women (88%) indicated a belief that women in their 40s benefit from screening mammography and that the choice to have a screening mammogram should be something that they themselves decide (63%) or a decision that is made together with their healthcare provider (37%). No member of this cohort felt that a healthcare provider should make this decision for them or expressed uncertainty about who should make this choice.

The section of the decision aid tool devoted to risk factors asked women what modifiable risk factors they wanted to address with the goal of reducing breast cancer risk and improving overall health. Bringing body weight into normal range (67%), eating more fruits and vegetables (63%), managing stress (55%), and exercising 30 minutes most days (51%) were the most popular responses. Reducing alcohol consumption (14%), reassessing hormone replacement therapy (14%) and smoking cessation (2%) were not chosen as often (Figure 18).

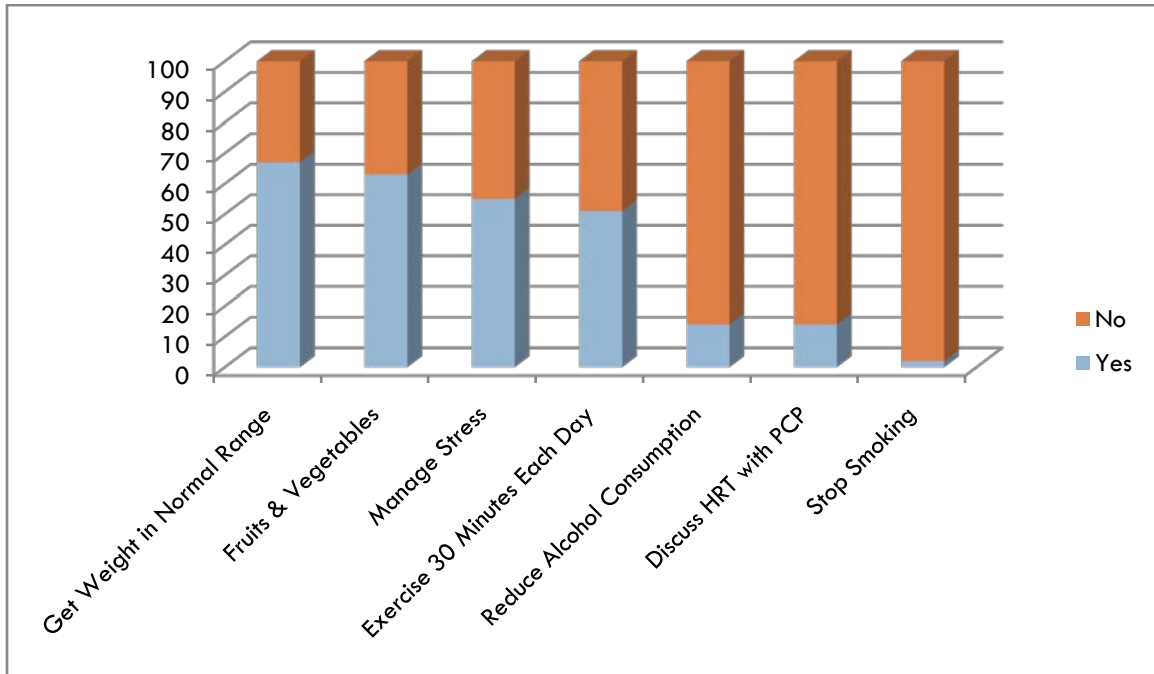


Figure 18: Percentage of women choosing to address select modifiable risk factors.

Within the section on the risks and benefits of screening mammography the concept of overdiagnosis was introduced and a specific type of overdiagnosis called Ductal Carcinoma in Situ (DCIS) was exemplified. Seventeen of our women (33%) had heard of DCIS before, 34 (67%) had not. Interestingly, the 33% who had prior knowledge of DCIS said it wasn't something they would factor into their decision about screening mammography whereas the 67% who had not heard of DCIS felt it was a factor worthy of consideration in making a decision^{49, 50}.

Within the context of values clarification, a series of 8 interactive sliders (Figure 12, Appendix C) were used to help women compare and contrast their values regarding the following 10 factors: time & access, peace of mind, embarrassment & pain, false positive test results, false negative test results, radiation exposure, cancer detection, overdiagnosis, stress & fear, and cost. This exercise concluded with a ranking page (Figure 13) where the woman was asked to rank the 10 factors into one of three buckets: (1) Most Important, (2) Moderately Important; or (3) Least Important. Catching cancer was ranked as a most important factor by 44 (86%) members of the cohort (Figure 19). This was followed closely by peace of mind (84%). Other factors ranked with high and moderate importance included avoiding false negative tests, avoiding false positive tests, overdiagnosis and radiation exposure.

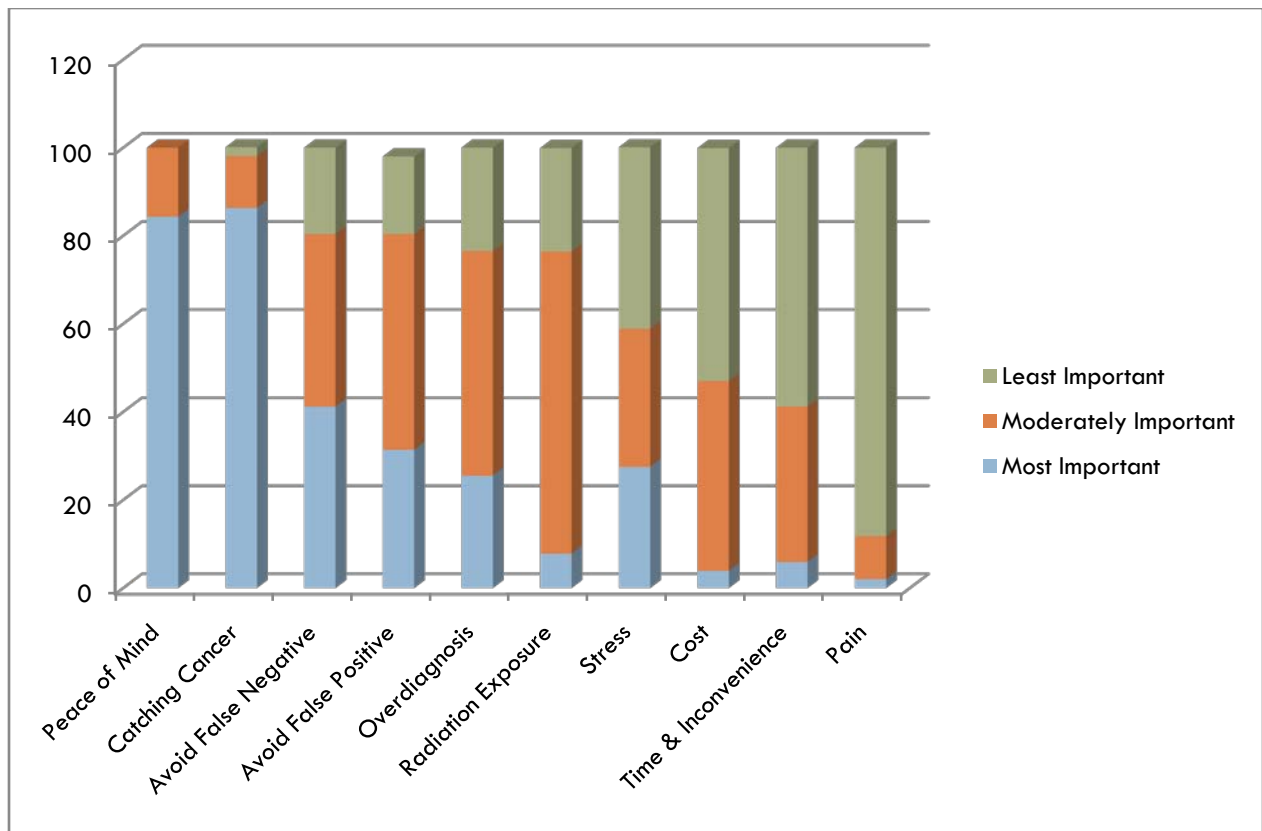


Figure 19: Ranking factors to consider when making a decision about screening mammography, by importance.

The key questions posed at the outset of this project were would this decision aid tool impact a woman’s choice about having a screening mammogram or the amount of conflict she experienced in making that decision. A Wilcoxon signed-rank test was used to compare a woman’s plans for screening mammography before and after participating in the decision aid tool (Figure 20). No significant change was seen ($Z = -1.5, p = 0.132$).

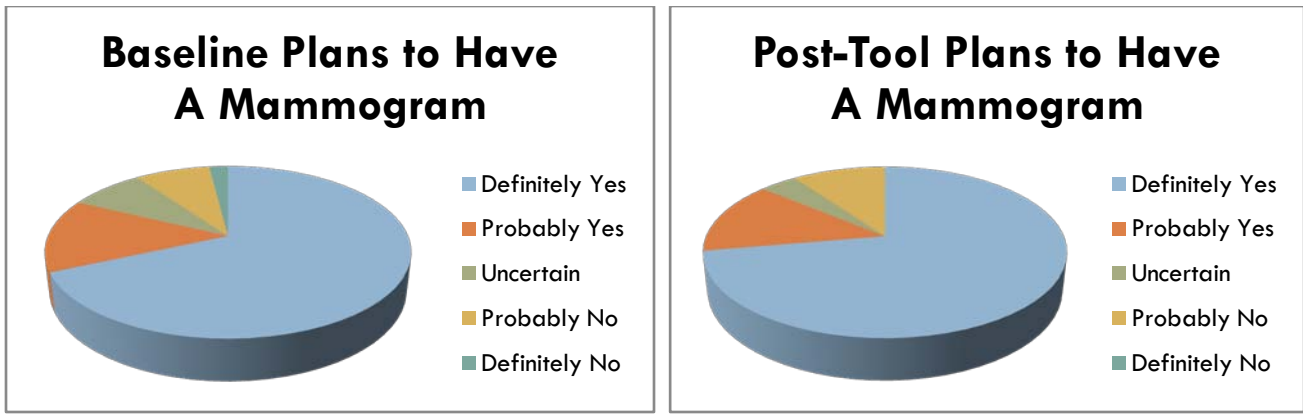


Figure 20: Intention to have a mammogram at baseline and following the completion of the decision aid tool.

Pre-post tool analysis of decisional conflict scores was undertaken using the same approach. A significant reduction in overall decisional conflict scores was observed ($Z = -5.3, p < 0.001$). Figure 21 offers a visual appreciation of the magnitude of the shift that occurred. In addition, a significant reduction in each of the decisional conflict subscores was seen: uncertainty ($Z = -4.7, p < 0.001$), feeling informed ($Z = -5.2, p < 0.001$), clarity ($Z = -5.0, p < 0.001$), and support ($Z = -4.0, p < 0.001$).

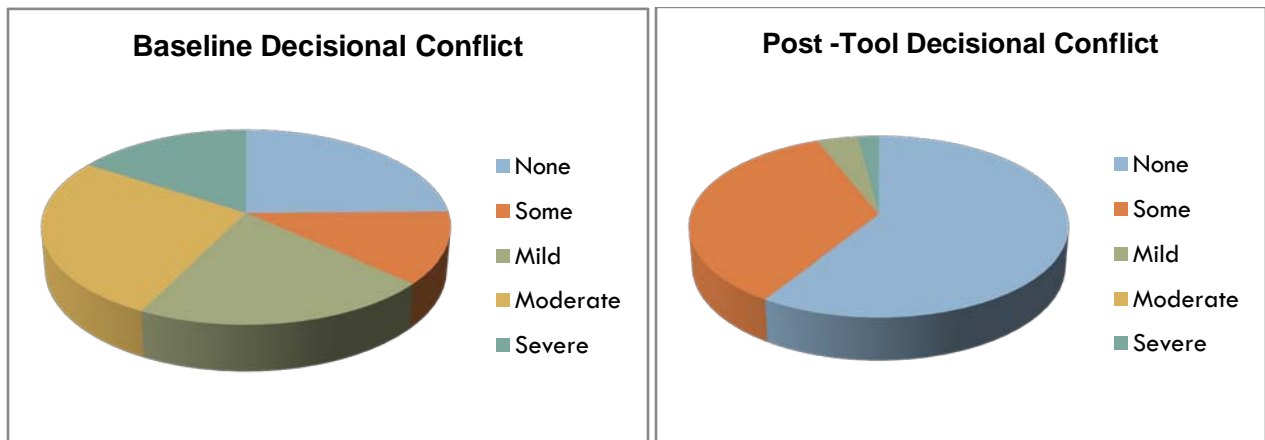


Figure 21: Decisional conflict scores at baseline and following the completion of the decision aid tool.

Subscore Category	Pre-Score	Post-Score	Delta	Statistic*
Certain	50.5	12.8	-37.7	Z = -4.7, p < 0.001
Informed	47.4	3.9	-43.5	Z = -5.2, p < 0.001
Clarity	51.0	5.9	-45.1	Z = -5.0, p < 0.001
Support	20.3	4.9	-15.4	Z = -4.0, p < 0.001

*Wilcoxon Signed-Rank Test

Table 3: Decisional Conflict Subscores.

THE EXPERTS

Five Subject Matter Experts (SME), one each from the National Cancer Institute; Agency for Healthcare Research & Quality; American Cancer Society; United States Preventive Services Task Force; and the American College of Obstetricians & Gynecologists; and 5 Clinician Experts (CE) working with either women’s health, medical decision making or both, from the Oregon Health & Science University in Portland, Oregon (2); the University of California in San Francisco; the National Cancer Institute in Bethesda, Maryland; and Metropolitan Hospital in New York City reviewed the breast cancer screening decision aid and participated in a semi-structured interview (Figure 22).

- 5 Subject Matter Experts

 - National Cancer Institute (NCI)
 - Agency for Healthcare Research & Quality (AHRQ)
 - American Cancer Society (ACS)
 - United States Preventive Services Task Force (USPSTF)
 - American College of Obstetricians & Gynecologists (ACOG)

5 Clinician Experts

 - 2- Oregon Health & Science University, Portland (OHSU)
 - University of California, San Francisco (UCSF)
 - National Cancer Institute (NCI), Bethesda
 - Metropolitan Hospital, New York City

Figure 22: The experts providing feedback on the breast cancer screening decision aid tool through a semi-structured interview process.

All interviews were initially organized around 12 previously known questions (Figure 15) reflecting 4 *a priori* themes: (1) user interface, (2) content, (3) environment, and (4) adoption factors. The experts also provided feedback on additional, unrecognized issues. Preliminary analysis of this information yielded 4 emerging themes: (1) language, (2) controversies, (3) tradeoffs, and (4) layout. Interviews varied in length from 19 to 83 minutes with a mean of 44 minutes and a mode of 37. One hundred ninety-seven pages of transcribed information were generated in addition to other comments forwarded by several of the experts.

A Priori Themes

User Interface

Both SMEs and CEs offered compliments about the breast cancer screening tool's user interface. Several found the ranking page particularly creative. None found the tool offensive or distasteful.

I like the look of the aide and lots of the elements are very nice (drag and drop page – awesome!).

I like what you have. I think it's fantastic. This is very badly needed, so I'm like so glad to see you doing this.

There were no graphics that made me want to . . . I've seen decision aids where you look and say, why did they pick that picture? That's a horrible picture for that. No, but I thought it was quite good.

. . . in addition to the results from the little gray boxes, the ones that you rank out which I think is a very cool idea by the way.

The greatest concern expressed by most of our experts was the length of the tool. In the form tested, it took about 35 minutes to complete.

. . . I would aim for 15-20 minutes. . .

I thought it was long. It was longer than it could, should be to do what it is attempting to do which is to give women something they could discuss with their provider. Um . . . and put them and their provider on the same page. And I could not find things that were easy to remove but I did think that it was long.

It seems a little long to me and a little clunky to use.

And one SME viewing the tool in Google Chrome experience great difficulty with her interface.

It was really, really slow. I don't know if that's – in fact, once it crashed because it timed out. And I don't know if that's something about my connection to you, just when my computer was interacting with your software at the moment or what but –

Content

The SMEs and CEs had a wide range of suggestions about the breast cancer screening decision aid content. Most found the tool comprehensive. There was concern about three topics women might avoid: (1) alcohol consumption, (2) income, and (3) family history.

I actually thought it was quite comprehensive to the issues that are relevant to this kind of a decision.

I would have streamlined this information a little more, gone more directly to the point. And actually, some statistics seems to me that they are repeated a couple times, and that, as I said, might lose interest of the reader. Otherwise, it's a great tool. I love it, and I certainly would recommend it to my patients.

The drinking question is somewhat oddly phrased because it asks only about daily use and not about daily over time. {...} And people may feel funny – I mean it's both a data collection issue and I can imagine it creating some consternation about reporting drinking. .

How much money you make.

The only part, I think, would be the family history, which comes in very early, in the sense of worried about discrimination regarding mutations, et cetera, in the family.

Yet there were differing opinions about the appropriateness, practicality and accuracy of the evidence cited.

Whether you get a digital or film mammography is really going to be a decision by your physician about where they send you. And digital is going to entirely replace film. It's just an administrative thing. So I think that is one thing you could just take out.

There is too much emphasis on radiation risk and overdiagnosis, two issues for which there is either considerable disagreement or little empirical evidence from which to estimate effects with measurable confidence.

. . .a more balanced discussion about the interval. {...} The greatest benefit if you're looking at mortality reduction or life years gained, is actually in intervals of a year. So you do sacrifice some of that by reducing the risk, by reducing the callbacks. So there is a balance there, which I didn't think was entirely explained that the more frequently – if we did mammograms every six months, we would actually have fewer inter-screen cancers. You know what I mean?

I think that the risk of radiation is overstated. { } I really, personally think that radiation is a non-issue. { } There are a lot of old studies and they continue to get quoted when they are probably obsolete.

So if you believe that, that the critical thing is to make people aware of what DCIS is, and that overdiagnosis is not really very applicable in this age group, then you could simplify it by leaving out overdiagnosis or not spending as much time on explaining what overdiagnosis is and just moving immediately to DCIS.

Also, there's a potential that you might have less invasive treatment. You might avoid chemotherapy. {..} So maybe that would be helpful to have some slider that says potential benefits of early detection would be maybe you would be less likely to die from the breast cancer. You might also have less invasive surgery.

The SMEs and CEs were divided in their opinions about the balance of information provided in the tool, as well.

I don't think it tries to get women to have or not have a mammogram and I think that's really quite important. {..} I think it's really good. I think you did a great job. I know it was quite a lot of work and you obviously understand the issues very carefully.

The information included in the tool is derived from the USPSTF perspective, and the accompanying bibliography also is largely made up of manuscripts that are highly biased against screening. In this respect, I'm afraid I'd have to say that the tool is not true to the basic requirements for informed decisions. To meet that requirement, the tool would need to state that the perspective (quite negative about screening before age 50 if you're at average risk) presented is not reflective of all scientist opinion or organizations that issue breast cancer screening recommendations, including the guidelines of the ACS, which are followed by a majority of referring physicians. Sorry, but the USPSTF is not the higher authority on this issue

I thought it did a very good job of showing of the evidence, and I personally believe the evidence pushes it away. So I wouldn't call it biased, but I think it's in-line with the evidence, which it's not really pushing people towards mammograms.

I think I was trying to make the case that the benefits of mammography are underestimated if you just use a meta-analysis from the randomized trials.

No, I don't feel it pushes a woman in one direction or another. {..} . . . – it's just a huge challenge. Huge challenge to being able to implement real shared decision making because, you know, you're talking about numbers that neither the patient nor the clinician really has a good way to conceptualize. Like 0.5 out of 1,000. {..} , the news about empowerment hides the inconvenient little truth that most of one's health is bad friggin' luck.

And one last, but somewhat different, perspective.

What concerns me about this argument about the balance of benefits and harms is that these are two metrics that cannot be judged on the same scale (hence, the notion of “balance” is misplaced).

Environment

The experts recommended adopting a wide variety of methods and platforms for accessing the breast cancer screening decision aid. There were mixed opinions about whether the tool, ideally, should be tethered to or part of the medical record or not.

I think you should have wide access through a variety of channels.

I don't think that there's really too many limits on how – a good way to access a decision aid. I think some people might like to do it while they're passing time in a waiting room. Other people would really value being able to do it in private – in a private situation like in their home. I don't know how many people in the country currently have personal health records. {...} All these I think are good. I wouldn't put it in Wal-Mart pharmacies 'cause I think that's a little too public and not – runs the risk of too many people being offended just by seeing the word breast when they're in public 'cause there is still that to deal with.

I don't think a computer system in the waiting room will work because the decision aid takes too much time. Odds are most women would not be done before they were called to see the clinician. The other routes would be good. The issue of separation from the medical record—seems as though her opinions and preferences are important to help the clinician support shared decision making.

. . .the hard part of things like this is that there is some kind of infrastructure that's required for patients to even have access to a computer in the office. {...} I think a lotta people would be enthused about doing it, but it's just the actual infrastructure of it. And that's where I guess potentially having the patient be able to access it from home where you could make your patient aware that this was available or even tell them about it when they were at their appointment {...} It seems to me like having that instant transaction where they do the tool and then they talk to the doctor right after that makes the most sense.

But I don't think something independent of her personal or medical records is a good idea. I think the more we learn about how to provide a first-class patient care, the more we integrate everything, the better care people get cause stuff doesn't get lost and all the information's in one place.

Let's see, probably you need to have multiple options in the office for people who have time and don't have access, but for anybody who has her own internet access, I'm sure she'll want to do it at home over the web. So maybe it's web accessed but with – through some – the provider system for people who don't have access at home, it could be offered either way and it's a web link.

. . . definitely not in the office because there will be – I would feel pressured doing it in the office. There should be a way for them to access this questionnaire, perhaps at home, take a look at it, so at their convenience.

. . . I kind of feel like all of the above, the thing is probably though - probably a web based interface independent of her record might be good. If there was a link out from her personal health record and then there was a screen that said, "Hi, this is just for you. It's not going to be recorded anywhere." Would be great. I think –{ . } And, then having it in the waiting room would be fantastic. Non trivial to do, but would be fantastic.

. . if you were going to do anything from the Personal Health Record it would be a link out to an entirely different site where women can do this themselves. . .

Adoption

The experts had a variety of suggestions for securing stakeholder buy-in at different levels.

. . . if it is going to be useful it has to be widely considered to be authoritative by groups that are involved in the breast cancer advocacy field. And that includes professional groups and consumer groups as well as the traditional advocacy groups.

Need the doctors and nurses to like it and need to guarantee that it will not interrupt patient flow. { . } And those are the kinds of things you got to also teach the clinicians about, so teach to those questions so be ready. These are the kinds of questions we think people may ask. These are the kinds of things you might want to sit and consider in answering them. So that you're setting it up to make – for the clinicians to succeed.

So my experience with primary care providers is that they do not support the concept of informed decisions about mammography, that they think women should simply have mammograms. So I think getting primary care buy-in is not an easy task . . .

You know, I bet the place where you get the best buy-in would be in the large organized care settings, the Kaisers, the group health. They would be more likely I think and to have systems in place and they can reach thousands of people, tens of thousands of people.

. . . I would put a big sign in the office, a big poster in the office. . . { } . . . we have tons of posters, and all the time, we get questions from the patients who have read something on a poster, and they want explanations.

That's a good question. You know I guess it depends which stakeholders. I mean I can think of several sets. So, clinicians like me, or you know we need to know about it, things like - for me, things like grand rounds or going to particular meetings of clinicians, which should be possible to do. { } . . . what about Aetna and Regents and all those guys?

And, every provider is scared about how long it's going take to do that in a 15 minute visit. So, any woman who walks in with this thing and they've already thought about it, it's huge.

So it just depends on the bent of each stakeholder, but showing the value, whether it's decreasing the time of the visit, decreasing patient anxiety, or increasing their satisfaction or – I don't feel this way: that any tool should increase a particular utilization rate around mammography. I mean it's obviously a preference-sensitive thing, but if you can show metrics around this, doing the right thing in that sense, however you can define "right" . . .

Specific suggestions for enhancing patient acceptance and adoption included:

So the other thing would be to set it up so that a nurse could go through it with them while they're in a waiting room or there's an educational placing them in the context of the office that they could go to take the survey, ask questions and turn on a red light when they have questions for the nurse, maybe something like that.

. . . in order to be useful to a provider it will be something that they will need to get used to seeing in that format. {.. } As you know, many women between 38 and 48 are just, you know 'give me my mammogram, I don't want to talk about it', "this is what I want". So, again, it is for the uncertain woman that this would be most useful.

It's fine. But I'm not sure she wants to see it or would know what to do with it. What are you doing to prepare her?

. . . if you could help them generate some questions you might want to ask when you talk with your doc about this. So to sort of to activate the patient to have them have the woman be ready to say, "So I'm confused by X, Y, Z," or, "I have two family members with a family – I have a family history but I didn't understand why I was a low risk."

So ranking all of these issues is helpful, but if there's sort of the one salient, primary concern for a particular patient – that might be a write-in, it might be – there might be five, at most, across the majority of patients of which there could be a pull-down to fill in.

Emerging Themes

The semi-structured format of the interview encouraged the experts to provide information on issues outside of the scope and context of the 12 questions asked of them. A number of additional themes emerged as a result of this open interviewing process.

Language

The quantity and specificity of comments related to language usage was appreciated but unexpected. Several experts provided detailed comments on word choices and concerns about conveying abstract concepts. One clinical expert went through the tool screen-by-screen during the interview process

. . . the only person that I think would understand this is someone with a college education or above. { } I think it's not the language, I think it's the concepts.

What does 1.44% probability mean or 1 percent probability mean? Sounds like I don't have much chance. {..} I think 1.44% probability is a very abstract concept so I think the picture first and the explanation of what it means and then giving the information – so yours is 1.44% I'm not sure that the second decimal place makes much difference to people.

. . . you have a lot of terms that need to be changed. For example, if I had a high school level education and didn't ever think about breast cancer screening, I would think a positive test result was a good thing. {...} So I think you could say something more like what I just said which is, "A test that suggests you might have it," versus, "Test that reassure you you probably don't." It's accurate. It's comprehensible.

Another expert emphasized the importance of using different denominators when talking about 10-year mortality risk and one year outcomes of screening mammography.

But when you're talking about communicating with average women I do just fear that the 1,000 – because it's really it's a different – it's a totally different lens. When you're talking about 10 years in mortality it's a totally different lens than one year outcomes of mammography.

. . . maybe you can set it up with a little more language or if you – or as an option, you know, contemplate using a different denominator, 10,000 even. Or just some – you know, just a different one so that it's – so that there's not the temptation to think of these things all as being on the same scale.

Several experts pointed out specific words they felt would challenge and confuse the average user of this decision aid tool. For example, one expert disliked the use of the word 'symptom'.

Like symptom – people may not know what that means cause, you know. {...} (It might be better to say) What is a feeling or finding or something that you – that might make you go seek a doctor's opinion. {...} And screening is looking for a condition, looking for a condition when there are no feelings or signs that would make you go to a doctor.

Another disliked the word 'harm'.

And I think it would be nice if there was some continuum of what you might call downsides. {...} Everything from inconveniences that are a little nerve wracking. Little to very nerve wracking depending upon how quickly they get resolved.

Controversy

The issue of conveying differing opinions about the harms and benefits of breast cancer screening for women in their 40s was raised a number of times⁶⁴. Several experts felt strongly that it was important to include women in this discussion, not shield them from it.

It wasn't clear to me whether there is bias but I know there is controversy and you didn't say that anywhere so I am suspicious. {...} And it sets the tone of the overall piece that it's not a propaganda piece; it's not necessarily a biased piece. It's just saying we know there's controversy, we're trying to keep it clean and simple. We're trying to convey what is known.

The funny thing is like everyone uses the same information and comes to a new conclusion. . .

So the tradeoff between those, all those false positives and the mortality reduction, is what they make some decision about and it's clearly – and that's that got them in trouble because it's clearly hard to compare. The consequence of false positives and over diagnosis and mortality, those are not straightforward - like adding or subtracting four and two.

...there has been controversy and that part of it is about the balance between those two groups of people: who will benefit, the people who are going to get cancer and who will not, people who will never get benefit but might be hurt by the process. So I think it's more acknowledging that you're aware that there is a controversy maybe than digging into the details of it so that –

You might say there is a chance that some cancers might never have, you know, produced symptoms if we had not detected them when we screened – when you went – underwent a screening mammogram. And by treating these cancers that never would have grown to become a health problem you would be treated unnecessarily. I mean those are just frightening words, aren't they?

Supposing you were to -- your tool was to say the organizations that issue different – issue guidelines, have a different perspective, have viewed the data, the historical data differently. And the Preventive Services Task Force estimates the benefit to be about this and the American Cancer Society estimates the benefit to be different and about this. They both agree that false positives are a reality. They both believe that women should be informed that mammography is not going to be as useful to everyone in the same way. You know, there's a whole host of characteristics and its effectiveness is gonna vary over the course of your life. It's gonna get more effective as you get older. It's a little less effective when you're younger. I wonder if that's a way to portray the information where there's organizational differences in how they interpret the data to go beyond any one individual.{..} I mean I need to always be reminded we're talking about dealing with people in the sixth to eighth grade level and they have a hard time lining those different perspectives up and enduring them as opposed to saying just give me the answer, which is actually something that Americans are more inclined to demand than other cultures.

Values Clarification

There is an ongoing discussion in the decision making community about how to elicit values clarifications and how to compare and contrast it with tradeoffs⁶⁵. It was no surprise, then, to see our experts touch on this very matter.

. . . there were a few slides regarding over-diagnosis and it was a bit confusing. . . { } . . . I think it's important for clinicians to know that it is true that not all DCIS progresses. And a lot of clinicians in my field don't know that. And so I think it is important for clinicians to be aware of it. I'm not sure how much that helps the woman making a decision. I don't know. I just – that's kind of a hard one for me to figure out how that plays into someone's decision-making process that if you get a mammogram and they might find a cancer, but maybe it won't actually become life-threatening and I think – it's hard for women to grapple with that, I think. . .

That (values clarification) was a little confusing to me because the only real benefit – this is something I guess I thought maybe was a bit biased. The only benefit derived from mammography that I saw was peace of mind. And like everything else was like over diagnosis, cost, hassle. { } “Well, if I am getting a mammogram because it provides me with peace of mind,” it almost sounds flip.

On some of your scales, did anybody question whether you put one thing you were concerned about on the left versus the right and whether to the left or the right represented a judgment call?

The priorities had awkward tradeoffs: time and access vs. piece of mind seemed like a false tradeoff, it was not clear what piece of mind meant (avoid false positive or knowing cancer was there); what is the reason for the embarrassment and pain?

I wasn't clear why some of the tradeoffs were chosen, and they seemed to somewhat be a false tradeoff to some extent and that you didn't need to tradeoff one for the other. And then you have, in another exercise, to put them in the weighing – almost in the scale or the different boxes – and yet it seems like there's a lot of effort, and yet, then at the end, there's just this sort of ranking, or maybe I missed it.

I think having that one (a slider)– falsely normal or falsely abnormal or however you put it in different places in the preceding information would be really helpful slider to have there to get people to clarify their own values around that like what's more concerning to them.

And then the issue with peace of mind, I think that being clear what you mean by that and whether or not peace of mind around knowing the truth. Is it having a lack of a false of positive or a lack of false negative or knowing – I guess it's not clear. When you say "peace of mind," what are you having peace of mind about?

On the slider screens, which I think are a cool idea overall, the one that balances peace of mind and stress and fear is unclear. And I wonder whether it should be really gaining peace of mind and avoiding stress and fear because I didn't understand how to balance those things. {..} But also maybe, as I think about it, if you did have a slider about peace, said something like, “Peace of mind means different things to different people. For you peace of mind means more not having a false negative, not having a false positive.” And then when you see peace of mind for the rest of the time, then you know what peace of mind means to you and you're answering it as you would answer it.

[Layout](#)

Although considerable effort went into the design and user interface of the decision aid tool, our experts envisioned that it could be much better.

. . . some areas were text heavy. {..} It was just a lot of dense information so I don't know how – it's always a problem. I don't know how to break it up, whether any of it can be in pictures, whether you can have more, you can flip through faster and see less, that was just my reaction. {..} It could be broken up and bulleted so you wouldn't see the whole paragraph.

The graphics are pretty simple and pretty dull. I think there's a lot more you could do artistically to improve the physical appearance to make it more interesting and more – I don't want to – I want to say seductive but that's not really what I mean. But I just – it's more visually satisfying to take and to be with. {..}. . . I think you could get somebody with a graphic sense to look at it once you get the content and it might make it more interesting.

Well, I think it could be made much more accessible than you'd have a length issue because to make it that much more accessible would take many more screens I think. Cause you can't – I don't think you should have screens that have seven or eight bulleted data points on them. So then you'd have to make a choice of things to cut.

The tree diagrams, I think are unintelligible for - for normal humans. The stuff you have in text is fantastic. {..} I wonder if there's a way to make them half-size to the left and text to the right explaining it.

I mean I think you should think about, for example, whether you could put two questions on a screen for example, things like that. Cause having to go through – whether there are places you could combine multiple items onto one screen because having to click through so many screens makes it feel longer than it actually is.

. . . layout needs some work I think overall. I'm not sure if the spacing is too tight or the paragraphs of text that are all tightly left-justified, tight line spacing that my 40 plus year old years found difficult being the appropriate age for the activity.

DISCUSSION

There was a high level of baseline decisional conflict in this convenience sample of 51 predominantly white, wealthy, well-educated women. This was surprising since this cohort was strongly inclined toward screening with 74% having had a prior mammogram and 82% indicating, at baseline, that they would have a screening mammogram in the next 1 – 2 years. It was equally intriguing that using the breast cancer screening decision aid tool caused significant reductions in overall decisional conflict, increased certainty and feelings of being more informed, clearer and better supported. We hypothesize that the high rates of baseline decisional conflict reflect the active debate about screening mammography in the national media^{6-10, 66-68}. Women, even those who are highly educated and may be in a better position to understand the controversy, are confused by the conflicting information and recommendations. In light of these findings, we suggest that decision aids may have a value-added role in providing an unbiased, easy-to-understand synthesis of the evidence base.

This cohort felt that finding cancer and having peace of mind were the most important factors to consider when making a choice about screening mammography. Avoiding false negative tests, false positive tests, overdiagnosis and radiation exposure were also ranked with high to moderate importance. Issues related to stress, cost, inconvenience and pain were of lower importance. Although not mutually exclusive (i.e., avoiding a false positive test may cause peace of mind), the ranking of these factors provided a perspective on what this cohort of women value. In general, the potential benefits of screening mammography were more important than the potential harms. This is consistent with literature that suggests that women tend to overestimate their breast cancer risk and underestimate the potential harms associated with screening^{11, 13}. One exception was the risk associated with radiation exposure. Most of the experts we interviewed concurred that radiation exposure is a non-issue in modern mammography⁶⁹⁻⁷¹, yet our cohort's perception of its importance and risk remained high.

While most of our subject matter and clinical experts felt the breast cancer screening decision aid was a balanced and accurate reflection of the current evidence, several were adamant that the tool discouraged routine screening. The nature and composition of our pilot cohort made it difficult to assess this criticism directly. There is evidence that most women, like those in our cohort, conditioned by years of successful public health campaigns promoting breast cancer awareness, are positively inclined toward routine breast cancer screening¹³. However, anecdotal evidence from this study suggests that merely using the decision aid tool heightened the awareness of one member of the cohort who was not initially inclined toward routine screening:

Thank you ...very informative. I dislike taking mammograms..but will make sure I have one at least every two years.

This idea was corroborated by one of the clinical experts.

So just to clarify, you're saying that just by giving women access to this type of information, it heightens their awareness of the problem and may push them towards wanting to have (screening) –

It might, yes. Yes.

This pilot study had a number of weaknesses. First, the women who volunteered were predominantly white, well-educated and well-off. They are not representative of the general population and thus the

findings from this study cannot be extrapolated. Second, the breast cancer screening decision aid was available only in an electronic format requiring users to have a computer and knowledge of how and means to access the internet. Conversely, users of iPads and smart phones were also excluded. Third, the tool was too long. During usability testing it took approximately 35 minutes to get through the tool. This is almost double the optimal amount of time recommended by our experts.

The study also had several strengths. First, the pilot cohort was age, risk- appropriate. Second, the tool was scalable to most computer-based platforms. That is, it could be accessed through the internet using most common browsers and operating systems. Third, the tool was interactive. Users were asked for specific input and provided with specific feedback both for themselves and to share with their healthcare providers.

On March 23, 2010, President Barack Obama signed the Patient Protection & Affordable Care Act into law¹⁴. A key provision of this legislation was section 3506 – Program to Facilitate Shared Decisionmaking. Substantial provisions related to shared decision making were outlined including:

1. Creating a new shared decision making program that
 - establishes a process to certify decision aids;
 - awards funding to produce and update aids;
 - creates Shared Decision Making Resource Centers; and
 - provides grants to health care providers for development, use and assessment of shared decision making using certified decision aids.
2. Under a new Center for Medicare and Medicaid Innovation (CMI), providing support to test innovations that assist individuals in making informed health care choices.
3. Providing support for new measures to assess shared decision making tools; and
4. Providing support for new measures to assess shared decision making tools.

The momentum being generated as a result of this legislation has a direct impact on the future development and use of the breast cancer screening decision aid developed, built and tested for this thesis.

CONCLUSIONS

In this pilot study, a predominantly upper socioeconomic cohort of women participating in a web-based breast cancer screening decision aid did not change their intention to obtain a routine screening mammogram. Eighty-two percent entered the study knowing they were having a screening mammogram in the next 1-2 years and their intentions did not change as a result of using the tool. They did, on-the-other-hand, experience a significant decrease in the amount of decisional conflict they experienced in making that choice. In fact, they felt more certain, better informed, better supported and demonstrated increased clarity in their decision making process. These findings led us to believe that, for this cohort, this decision aid tool brought value to patient care not by impacting *what* a woman chose but by impacting *why* or *how* she chose it.

The gracious and enthusiastic feedback provided by the subject matter and clinical experts resulted in a long list of suggestions for retooling and streamlining the decision aid tool. This is the focus of future work. The comments that the experts provided on the *a priori* themes confirmed that the breast cancer screening decision aid tool must:

1. Be accurate, comprehensive, unbiased and patient-centric.
2. Be a reasonable length (15-20 minutes), convenient, interactive and secure.
3. Be supported on a variety of platforms with seamless integration into a health record, if desired.
4. Convey information in an understandable yet engaging manner.

The experts also raised unforeseen concerns about reading level and consistency in terminology, conveying the controversy surrounding the screening mammography guidelines, confusion regarding values clarification versus tradeoffs, and the aesthetic layout of the breast cancer screening decision aid tool.

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APPENDIX A: THE RESEARCH TEAM

Karen Eden, PhD

As an OHSU faculty member, the IRB required that Karen Eden serve as the Principle Investigator on this project. In this role she was responsible for oversight on the decision aid development, testing and implementation. Karen has been the lead developer of a series of previous interactive preference-based decision aids. She is currently working with the International Patient Decision Aid Standards (IPDAS) steering committee to set standards for patient decision aids. This group most recently updated the Cochrane review on the effectiveness of decision aids to improve the decision making process. Karen has successfully created and evaluated evidence-based decision aids for childbirth choices and for harm reduction in domestic violence. These decision aids have been designed for patients with low literacy, using a presentation format that has been well received by participants in preliminary studies. The format includes multiple media (text, graphics, and voice-over narration for all text). All user input is performed with simple “point and click” motions using a mouse. Karen is an Associate Professor in the Medical Informatics and Clinical Epidemiology Department at Oregon Health & Science University. She teaches courses on medical decision making to MS, MBA and PhD students. She is the Associate Director of the Biomedical Informatics Doctoral Programs.

Paula Scariati, DO, MPH, ABIHM, FACPM

As a co-investigator on the study, Paula Scariati was responsible for the decision aid development, study design, study implementation, and data analysis. Paula is a physician with 20 years of clinical and academic experience. She is board certified in both Preventive Medicine & Public Health and Holistic Medicine. She is an Associate Clinical Professor in the Department of Preventive Medicine at Loma Linda University as well as an Adjunct Clinical Professor in Family Medicine at the Virginia College of Osteopathic Medicine, where she was Founding Chair of the Department of Preventive Medicine. She was an Epidemic Intelligence Service (EIS) Officer at the Centers for Disease Control and Prevention where she trained as a medical epidemiologist. Currently, Paula is a Clinical Informatics Fellow with the National Library of Medicine completing her Master’s work at the Oregon Health & Science University in Portland. She has published a number of peer-reviewed articles on preventive medicine-related topics as well as several chapters in a text on osteopathic manipulative medicine. She is a question writer for the National Board of Osteopathic Medical Examiners and has provided peer

review for several journals and grant processes. Her current interests are secondary uses of Electronic Health Record data, healthcare quality, and personalized medicine

Elizabeth Nelson

As a co-investigator on the study, Elizabeth Nelson was responsible for the technical implementation of the decision aid including technical design, programming, usability testing and deployment. Elizabeth is a Masters student in the Department of Medical Informatics & Clinical Epidemiology at Oregon Health & Science University in Portland, OR. She has held a variety of technical and managerial positions in information technology, most recently at Partners Healthcare in Boston as team lead on Partners' web-based patient portal. She managed the technical aspects of a large research project leading to several publications. Prior positions include database administration for a large financial firm, co-founding a software start-up for a vascular imaging product for which she wrote the edge detection software, and managing the technical team for human resources and payroll at a large utility company. Elizabeth received her BA in government from Saint Lawrence University in 1981 and a Certificate in Biomedical Informatics from Oregon Health & Science University in 2009. Her current interests are participatory medicine and consumer health informatics.

Jayashree Kalpathy-Cramer, PhD, MS

As a collaborator on the project, Jayashree provided key feedback on the project's content and timeline. She was an instructor in the Department of Medical Informatics at OHSU from 2009-2011 funded through a K99/R00 grant through the National Library of Medicine. Prior to joining OHSU, she worked for many years in the semiconductor industry. She is currently at the A A Martinos Center for Biomedical Imaging, Massachusetts General Hospital and Harvard Medical School, Boston, Massachusetts, USA. Her current area of research is in the use of image processing and machine learning techniques for medical image analysis and retrieval, quantitative imaging for oncology and the development of statistical methods for the analysis of cancer related data. She continues to teach a class on quantitative research methods in informatics at OHSU and is passionate about data.

Steven Bedrick, PhD

As a consultant on the project, Steven provided technical support on the programming of the decision aid tool. Steven is a Post-Doctoral Fellow at OHSU. He earned his BA in Biology from The Colorado College and was a software engineer for several years before returning to academia. Steven's research interests focus on the intersection of medical informatics, public health, and global health, although he has side projects in image retrieval and social networking.

APPENDIX B: TIMELINE

July 2010

- Review Literature
- Meet with Army of Women Cohort Project Manager
- Funding Commitment from DMICE for Army of Women Cohort Access Fee of \$1500

August 2010

- Review Literature
- Analyze and Review 2x2 Tables for BCSC Data

September 2010

- Review Literature (ongoing)
- Review of IPDAS Criteria for Decision Aids
- First Draft of Decision Aid
- Secure Programmer

October 2010

- Review Literature (ongoing)
- Finalize Thesis Committee
- Establish Parameters for Data Collection / Database
- Second Draft of Decision Aid
- Secure Server and Determine Appropriate Software Interface

November 2010

- Review Literature (ongoing)
- Ongoing Decision Aid Development
- Begin programming
- Trial Proposal Defense with Thesis Committee

December 2010

- Review Literature (ongoing)
- Programming ongoing

- Establish Backend Database Interface
- Part I: Proposal Defense

January – April 2011

- Review Literature (ongoing)
- IRB Submission
- Usability Testing of Decision Aid (Informal)
- Revise Decision Aid in Response to Testing
- Database Testing

May - July 2011

- Review Literature (ongoing)
- Army of Women Submission (6 week turn around)
- Usability Testing of Decision Aid (Formal and Informal)
- Mass email approvals
- Database testing

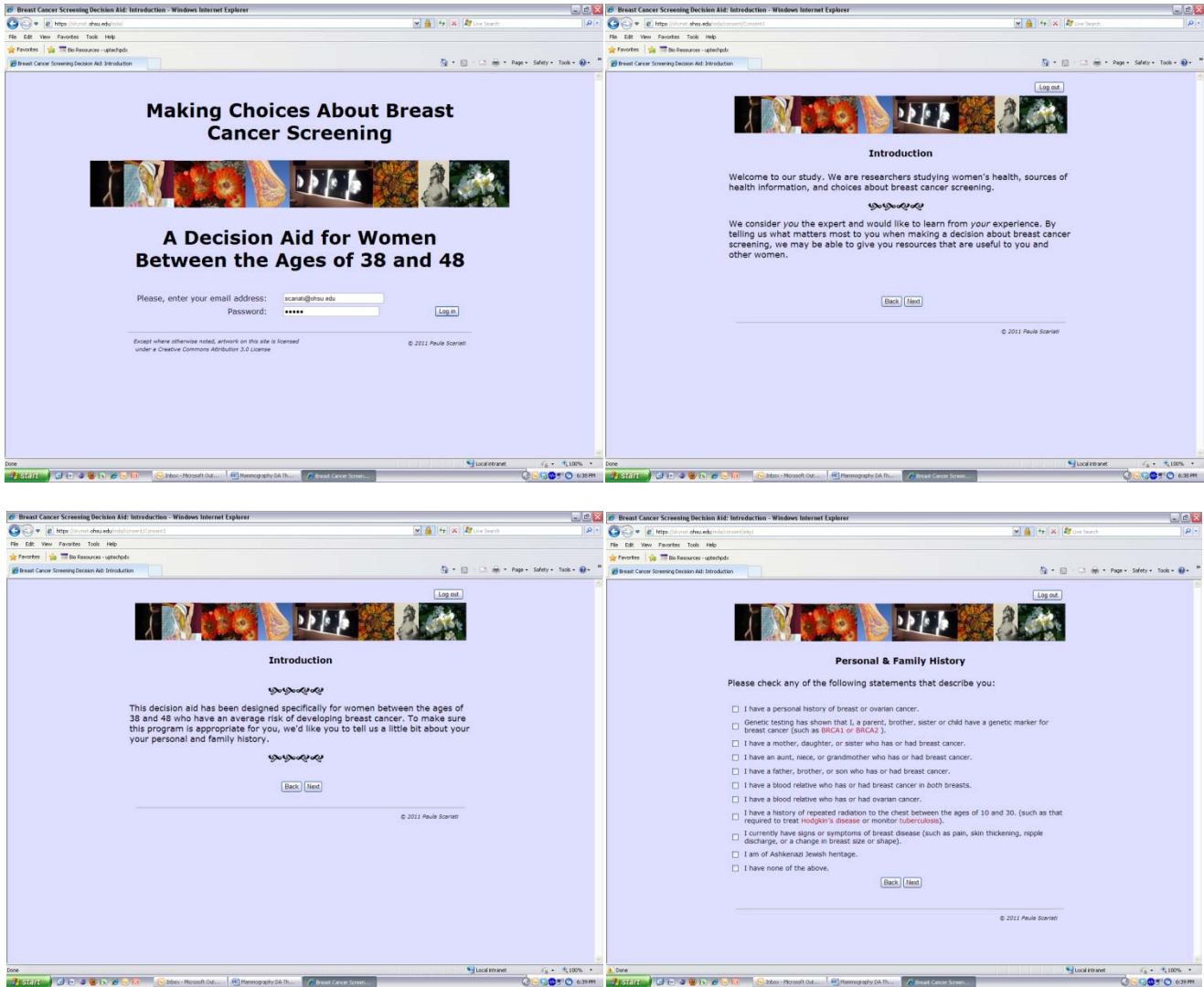
August - November 2011

- Review Literature (ongoing)
- Data Collection
- Data Analysis
- Thesis Submission
- Part III: Thesis Defense

APPENDIX C: DECISION AID SCREEN SHOTS


<https://skynet.ohsu.edu/mda/>

Main Pathway: Eligible Subjects



Breast Cancer Screening Decision Aid: Introduction - Windows Internet Explorer

Log out



Option to Participate in the Study

Your responses suggest that you have an average risk of developing breast cancer so this program is appropriate for you.

As a participant in this study it is important that you know your rights and responsibilities. The link below will take you to our consent form. Please, read it carefully and sign it electronically by clicking the appropriate box at the end.

[Back](#) [Consent Form](#)

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Breast Cancer Screening Decision Aid: Introduction - Windows Internet Explorer

Print this form

OREGON HEALTH & SCIENCE UNIVERSITY (OHSU)
Information Sheet

TITLE OF PROJECT: Making Choices About Breast Cancer Screening: A Decision Aid for Women Between the Ages of 35 and 48

PRINCIPAL INVESTIGATOR: Karen Eden, PhD (edek@ohsu.edu), (503) 494-2456

CO-INVESTIGATORS: Paula Scanlet, PhD, MPH (psca@ohsu.edu)
Lisa Nelson (lnelson@ohsu.edu)

Department of Medical Informatics & Clinical Epidemiology, National Library of Medicine

SPONSORS:

PURPOSE OF STUDY: The purpose of this study is to evaluate a breast cancer screening decision aid and assess its impact on mammography choices. You have been invited to participate in this research study because you are a woman between the ages of 35 and 48, at average risk for developing breast cancer, who might be considering a screening mammogram.

You do not need to have computer skills to participate in the study.

We are seeking a minimum of 50 women to enroll.

PROCEDURES: If you agree with the information provided in this consent form, you will proceed to the decision aid. This will take about 35 minutes to complete.

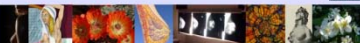
The decision aid begins with a series of questions about your current plans for breast cancer screening, the sources of information you consider when making this decision and your opinions about screening mammography. Research and education information, like that collected by most websites that you visit, will be recorded. This information will be used to help us improve the appearance of the website on different computers in the future. The next part, which is the bulk of the program, provides you with the most current information about breast cancer screening. This includes information on risk factors, plain film mammograms compared with digital mammograms, the risks and benefits of screening mammography, and a discussion of several newly recognized issues in breast cancer screening. You are then asked to evaluate a series of factors and rank their importance in your decision making process. The study concludes with a second round of questions and provides you with additional information on resources.

During your use of this web-based decision aid computer program, our research team will be close by to answer questions. You may also contact Karen Eden (edek@ohsu.edu) or Paula Scanlet (psca@ohsu.edu) directly, now or at any point in the future if you have questions.

RISK/DISCOMFORTS: Some of the questions you are asked as part of the study may seem

Breast Cancer Screening Decision Aid: Introduction - Windows Internet Explorer

Log out



Decision Aid + Research Study


- This program is a decision aid. It will provide you with the latest information on many aspects of breast cancer, breast cancer screening, risks and benefits -- and help you to clarify your values in making a decision about breast cancer screening.
- This program is a research study. You will be asked questions about what you think, how you think, where you get your information and what you value. You can skip any question you don't feel comfortable answering.

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Organization & Timing

This decision aid program is organized into 6 sections:

- Welcome
- Values Clarification
- Risk Factors
- Summary
- Mammography
- Final Questions

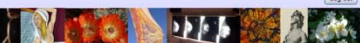
This program will take about 40 minutes to finish. You'll see a status bar, like the one shown here, in the bottom left corner of each screen. It indicates how much of the program you have completed. For example, this status bar indicates that you have completed approximately 30% of the program.

[Back](#) [Next](#)

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Log out



Logging Out

We recommend that you complete the program in one sitting but if that isn't possible, don't worry. Each screen has a "log out" button, like the one shown here, in the upper right corner. Use this button to exit the study at any time.


Your password is good for 7 days so you can come back at any point during that time and pick up where you left off. Just sign in again using your email address and password.

[Back](#) [Next](#)

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Log out



Contacting Us

Finally, once you enter the decision aid, you'll see that each screen has a "Email the Research Team" link, that looks like the example here.

[Email the Research Team](#)

It will be located in the bottom left corner of the screen. If at any point you have a question about the study, click on it and send us an email. A member of our team will respond within 24 hours.

Are you ready to start?

[Back](#) [Start](#)

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Log out

Welcome Values Clarification
 Risk Factors Summary
 Mammography Final Questions

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Log out

What is Breast Cancer Screening?

- Breast cancer screening is an attempt to find cancer when there are no symptoms of a problem.
- The goal is to find breast cancer early, when it is small and less likely to have spread to other parts of the body.
- The most common method of breast cancer screening is a mammogram.

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Log out

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.

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Log out

This decision aid program is designed for average risk women who are approaching or in their 40s who are making choices about screening mammography.

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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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Log out

Have you ever had a mammogram that was initially thought to be suspicious but then found to be negative on further follow-up?

- Yes, I have
- No, I have not
- I am not sure

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Log out

Are you planning to have a mammogram in the next 1 or 2 years?

- Definitely yes
- Probably yes
- Undecided
- Probably no
- Definitely no

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Log out

The Details of Making a Choice

We are interested in knowing what information you considered when making a choice about screening mammography.

Please respond Yes, Unsure, or No to each of the following questions.

Do you know what mammography screening options are available to you?

Do you know the benefits of each option?

Are you clear about which benefits matter most to you?

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The Details of Making a Choice (cont)

Please respond Yes, Unsure, or No to each of the following questions.

Do you know the risks and side effects of each option?

Are you clear about which risks and side effects matter most to you?

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Log out

The Details of Making a Choice (cont)

Please respond Yes, Unsure, or No to each of the following questions.

Do you have enough support from others to make a choice?

Are you choosing without pressure from others?

Do you have enough advice to make a choice?

Are you clear about the best choice for you?

Do you feel sure about what to choose?

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Log out

Who should be screened?

Medical studies have proven that some groups of women benefit from mammograms.

Check all groups for which you think that is true:

- 18 - 39 years of age
- 40 - 49 years of age
- 50 - 74 years of age
- 75 and older

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Breast Cancer Screening Decision Aid - Windows Internet Explorer

Log out

Who Decides?

Who should decide whether or not you start having screening mammograms?

- I should, after thinking about the advice I received from my health care provider.
- I want to share the decision-making with my health care provider.
- I want my health care provider to decide
- I am unsure

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Log out

What is Breast Cancer?

- Cancer is a group of diseases that cause cells in the body to change and grow out of control.
- Most types of cancer cells eventually form a lump or a mass called a tumor.
- Breast cancer begins in the breast tissue which is made up of the glands that produce the milk and the ducts that connect the glands to the nipple.
- The rest of the breast is made up of fat, connective tissue and lymphatic tissue.

Progress bar and navigation arrows.


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Log out

How Common is Breast Cancer?

Breast cancer remains the second leading cause of cancer death in women, overall. Lung cancer is the first.



Progress bar and navigation arrows.

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Breast Cancer Screening Decision Aid - Windows Internet Explorer

Log out

Breast Cancer, Lung Cancer & Heart Disease

- For women in their 40s, the risk of death from breast cancer is about the same as the risk of death from heart disease. After age 60, heart disease becomes the largest cause of death in women.
- For women who smoke, the chances of dying from either heart disease or lung cancer exceeds the chance of dying from breast cancer from the age of 40 on.

Progress bar and navigation arrows.

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Breast Cancer Screening Decision Aid - Windows Internet Explorer

Log out

If your current age is...	For women like you the probability of developing breast cancer in the next 10 years is:	or 1 in:
20	0.06%	1760
30	0.44%	220
40	1.44%	69
50	2.39%	42
60	3.40%	29
70	3.73%	27
Lifetime Risk	12.08%	8

Progress bar and navigation arrows.


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Breast Cancer Screening Decision Aid - Windows Internet Explorer

Log out

Here's an Illustration of the Same Concept

If we put 69 women in their 40s in a room together and observed them for the next 10 years, we'd expect one of them to develop breast cancer.



Progress bar and navigation arrows.

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Breast Cancer Screening Decision Aid - Windows Internet Explorer

Log out


But What About Me?

- This information about population risk gives us a solid idea of what to expect when screening large groups of women.
- It doesn't answer the question "What is my personal risk of developing breast cancer?"
- Many factors must be considered when determining personal risk.
- Some of the better known risk factors are discussed on the following screens.
- Problem is, we don't have mature tools that allow us to use this information to accurately predict what will happen to you or any other specific woman.
- Individualized genetic testing may help us do a better job of this in the future.

Progress bar and navigation arrows.

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Back to Our Illustration



So, while we are confident that 1 out of 69 women in their 40s will develop breast cancer in the next 10 years, we remain unable to accurately predict which one.

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Welcome

Risk Factors

Mammography

Values Clarification

Summary

Final Questions

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Risk Factors

- Risk factors are characteristics or habits that have been shown to increase or decrease your chance of developing breast cancer.
- Categorizing them as *major*, *moderate*, and *minor* helps us appreciate the magnitude of impact they can have on developing breast cancer.
- Some risk factors can be modified (like whether you use birth control pills), others can't (like your age).
- Most women who develop breast cancer have no risk factors.

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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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Major to Moderate Risk Factors

Dense Breasts

- Breast density is a recently identified risk factor for breast cancer.
- The denser the breast tissue, the greater the risk of developing breast cancer.
 - Very dense breasts are a major risk factor.
 - Somewhat less dense breasts are a moderate risk factor.
- An x-ray is required to determine breast density

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Moderate Risk Factors

Birth Control Pills & Second-Degree Relative

- Current use of birth control pills or use within the last 5 years is a moderate risk factor for developing breast cancer.
- Having a close family member (grandmother, aunt, niece) who had or has breast cancer is also a moderate risk factor.

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Minor Risk Factors

Most other risk factors for developing breast cancer are minor. Some examples include:

- Having your first period at an early age (12 or younger).
- A history of using birth control pills at any time.
- A history of smoking at any time.
- Mild to moderate alcohol consumption (less than 7 alcoholic drinks per week).
- Not having children.
- Having benign breast disease.
- Being overweight after menopause.

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Modifiable Risk Factors

- The choices you make about things like what you eat and drink, how much you exercise, whether you smoke or not, and more, all work together to have an impact on your breast cancer risk.
- Scientists believe that these lifestyle choices, along with other factors such as hormone use and stress, create an environment in the body that can either foster or discourage the development of breast cancer cells.

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Reducing My Breast Cancer Risk & Improving My Health

(Please, check the things you want to do)

- Reduce the amount of alcohol I drink.
- Exercise until I break a sweat at least 30 minutes most days.
- Get my weight into a normal range and keep it there.
- Stop smoking.
- Eat more fruits and vegetables.
- Manage my stress with something like meditation.
- Discuss alternatives to birth control pills or hormone replacement therapy with my healthcare provider.

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It Makes Good Sense For Many Reasons

Making healthier choices not only helps to reduce your risk of breast cancer, it can also reduce your risk of:

- ✓ Heart Disease
- ✓ Diabetes
- ✓ Other Types of Cancers
- ✓ Depression
- ✓ Osteoporosis...and more!

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Welcome

Risk Factors

Mammography

Values Clarification

Summary

Final Questions

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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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Log out

How a Mammogram Works

- A special low-dose x-ray is then used to look for breast patterns or lumps that are not normal. These may be too small for you or your health care provider to find by feeling your breast.
- The same procedure then occurs with the other breast.
- Many women say having a mammogram hurts - but not so much that they would consider it a deterrent from future screening.

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Digital Mammogram

- Digital mammograms are performed the same way except the images are captured on a computer instead of on film.
- The quality of the digital mammogram is about the same as that of a plain film mammogram.
- The added-value of a digital mammogram is that digital images can be magnified or enhanced to clarify questions more easily. This often reduces the need of having a woman return for more images when there are questions.
- Digital mammograms are recommended for pre-menopausal women and women with dense breasts.

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Are Mammograms Safe?

- The amount of radiation that you get from a screening mammogram is about what you would receive over 3 months from your usual surroundings (e.g. sun, rocks, soil, buildings, air and food).
- Young breast tissue is more sensitive to radiation. Some studies suggest that if screening mammograms were performed on women in their 30s, more cancers would be created than prevented. For women like you, in their 40s, there appears to be a balance between the risk and the benefit. After age 50, the benefits derived from mammography outweigh the risk of the radiation exposure.

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Timing Between Screening Mammograms

- Scientists have also found that screening every 2 years gives the greatest benefit of detecting a breast cancer while minimizing a variety of risks including radiation exposure.
- Radiation exposure is cumulative. Your total exposure to radiation from screening mammograms will depend on the number of mammograms you have had.
- X-ray technologists are experts in breast positioning and know how to reduce the amount of radiation you receive.

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So, if 1000 Women Like You (A) Participate in Screening Mammography, What Do We Expect?

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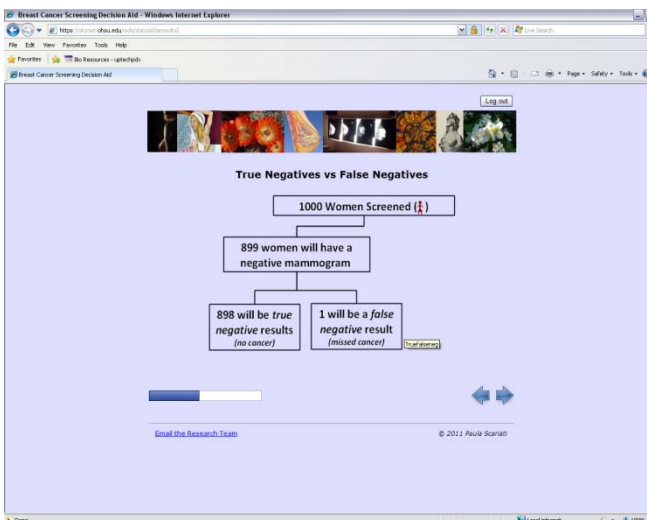
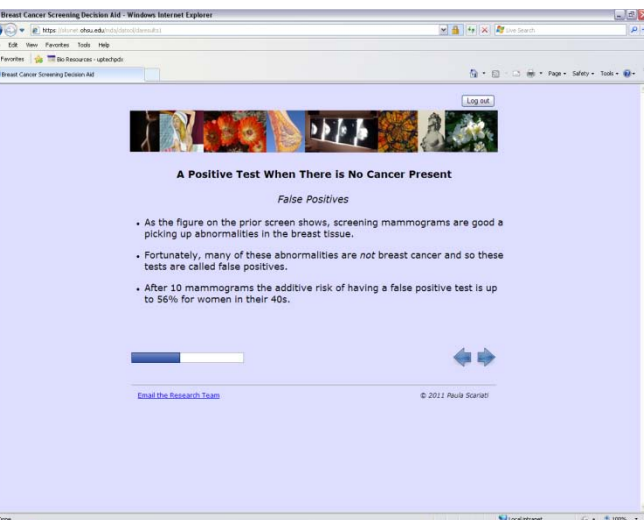
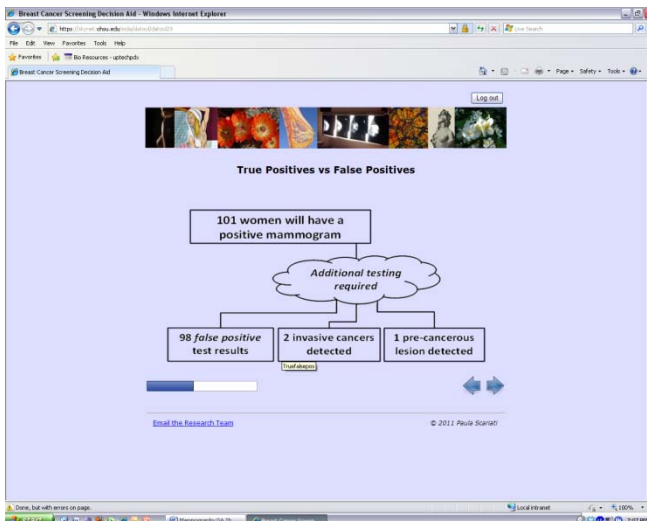
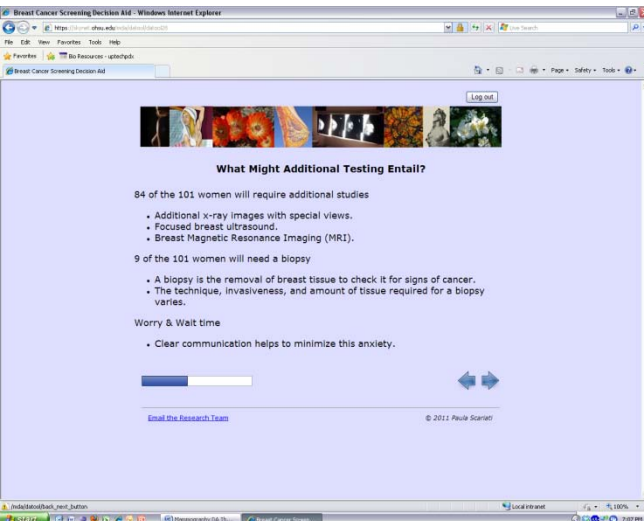
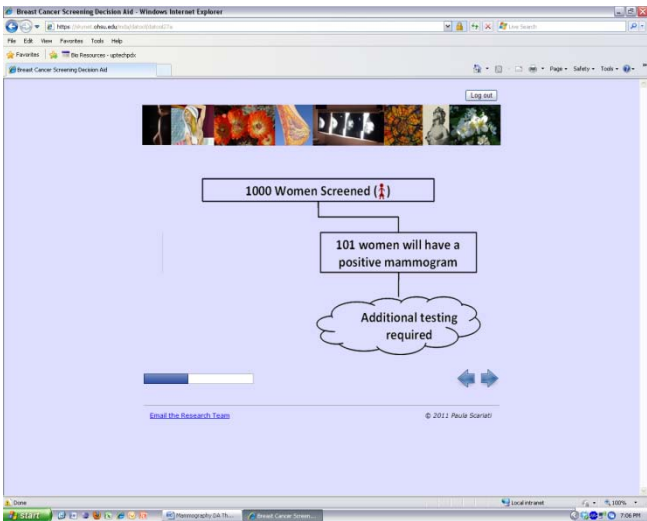
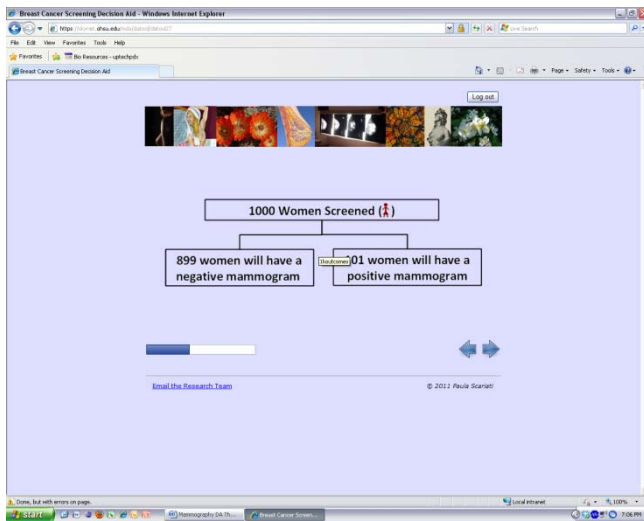
Log out

Possible Outcomes of Breast Cancer Screening

```

graph TD
    A[You Have a Screening Mammogram] --> B[- Test Result]
    A --> C[+ Test Result]
    B --> D[No Breast Cancer  
(Original Test is a True Negative)]
    B --> E[Missed Breast Cancer  
(Original Test is a False Negative)]
    C --> F[Further Testing Required]
    F --> G[Breast Cancer Found  
(Original Test is a True Positive)]
    F --> H[No Breast Cancer Found  
(Original Test is a False Positive)]
  
```

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A Negative Test When Cancer is Present

False Negatives

- Mammograms can miss a cancer. This is called a false negative test.
- While this happens less frequently, it is important to remember that a negative screening mammogram does not guarantee that you don't have breast cancer.
- Any symptoms or concerns, regardless of when you had a mammogram, should always be promptly investigated.

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Cancer Between Screenings

- New breast cancers can also occur between routine screening mammograms.
- Breast cancer in pre-menopausal women tends to act differently than breast cancer in post-menopausal women.
- Pre-menopausal breast cancer often develops more rapidly and progresses more aggressively.
- Post-menopausal breast cancer usually progresses more slowly.
- Again, a negative mammogram should not create a false sense of security. Prompt investigation of any signs or symptoms is always recommended.

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The Issue of Overdiagnosis

- Overdiagnosis is when cancers are detected by screening mammography -- and treated -- that would never have progressed to cause symptoms or result in death.
- In our example of the 1000 women in their 40s, it is estimated that between 1 and 5 will be diagnosed and treated for a cancer that would have never have progressed to cause symptoms. This case has been *overdiagnosed*. Some studies suggest higher rates of overdiagnosis than this.
- It is not possible to distinguish between cancers found on screening that will progress to cause symptoms and possible death, and those that will not.

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An Example of Overdiagnosis

- One cause of overdiagnosis is a precancerous lesion that can ONLY be detected by mammogram called *ductal-carcinoma-in-situ* or *DCIS*.
- Less than 50% of the time DCIS goes on to become an invasive cancer -- the rest of the time it does not.
- Since doctors can't determine which DCIS diagnoses will progress to invasive cancer, everyone with DCIS gets treated. This entails receiving surgery, hormones or radiation.
- These treatments may have side effects and provide no benefit for the women who would have never gone on to develop cancer.

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DCIS

Had you heard about DCIS before this decision aid?

Yes
 No

Is information about DCIS something you want to factor into your decision about getting a mammogram?

Yes
 No

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Screening vs No Screening

- Of 1000 women in their 40s who have a screening mammogram, 3 will die from breast cancer over the next 10 years (997 will not).
- Of 1000 women in their 40s who do not have a screening mammogram 3.5 will die of breast cancer over the next 10 years (996.5 will not).
- Overall, of every 1000 women in their 40s, 0.5 avoid death from breast cancer as a benefit of screening mammography.
- Another way of saying this is that a total of 1904 women in their 40s need to be invited for screening mammography to prevent 1 breast cancer death in this age group.

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In Summary

Screening 1000 women in their 40s for next 10 years results in:

- 0.5 less deaths from breast cancer
- 2 women diagnosed with invasive breast cancer
- 1 woman diagnosed with a pre-cancerous breast lesion
- 98 women undergoing additional testing to find that their mammogram detected something that was not cancer
- 998 women being correctly reassured they do not have breast cancer
- 1 woman with breast cancer that was missed

Log out

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Welcome Risk Factors Mammography

Values Clarification Summary Final Questions

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Instructions: Using a Slider Bar

- Several times in this program, we ask you to use a slider bar like the one below.
- In each case, one end of the slider is labeled with one option (for example, black) and the other end is labeled with another option (for example, white).

Black White

- The box on the bar can be moved. Simply place your pointer on it, left click, hold and drag the box side-to-side to the desired location on the bar. Once it is in the right position, release your left click. Go ahead, give it a try.
- In the example here you'd slide the box to indicate your choice between black on the far left end of the bar, white on the far right end, or some shade of grey, in between.

Log out

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What Matters to You?

- This program has provided you with a lot of information about breast cancer and breast cancer screening.
- It is now time for you to take that information and decide what it means to you in light of your personal values and circumstances.
- The next few slides present information about possible benefits and risks of screening mammography. Please, consider each statement carefully and then, by moving the sliding box on the bar, indicate which aspect is more important to you.

Log out

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Time & Access

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?

Peace of Mind Time & Access

Log out

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Embarrassment & Pain

Which is more important to you, the peace of mind that can come from having a screening mammogram or the possible embarrassment and pain of having your breasts compressed?

Peace of Mind Embarrassment & Pain

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Log out

Positive Tests

Which is more important to you, having a positive test when cancer is present or avoiding a positive test when cancer is not present?

Having a Positive Test When Cancer Is Present

Avoiding a Positive Test When There Is No Cancer

Peace of Mind

Stress & Fear

0% 100%

← →

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Negative Tests

Which is more important to you, having a negative screening mammogram test when cancer is not present or avoiding a negative screening mammogram test when cancer is present?

Having a Negative Test When There Is No Cancer

Avoiding a Negative Test When There Is Cancer

Peace of Mind

Stress & Fear

0% 100%

← →

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Radiation Exposure

The amount of radiation that you get from a screening mammogram is about what you would receive over 3 months from your usual surroundings (e.g. sun, rocks, soil, buildings, air and food). But, it is cumulative over time. Which is more important to you, detecting breast cancer early or concerns about radiation exposure?

Detecting Cancer Early

Radiation Exposure

Peace of Mind

Stress & Fear

0% 100%

← →

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Overdiagnosis

Screening mammograms may detect cancers that would never go on to create further problems. This is called overdiagnosis. Which is more important to you, detecting a cancer that could be fatal or avoiding the detection of a cancer that would never be fatal?

Detect a Cancer that Could be Fatal

Avoid Detecting a Cancer that Would Not be Fatal

Peace of Mind

Stress & Fear

0% 100%

← →

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Stress & Fear

Which is more important to you, the peace of mind that can come from having a screening mammogram or the potential stress & fear that can result if follow-up testing is required?

Peace of Mind

Stress & Fear

Peace of Mind

Stress & Fear

0% 100%

← →

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Cost

How much would you spend for a screening mammogram test?

\$0

\$150

Peace of Mind

Stress & Fear

0% 100%

← →

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Cost

Does your health insurance company pay for screening mammograms?

- Yes, it covers 100%
- Yes, but with a copay
- No
- I don't know
- I don't have health insurance

Progress bar: []

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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 Cost	Peace of Mind Catching Cancer Early	Avoiding False Negatives Overdiagnosis Stress & Fear
	Embarrassment & Pain	Time & Access
	Radiation Exposure	

Progress bar: []

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Welcome to the Breast Cancer Screening Decision Aid

Values Clarification
Risk Factors
Mammography
Summary
Final Questions

Progress bar: []

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Log out

Collecting Your Thoughts

- As we draw towards the end of our program, let's digest some of the key points that we've explored.
- While no one can tell you what the right decision is for you to make when it comes to screening mammography, collecting your thoughts and evaluating your priorities should make the decision process easier.
- Remember, this is not a decision you are expected to make alone. The information that you've learned here is meant to be shared with your healthcare provider as part of a shared decision making conversation.

Progress bar: []

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1. Risk Factors

- In women like you, at average risk of developing breast cancer, age is the #1 risk factor. This is why screening mammography guidelines are based on age.
- In a group of women in their 40s we expect 1 out of 69 to be diagnosed with breast cancer in a 10 year period. Right now, we are unable to accurately predict which one.
- Many risk factors can not be changed. Some can.

Progress bar: []

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Modifiable Risk Factors That You Chose to Address

- Manage my stress with something like meditation.

Progress bar: []

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No Guarantees

- There are women who do everything that is recommended who still develop breast cancer.
- There are women who do nothing that is recommended who never develop breast cancer.
- Nothing you do can guarantee a perfect outcome.
- Be proactive! Ask questions! Seek education!

Progress bar: []

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2. Risks & Benefits of Screening

- Screening mammography can not accurately detect breast cancer 100% of the time. There are trade-offs.
- In fact, for every 1000 women like you that have a screening mammogram we expect:
 - 0.5 less deaths from breast cancer
 - 2 women diagnosed with invasive breast cancer
 - 1 woman diagnosed with a pre-cancerous breast lesion
 - 98 women undergoing additional testing to find that their mammogram detected something that was not cancer
 - 898 women being correctly reassured they do not have breast cancer
 - 1 woman with breast cancer that was missed

Progress bar: []

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3. Your Priorities

Most Important
Avoiding False Positives
Cost

Moderate Importance
Catching Cancer Early
Peace of Mind

Least Important
Avoiding False Negatives
Overdiagnosis
Stress & Fear

Progress bar: []

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4. Other Issues I want to Discuss With my Healthcare Provider

(Please, type anything you want to remember in the text boxes below)

Text input boxes:

Progress bar: []

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Log out

Welcome Risk Factors Mammography

Values Clarification Summary Final Questions

Progress bar: []

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Has Your Thinking Changed?

Are you planning to have a mammogram in the next 1 or 2 years?

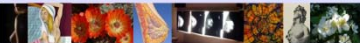
Definitely yes
 Probably yes
 Undecided
 Probably no
 Definitely no

Progress bar: []

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Log out



What You Consider When Making a Choice About Screening Mammography

Again, please respond *Yes, Unsure, or No* to each of the following questions.

Do you know what mammography screening options are available to you?

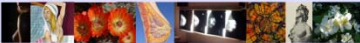
Do you know the benefits of each option?

Are you clear about which benefits matter most to you?

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What You Consider When Making a Choice About Screening Mammography (cont)

Again, please respond *Yes, Unsure, or No* to each of the following questions.

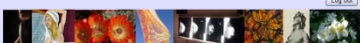
Do you know the risks and side effects of each option?

Are you clear about which risks and side effects matter most to you?

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What You Consider When Making a Choice About Screening Mammography (cont)

Please respond *Yes, Unsure, or No* to each of the following questions.

Do you have enough support from others to make a choice?

Are you choosing without pressure from others?

Do you have enough advice to make a choice?

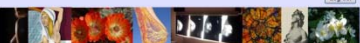
Are you clear about the best choice for you?

Do you feel sure about what to choose?

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Are You Worried?

How do you feel about your risk of breast cancer?

- Very worried
- A little worried
- Undecided
- Not worried


How do you rate your overall health?

- I am in good health
- My health is okay
- I am in poor health

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Preventive Measures

Do you have a breast exam with a health professional as part of your regular health check-up?

- Yes
- No

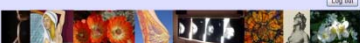
Do you limit alcohol to less than 1 drink each day?

- Yes
- No

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Other Screening

When was the last time you had a PAP smear?

- Less than a year ago
- Between 1 and 3 years ago
- More than 3 years ago
- Never
- Unsure

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Weight and Exercise

Do you have a healthy body weight?

Yes
 No

Do you do moderate exercise for at least 30 minutes on most days (Examples of moderate exercise are brisk walking or swimming)?

Yes
 No

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What Have I Learned?

On a scale of 1 to 10, with 1 being the lowest and 10 being the highest, how much new information did you learn from participating in this program?

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General Life Outlook

When it comes to handling problems in general, where would you place yourself on the scale below?

Are you proactive and more likely to face problems early on? Or are you a procrastinator - someone who likes to wait until the last possible moment?

Proactive Face Problems Early On Procrastinator Wait Until the Last Moment

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Someone with Breast Cancer

I know someone who has or had breast cancer.

No
 Yes, a family member
 Yes, a friend
 Yes, an acquaintance

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Year of Birth

I was born in:

1960 1967
 1961 1968
 1962 1969
 1963 1970
 1964 1971
 1965 1972
 1966 1973

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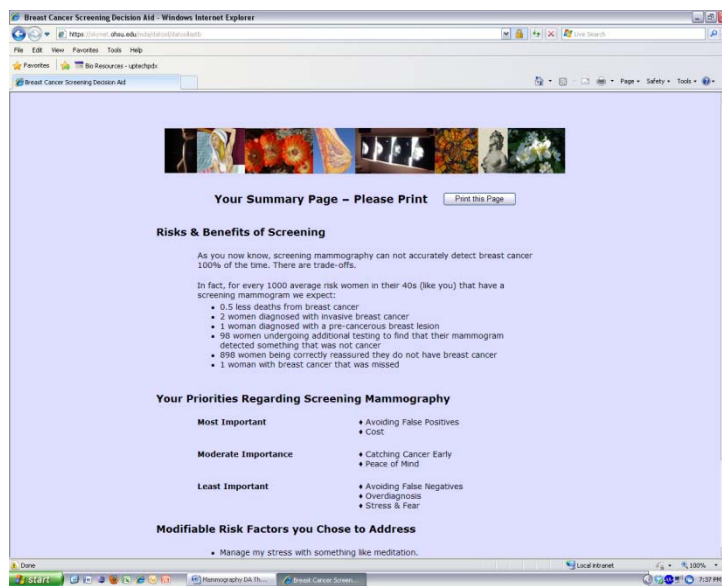
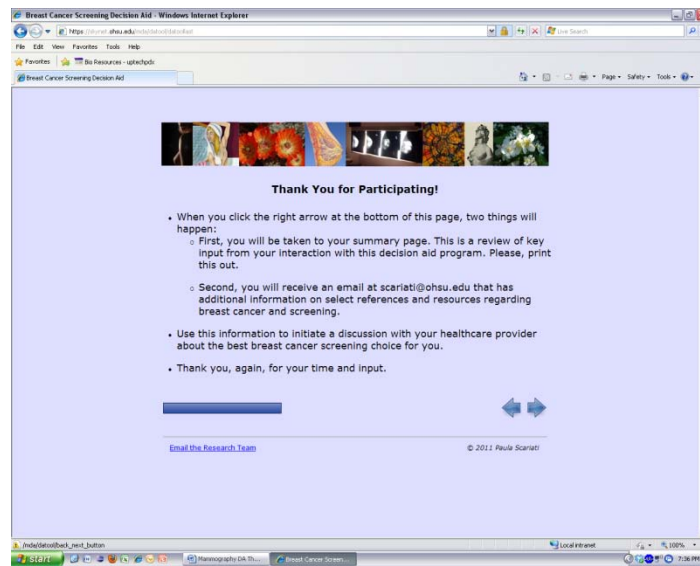
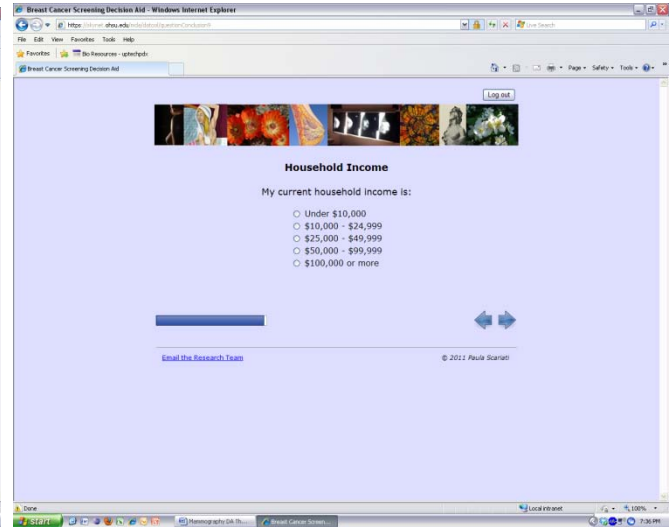
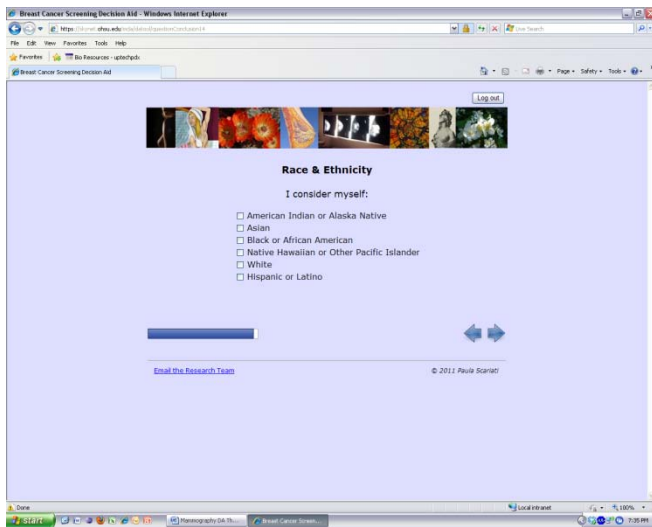
Log out

Education

The highest level of education that I have completed is:

Grade 8 or less
 Some high school
 High school diploma
 Some College
 College degree
 Some graduate school
 Graduate degree

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Alternate Pathway: Ineligible Subjects

Making Choices About Breast Cancer Screening

A Decision Aid for Women Between the Ages of 38 and 48

Please, enter your email address:
Password:

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Introduction

Welcome to our study. We are researchers studying women's health, sources of health information, and choices about breast cancer screening.

We consider you the expert and would like to learn from your experience. By telling us what matters most to you when making a decision about breast cancer screening, we may be able to give you resources that are useful to you and other women.

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Introduction

This decision aid has been designed specifically for women between the ages of 38 and 48 who have an average risk of developing breast cancer. To make sure this program is appropriate for you, we'd like you to tell us a little bit about your personal and family history.

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Personal & Family History

Please check any of the following statements that describe you:

- I have a personal history of breast or ovarian cancer.
- Genetic testing has shown that I, a parent, brother, sister or child have a genetic marker for breast cancer (such as BRCA1 or BRCA2).
- I have a mother, daughter, or sister who has or had breast cancer.
- I have an aunt, niece, or grandmother who has or had breast cancer.
- I have a father, brother, or son who has or had breast cancer.
- I have a blood relative who has or had breast cancer in both breasts.
- I have a blood relative who has or had ovarian cancer.
- I have a history of repeated radiation to the chest between the ages of 10 and 30. (such as required to treat Hodgkin's disease or monitor tuberculosis).
- I currently have signs or symptoms of breast disease (such as pain, skin thickening, nipple discharge, or a change in breast size or shape).
- I am of Ashkenazi Jewish heritage.
- I have none of the above.

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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.

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Thanks for your help!

Any information about your medical history has been deleted from our database.

If you have any further questions please email the research team by clicking [here](#).

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APPENDIX D: RESOURCE SHEETS

Main Pathway: Eligible Subjects

SELECT REFERENCES IN THE MEDICAL LITERATURE

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RESOURCES FOR ADDITIONAL INFORMATION

1. *Your personal healthcare provider*

2. *American Cancer Society*
800-ACS-2345 (800-227-2345)

http://www.cancer.org/asp/contactUs/cus_global.asp

The American Cancer Society (ACS) is a nationwide, community-based health organization that supports cancer research, education, advocacy, and service. To send a question by e-mail, use the form provided on the “Contact Us” page on www.cancer.org. Questions are answered within one to two business days. If you need immediate information, call the toll-free number; calls are answered 24 hours a day, seven days a week. Questions are taken in both English and en Español.

3. *National Cancer Institute*
800-4-CANCER (800-422-6237)

www.cancer.gov/help

The National Cancer Institute (NCI) is a component of the National Institutes of Health and is the federal government’s principal agency for cancer research and training. Call or have a confidential online text chat to get answers about cancer questions from an NCI information specialist. Questions are taken in both English and en Español. Calls are answered 9:00 AM to 4:30 PM ET, Monday through Friday. Online chats are available 9:00 AM to 11:00 PM ET, Monday through Friday.

4. *Susan G. Komen for the Cure*
877-GO-KOMEN (1-877-465-6636)

<http://www5.komen.org/BreastCancer/1877GOKOMEN.html>

Susan G. Komen for the Cure supports breast cancer research and community-based outreach programs. The Breast Care Helpline provides general information about breast health, facts about disease and treatment options, and information about community resources and support groups. Calls are answered 9:00 AM to 7:00 PM EST, Monday through Thursday, and 9:00 AM to 5:00 PM ET on Friday.

Alternate Pathway: Ineligible Subjects

FACTORS THAT MAY INCREASE YOUR RISK OF DEVELOPING BREAST CANCER

Personal Factors:

1. A history of breast or ovarian cancer.
2. A history of a genetic marker for breast cancer (for example, BRCA1 or BRCA 2)
3. A history of repeated radiation to the chest between the ages of 10 and 30 (such as that required to treat *Hodgkin's Disease* or monitor *tuberculosis*).
4. Current signs or symptoms of breast disease (such as pain, skin thickening, nipple discharge, or a change in breast size or shape).

Family Factors:

1. Having 2 first degree* relatives who have or had breast cancer – one of them before the age of 50.
2. Having 3 or more first* or second* degree relatives who have or had breast cancer at any age.
3. Having a first degree (second ..??) relative who has or had breast cancer in both breasts.
4. Having 2 or more first* or second* degree relatives who have or had ovarian cancer at any age.
5. Having a male relative (father, brother or son) who has or had breast cancer.
6. Being of Ashkenazi Jewish heritage and having 1 -first* degree or 2-second* degree relatives who have or had either breast or ovarian cancer.

***First Degree Relative = mother, sister, daughter**

***Second Degree Relative = grandmother, aunt, cousin**

Source: Amir E, Freedman OC, Seruga B, Evans DG. Assessing Women at High Risk of Breast Cancer: A Review of Risk Assessment Models. *JNCI* May 19, 2010, Vol 102, Issue 10, pages 680-691.

SELECT RESOURCES FOR ADDITIONAL INFORMATION

1. *Your personal healthcare provider*

2. *American Cancer Society*

800-ACS-2345 (800-227-2345)

http://www.cancer.org/asp/contactUs/cus_global.asp

The American Cancer Society (ACS) is a nationwide, community-based health organization that supports cancer research, education, advocacy, and service. To send a question by e-mail, use the form provided on the “Contact Us” page on www.cancer.org. Questions are answered within one to two business days. If you need immediate information, call the toll-free number; calls are answered 24 hours a day, seven days a week. Questions are taken in both English and en Español.

3. *National Cancer Institute*

800-4-CANCER (800-422-6237)

www.cancer.gov/help

The National Cancer Institute (NCI) is a component of the National Institutes of Health and is the federal government’s principal agency for cancer research and training. Call or have a confidential online text chat to get answers about cancer questions from an NCI information specialist. Questions are taken in both English and en Español. Calls are answered 9:00 AM to 4:30 PM ET, Monday through Friday. Online chats are available 9:00 AM to 11:00 PM ET, Monday through Friday.

4. *Susan G. Komen for the Cure*

877-GO-KOMEN (1-877-465-6636)

<http://www5.komen.org/BreastCancer/1877GOKOMEN.html>

Susan G. Komen for the Cure supports breast cancer research and community-based outreach programs. The Breast Care Helpline provides general information about breast health, facts about disease and treatment options, and information about community resources and support groups. Calls are answered 9:00 AM to 7:00 PM EST, Monday through Thursday, and 9:00 AM to 5:00 PM ET on Friday.

APPENDIX E: FEEDBACK FROM ROUND TWO USABILITY TESTING

- *I thought it was a bit confusing. Too many leading in questions.*
- *Redundant questions. Also, if it's addressed in the informed consent, don't restate it in a separate slide.*
- *Can it (results) be printed out to take to an appointment?*
- *From a public health perspective I question the value compared to other areas where we can be spending money i.e. nutrition awareness, exercise programs, etc.*
- *My wife and I discussed this in depth. We would've liked to read more about the effect that breast feeding has on cancer risk. Another thing that might be helpful is to include some good breast cancer info links at the end of the aid.*
- *Include something about how health is ultimately the responsibility of the individual. There are many things women can do to mitigate their risk of breast cancer. If one fails to make healthy decisions or to seek knowledge about their health then they are putting more of a burden on their families, physicians, community, etc.*
- *It was way more engaging than just a pamphlet or a sound byte. Frankly, I would like to post this on our Facebook page to see what kind of responses we would get from our female friends. It's an engaging tool.*
- *(Re: Items not answered honestly if now doctor will see.) I think the questions about alcohol are always tricky. This is particularly relevant if the patient is taking some sort of pain medication and doesn't want the provider to know about their alcohol consumption.*
- *It was instructive that the relative risk for my age group is pretty low; makes me not worry so much about screening until ~ age 50 or so. However, I have pretty good coverage and would not lightly forego the opportunity for a screening every two years, as the tutorial also indicated that radiation cumulative is mitigated with this strategy, when compared to an annual mammogram.*
- *Interestingly as well, I was told my breast tissue is dense, and therefore a digital mammogram would be better; I had always assumed this meant more accurate. Now I have a better understanding that its value is enabling the reviewer to "zoom in " on spots of interest.*
- *(RE: Things to exclude) I wrote down three things that caught my attention; not sure I'd exclude them per se, but wanted to share my thoughts/reactions to each:*

1. *The word choice about “have you ever had a “positive” . . . (mammo that turned out to be negative) made me feel “backed into a corner” when trying to answer. When deciding how best to answer, I erred on the side of “no” because technically I was never told that my mammo was “positive.” However, if you are interested in learning if the respondent has ever been called back for further screening, or another look, perhaps you could “broaden” that question a bit. Having dense breast tissue, I was called back several times for another look; yet the staff were always very cautious about the wording . . . they explained in great detail that the radiologist wanted another image from a different angle or whatever and made it clear that it was not an indication of anything abnormal or cause for worry at the time.*
2. *The sliding scale exercise: this came after the tutorial about radiation risk and differences in how the disease progresses more slowly in an older woman than a younger woman. So I was hesitant to choose a side of the scale. Should I “prefer” catching it early, even though at my age cancer would progress more slowly (leading me to believe that I could afford to wait longer for a screening) or should I err on the side of minimizing radiation exposure? It kind of felt more like a “test question” than a preference question.*
3. *The most disturbing part for me was the last bullet on the “risk factor” screen. After having emphasized risk factors I’m familiar with (age, exercise, weight, smoking, alcohol consumption, etc.), I was stunned to read, “Most women who have breast cancer have none of these risk factors.” It makes me feel as though the label “major” should not be used with any of these alleged risk factors. It would be more helpful to characterize the disease as MOSTLY not associated with any particular set of risk factors, with an indicator of how frequent these so-called “major” risk factors are present in breast cancer patients.*
 - *More false positives and higher number needed to screen to avoid one death than I thought.*
 - *Condense the intro a bit. Avoid redundancy where possible to make this a 20-30 minute process. People might start to tune out or really absorb if it’s too wordy or lengthy.*
 - *More than enough information. It might have been useful if the values assessment would go on to suggest where you ultimately fall in terms of proceeding with screening but that might open a can of worms about dispensing advice*
 - *Feed back on the values section that might suggest if they are naturally predisposed for or against early screening.*

- *I was surprised about the data relating to the low occurrence of breast cancer in this age range of women*
- *Much of the material was repetitious. I did not count the number of times data was repeated, but it seemed like too much.*
- *(RE: Information on why screening changed) The aid appeared absent of data supporting screening mammograms for women aged 38-48. What data was the old recommendation based on? What new information has come to light that has caused the recommendation to change?*
- *The question about cup size was distasteful, primarily because it didn't appear linked to any of the rest of the material. If there is a connection between breast density and cup size, that should have been discussed in the decision aid, and would have made the question seem more appropriate.*
- *Although the decision aid was consistent in its language to encourage women to discuss this decision with their healthcare provider, the data seemed biased towards discouraging a screening mammography in women in this age group.*
- *The decision aid is fairly clear that age is the greatest risk factor in this age category. If I were going to discuss anything, it would be those modifiable factors I identified. The tool would be more useful by making a stronger connection between those modifiable behaviors and other/additional diagnosis I could reduce my risk of by modifying those behaviors.*
- *(RE: Would not recommend to a friend because) I learned that age was the primary risk factor, I wouldn't propose spending 30-45 minutes to figure that out.*
- *Because I have recently begun getting mammograms, I felt that it solidified my beliefs*
- *I was confused by the questions that asked about "the screening options available", I was waiting to read about different types of mammograms*
- *(RE: Additional Information would like to see) Include info on the different types of options available*
- *However, some the questions were asked after the "facts" were presented, possibly causing the patient to regurgitate what they just read*
- *(RE: Would recommend to a friend because) If she were weighing her options and decided NOT to get a mammogram, this decision aid might help her pinpoint her obstacles*
- *some women might not be truthful about alcohol intake*
- *It provided useful information in a manner that was understandable.*
- *I feel it address misconceptions and provides useful information in a simple and intuitive manner. Most woman would find it informative and helpful.*

- *Typo → the word vegetable is misspelled.*
- *I was really unaware of the over diagnosis situation.*
- *I don't understand why at the very end it asks your bra size. Maybe if there was an explanation as to why it was being asked it would be more relevant to the user of the decision of the model.*
- *Maybe a comparison of physical breast exams vs. mammograms would have been helpful.*
- *I was a little put off when it asked my bra size at the end.*
- *It wasn't much different than any other survey a person might be involved with.*
- *I think getting a summary email is a good idea. That way the person can print of the summary and take it with them to a doctor's appt or they can access it from their smart phone.*
- *I think people sometimes just do as they are told or don't do anything at all out of fear, but having some good facts can really help someone make a good decision for themselves.*
- *I did not realize how much more of a risk women had for breast cancer between the ages of 40 to 60, relative to other cancers/cardiac disease.*
- *Last part on demographics was understandable, but unexpected. Overall, I thought the pace, layout, and language were very clear. I would not leave out anything. However, not sure if women would be completely honest about how much they drink on a daily basis.*
- *Perhaps a range of pricing for mammograms , specific to the area. (ie, Portland vs Seattle, Oregon vs California) It would give me some idea if, after hearing this information, I would be willing to pay for a mammogram out-of-pocket if I did not have coverage.*
- *(RE: making it User Friendly for providers) I would recommend some sample questions to ask. For people not familiar with clinical and medical vocabulary, it may be helpful to hear the wording they should use when approaching their care provider.*
- *There is some great information, especially the diagrams and graphs which help to put the screening mammography decision in context of other health behaviors/decisions.*
- *(RE: Questions a woman wouldn't answer honestly) As stated above, I don't know if there would be an honest answer to the amount of daily drinking.*
- *(From an MD) I like that the decision aid does a good job of showing that screening and medicine in general is not infallible. I think more decision aids like this deployed in doctor's offices would go a long way toward helping patients understand their options better.*
- *Informed me that there was little value to having a mammography but encouraged it.*
- *The decision aid seemed to drive the user to go for early mammography even though the evidence was not firm that the testing was of great benefit.*

- *Is there any way to navigate back to different sections? I became confused when asked about the different options at the end and needed to go back to the section that explained it but clicking on the back arrow was time consuming so I gave up.*
- *What matters most to me? Slide – avoiding false negatives does not fit in box. The pop up dialogs when moving boxes is annoying. Any way to attach definitions to this page for the categories? It is hard to remember what each one means and some are confusing. Are these based upon the definitions provided in the earlier slides? You can move boxes on top of each other and the bottom box will be covered up.*
- *Email the research team – should take you to a web form. This opens whatever default client you have for email. Could be insecure if the study recipient does not have secure email. Any response to the recipient should be encrypted if it contains PHI.*
- *(I would not recommend this to a friend because ...) It does not provide clear options for alternatives to mammography. If the mammography option had a high success rate then I would point the individual to it but as is the study appears biased toward overuse of the testing option which raises health care costs with little benefit.*
- *This study information should be independent of the medical record and available through the organizational web site, not linked to health information. If the assessment was to be used for treatment purposes and decision making of the provider then it would need to be integrated into the medical record. If not, it should remain separate from the medical record.*
- *This information could be defined as part of the legal medical record and potentially used as part of malpractice case.*
- *Decreased concern about radiation exposure. Made me think about fewer mammos in 40's and wait until 50's to really ramp up.*
- *Maybe just a little more info about the mammo: how long it takes, timing, etc. I know most places now will obtain further imaging same day and get a biopsy done within a few days.*
- *Including some online resources for the high risk patients would be nice. Once they are kicked out of the system, I am thinking that they are highly anxious and might benefit from a referral to a CDC or Komen website... something like that.*
- *(RE: Yes would refer to a friend) It appears very thoughtful and uses understandable language. It guides one through making a decision without bias, allowing a person to really explore their own feelings about the mammo.*
- *I was a bit surprised that only 1 in 69 women would develop breast cancer in the next ten years. The odds seemed lower than I expected.*

- *There was a lot of information and it was hard to take it all in. It was a bit overwhelming. I wonder if there is a better way to present it.*
- *As mentioned previously, the actual decision aid contained a lot of information. However, the screen that takes you out of the Decision Aid if you have an above average risk did not have any resources at all. I felt like these are the women who really need to know some background information on breast cancer. Perhaps providing some links to information would make these folks feel less helpless.*
- *I think it can be difficult for people to actually formulate questions to ask their doctor, even with information in hand. Perhaps there needs to be a screen that offers sample questions.*
- *I am not sure if I would recommend any decision aid to a friend. I tend to not say anything about other people's health. I would probably recommend this decision aid to a family member, though. I think it contains a lot of good information and weighs the risks versus benefits of being tested.*

APPENDIX F: EMAIL INVITATION TO SUBJECT MATTER & CLINICAL EXPERTS

Dear Dr. {Name},

Would you be willing to evaluate a web-based breast cancer screening decision aid that my team and I have developed? The tool has been designed specifically for average risk women in their late 30s and 40s who are considering whether to have a screening mammogram.

About Me: I am a post-doctoral NLM Fellow in Biomedical Informatics at Oregon Health & Science University (OHSU).

About the Project: As part of the 2009 updated mammography screening guidelines the USPSTF stated:

“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”.

This project was developed in response to that recommendation.

How You Fit In: We've just completed the last phase of usability testing and are now seeking feedback from three different groups: (1) policy makers, (2) clinicians, and (3) age and risk appropriate end users. We believe that evaluating and incorporating the perspective of these 3 voices will allow us to improve the value and effectiveness of this tool in clinical settings.

Time Requirement: 60-70 minutes

Task: You will log into the decision aid which can be accessed from any computer. iPads are not a supported platform. After completing a test run of the decision aid (between 30 and 40 minutes) we will discuss a series of questions by phone about the strengths and weaknesses of the tool (anticipate 30 minutes). You will have a list of those questions before you access the decision aid.

Warning: During usability testing, experts using the tool spent more time providing feedback than we anticipated. Let's just say they share our passion for creating the best resource possible for women!

Funding: This project reflects the bootstrap efforts of two OHSU masters' students with no funding from any grant, organization or foundation.

If you are willing to contribute your time and subject matter expertise, please respond to this email and we will follow-up with you promptly.

Sincerely,

Paula Scariati

Paula Scariati, DO, MPH, ABIHM, FACPM

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APPENDIX G: STUDY PARTICIPATION INSTRUCTIONS FOR AGE-RISK APPROPRIATE WOMEN

Hello and thank you for volunteering to participate in our decision making study. This survey is meant for women between the ages of 38 and 48 who have no known risk factors for breast cancer.

HERE'S HOW YOU GET IN:

Go To: <https://skynet.ohsu.edu/mda>

Your User Name: Is your email address – the one you are receiving this message at ([name@xxxxx.xxx](#)).

Your Password: [abcd1234](#)

****Please, do not share your username or password with anyone else. If you know someone who is interested in the Decision Aid, just have them email us at mammographyda@ohsu.edu and we'll be happy to set-up access for them.**

Note: The decision aid supports most browsers (i.e., Firefox, Internet Explorer) but is not configured to work on an iPad. Also, several people have told us that the tool responds slowly on certain WIFI connections (i.e., Verizon).

THEN WHAT?

Password: Please, change your password when prompted to do so. Your username and this new password will be valid for 7 days.

Questions & Prompts: The rest of the tool is self explanatory.

Eligible women completing the survey will receive a \$15.00 Starbucks Card eGift by email as a token of our appreciation.

HAVE WE FORGOTTEN ANYTHING?

We hope not. But, if you have any questions, feel free to send us an email.

Thanks again for helping us make this the best tool possible for women in their 40s seeking information about screening mammography.

Paula