# Qualitative Analysis : Making choices about breast cancer screening

Qualitative Analysis

Making choices about breast cancer screening

Capstone Project Report

By

Latha R Kalaga

Presented to the Department of Medical Informatics & Clinical Epidemiology and

the

Oregon Health & Science University

School of Medicine

In partial fulfillment of the requirements for the degree of

Master of Biomedical Informatics

March 2013

School of Medicine

Oregon Health & Science University

_____

**CERTIFICATE OF APPROVAL**

_____

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

**Latha R. Kalaga**

Qualitative Analysis: Making choices about breast screening

Has been approved

_____

Karen Eden, Ph.D., Associate Professor

# Table of Contents

# Acknowledgements

I would like to thank Dr. Paul Gorman, my advisor, for introducing me to Dr. Karen Eden who was working on a project that caught my interest. Thanks to Dr. Karen Eden who took the time to discuss multiple capstone projects with me. After the discussions Dr.Eden and I decided that the qualitative analysis of a Breast Cancer Screening Decision Aid developed by Dr. Paula Scariati, DO, MPH would be a good fit. Thanks to Dr. Scariati for taking the time to explain her thesis work and providing me with data for the qualitative analysis. When starting on this project I had no idea how to conduct a qualitative analysis. Thanks to Dr. Erika Cottrell for helping me understand qualitative analysis and then providing qualitative analysis software, reading material and time taken for conference calls to think through the data and the plan of the project. Thanks to Lindsey Watson, who interned for Dr. Eden and was my partner in coding the interviews. I would not be doing a good job if I do not thank Diane Doctor, Educational Programs coordinator at DMICE who always responded to questions regarding the program and helped with the next steps on any course work. But for her I would be lost trying to juggle my job and keeping the course work straight. Last but not the least thanks to OHSU and the Department of Medical Informatics and Clinical Epidemiology for all the support given to the students. Dr.Scariati in her acknowledgements of her thesis report states "I firmly believe that when a project is meant to happen the stars come into alignment" – I am a firm believer of this statement as well. The stars aligned for me as my qualitative analysis of the Decision Aid was meant to happen, the stars being my teammates, my mentors and my advisors.

# Abstract

## Objective:

The objective was to perform a qualitative analysis of data collected by Dr. Paula Scariati, DO MPH who as part of her thesis work designed and tested a Decision Aid to facilitate decision-making about mammography screening for women ages 38-48. Dr. Scariati, conducted semi-structured interviews of five clinical experts and five subject matter experts.
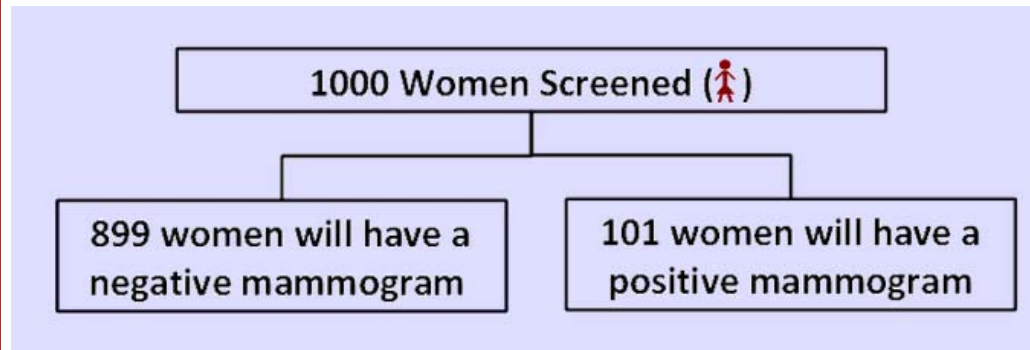
## Methods:

This qualitative study analyzed transcripts from the semi-structured interviews to find recurrent themes. Two coders analyzed the transcripts individually and then group consensus coding sessions helped derive the results of the analysis.

## Results:

The coders of the interviews reached a group coding interreliability > 80% across all themes. There were approximated 21 main themes across 163 total nVivo nodes. The qualitative analysis found that the information presented by the Decision Aid was higher than an eight-grade reading level. The time taken to go through the questions asked by the Decision Aid was too long. The semi-structured interviews also revealed that numerical data presented in the Decision Aid had to be simplified and explained in simpler terms with regards to the outcome. For example in the flow chart shown below the words "Negative mammogram" and "Positive mammogram" had to be explained as "tests that indicate that you may not have" or tests that indicate that you may have" the disease.

```
                    1000 Women Screened ( )

    899 women will have a          101 women will have a
    negative mammogram             positive mammogram
```

All the interviewees agreed that the Decision Aid would be a very useful tool to help women make informed decisions about their breast health and that the Decision Aid had to be made easily accessible.

## Conclusion:

Nine out of ten of the interviewees said that they would recommend the Decision Aid to their patients and friends.

Dr. Paula Scariati, DO, MPH developed a web-based Breast Cancer Screening Decision-Making Aid as part of her Masters thesis project [1]. This Breast Cancer Screening Decision Aid (Decision Aid) was developed to help women between the ages of 38 – 48 years with an average risk of breast cancer make an informed decision about when to start screening. This Decision Aid was presented to 51 age and risk appropriate women. It was also presented to 5 clinical experts and 5 subject matter experts. Dr. Scariati interviewed these clinical and subject matter experts via phone.

This project performs a qualitative analysis of the interview data collected by Dr. Scariati. This analysis will help facilitate an understanding of strengths and weaknesses of the Decision Aid. The qualitative data analysis will provide preliminary data for applying for grants to improve the Decision Aid. Currently there are no known Decision Aids that help women make more informed choices about when to begin breast cancer screening. Decision Aids such as the one being analyzed will allow women to actively participate in informed decision-making.

# Introduction

The Breast Cancer Decision Aid was tested in a convenience sample of 51, age, risk-appropriate women to provide a preliminary assessment of the impact of the Decision Aid on screening choices and decision conflict. This work was analyzed and presented in her thesis [1]. Dr. Scariati also conducted semi-structured interviews of five clinical experts and five subject matter experts. These experts used the Decision Aid and provided critical reviews of the aid. The transcripts of these interviews were qualitatively analyzed in this capstone project. The results of the qualitative analysis will be used to improve the Decision Aid.

# Methods

Qualitative modes of data analysis provide ways of discerning, examining, comparing, contrasting, and interpreting meaningful patterns or themes. [2] Qualitative analysis involves the iterative analysis of interviews and coding these interviews into codes or themes. A **Code** in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data. [3]

The Decision Aid was presented to ten individuals. Five of them were clinicians and five of them were subject matter experts. Feedback from these experts and clinicians was obtained through semi-structured interviews. The transcribed interviews were given to the team that conducted the qualitative analysis of these interviews.  Two coders coded the interviews with different approaches. One coder initially coded the interviews using the questions in Appendix I as the main nodes. The second coder coded by over arching themes and used the themes as nodes. After coding two interviews, a themes list or code list was put together, Appendix II.

These were entered into the software, nVivo [4] by the individual coders. The coders added additional themes as required. Each interview was read, coded and additional themes were added. The final step was the to review the themes identified by the coders for consistency. Consistent themes for changes that had to be made to improve the Breast Cancer Screening Decision Aid were identified in the analysis. In qualitative analysis, regardless of the approach taken to code the interviews by revising the code book and the themes, the coders usually end up with almost similar outcomes. **Intercoder reliability** (often called interrater reliability and sometimes interjudge reliability) in content analysis is the extent to which two or more independent coders agree on the coding of the content of interest with an application of the same *coding scheme*. [5] The rule of thumb in qualitative analysis is to achieve 80% intercoder reliability. In the analysis of the data collected the coders achieved greater than 80% intercoder reliability. The results were tabulated in both a verbal form and in the form of screen captures to help understand the changes that were required to be made in the Decision Aid.

## Fig 1.Individual Coding

Coding in Qualitative analysis is an iterative process. The Coder reads the interview transcript (in the case of this capstone the transcript from the 10 semi-structured interviews) and analyzes the interview for codes or recurring themes. An example of a theme or code would be Decision Aid – Usability. Under this node all information the interviewees expressed about the Decision Aid's usability will be entered.   In case this theme was not discovered earlier then a new node is created in nVivo to represent this theme.

Read and analyze transcribed interviews

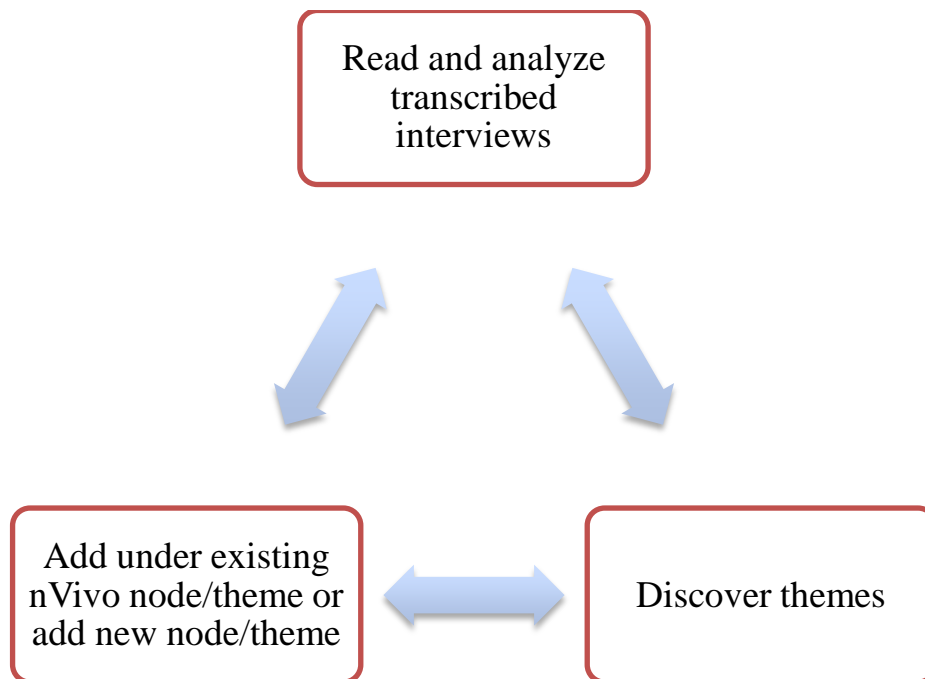Add under existing nVivo node/theme or add new node/theme
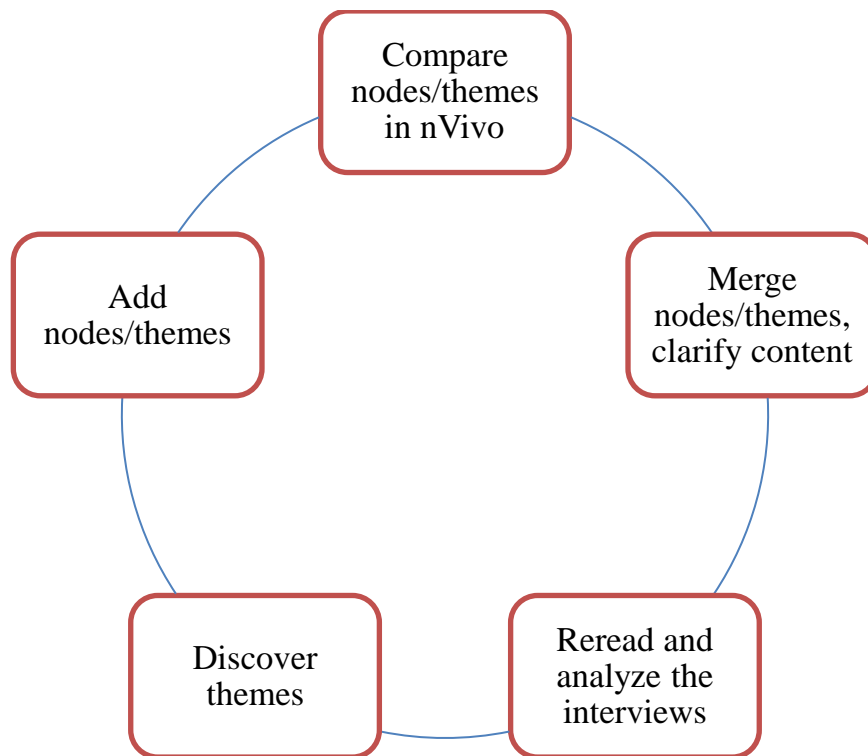
Discover themes

## Fig 2. Group Coding

Group coding is an iterative process where the coders compare the nodes/themes entered individually in nVivo. If there are themes that are similar but differently worded, the nodes are merged. If content under a node/theme is unclear, the content is clarified. The coders than reread the interviews to discover any themes that might have been missed and add new themes/nodes. The coders compare the themes to derive the intercoder reliability.

Compare nodes/themes in nVivo

Merge nodes/themes, clarify content

Reread and analyze the interviews

Discover themes

Add nodes/themes

# Results

Each of the interviewees answered ten questions (Appendix I). These questions were expected to illicit answers that would help improve the Breast Cancer Screening Decision Aid and to determine additions and changes that needed to be made to the Decision Aid. The semi-structured interviews were analyzed and grouped under over arching themes or nodes. The qualitative analysis reached an intercoder reliability > 80% across approximately 21 themes. The 21main themes were identified from 163 total nodes(Appendix II). The results of this analysis are shown in the tables below:

*What the Decision aid does really well:*

| Graphics | Nice use of graphics to present complex numerical information |
|---|---|
| Existing notions | The Decision Aid does not change the existing notions about breast cancer or the screening procedures. |
| Offensive | The Decision Aid was not offensive to the users. |

*Suggested changes:*

| Time to use the Decision Aid | Current: Needed more than 20 minutes to answer the questions posed by the Decision Aid.<br>Change: Keep the length of the Decision Aid to 20 minutes.<br>Note: All the subject matter experts and clinicians interviewed expressed that the Decision Aid was too long. |
|---|---|
| Education level of users | Current: Requires user to have at least a college level education to be able to understand and answer the Decision Aid questions.<br>Change: Use simpler language to explain concepts and get the point across to the user.<br>Flow charts and bulleted list hard to comprehend. |
| Radiation Risks | Current: Risk of radiation listed as a risk<br>Change: Risk of radiation a non issue, explain that the risk is low and base the information on latest research if any. |
| Over diagnosis | Current: Slides on over diagnosis are very difficult to understand and could be confused with population risk. The calculation is very complex. The Decision Aid spends too much |

| | |
|---|---|
| | time on the topic of over diagnosis.<br>Change: Find a simpler way to explain over diagnosis. |
| Output | 1.Display resources first and references last<br>2. Frame output in a more colloquial manner<br>3. Offer printable informational documents |
| Tree diagrams | Current: Tree diagrams are too complex to understand for ordinary users<br>Change: Add text to the tree diagrams. |
| Word smithing | 1. Change the terms positive and negative results with phrases like "tests that suggest you might have" or "results that reassure you that you probably don't".<br>2. Summary page – change the word digest.<br>3. Clarify biopsy technique.<br>4. Clarify prior negative biopsy risk.<br>5. Define breast density.<br>6. Define mammography options.(Appendix III g)<br>7. Define mature tools.(Appendix III i)<br>8. Define values clarification.<br>9. Define population risk.<br>10. 1.44 percent in one figure is a very abstract concept for people to understand. The second decimal place does not make much of a difference to people.<br>11. Too much text on a page |
| Layout | 1. Add mouse overs, hyperlinks or pop ups to clarify terms.<br>2. Bulleted lists are off-putting.<br>3. Change asterisk style on "family factors"<br>4. Design could be more aesthetically pleasing, seek user interface designer guidance.<br>5. Keep forward arrow in the same position(Appendix III a) on each screen.<br>6. Organization and timing slide: change side-by-side list to vertical.<br>7. Organization and timing slide: example bar percentage bar is confusing.<br>8. Present 1 in 69 graphic before 1.44 probability. Put graphics before calculations to help user understand better.<br>9. Present objective and outline at the beginning of the Decision Aid<br>10. Graphics are pretty simple and pretty dull. There is a lot more that can be done artistically to improve the appearance and make it more interesting. Consult someone with a graphical sense to make it more |

| | |
|---|---|
| | interesting. |
| Sensitivity to ineligible women | 1. Provide link to resources.<br>2. Provide risk factor information to ineligible women. |
| Risk factors | 1. Define one drink.<br>2. Delayed parity is also a risk.<br>3. Put risks in context of other screenings. |
| General content changes | 1. Disclose age of literature.<br>2. Explain average risk.<br>3. Income question – add a "prefer not to answer option".<br>4. Pap screen question – "add irrelevant option". |
| Unanswered questions | Question in slide "who should be screened" is unanswered in the Decision Aid |

*General recommendations*

| | |
|---|---|
| Access | Allow access to the Decision Aid at the doctor's office, as an independent web based interface, as part of the personal health record.<br>Note: Privacy and security is very important in all forms of access to the decision aid. |
| Stake holder buy in | -Work with insurance companies like Aetna.<br>-Attend grand rounds and clinician meetings.<br>-Work with Kaiser Permanente.<br>Foundation for Informed Medical Decision Making (FMDM)(Subject matter expert 3).<br>- Advocacy organizations that are considered to be authoritative in the area of breast cancer advocacy.<br>- Posters in doctor's office. (Clinician 4)<br>- Getting provider buy-in by showing them the value of using the decision aid.<br>- Work with Chick Kilo (CMO) who is working with Heidi Nelson on screening guidelines.<br>- Do not put it in Wal-mart pharmacies or similar public places as one runs the risk of too many people being offended just by seeing the word breast when they are in public. |

Some of the specific statements made by the experts are listed below:

*Stake holder buy-in recommendations*

- Subject matter expert 2:Physicians & Providers – ".  I think that the physicians or

15

providers that are currently just saying, "I recommend a mammogram. Do you wanna have one?" Okay. Then it probably would slow them down. But I think if you really want your patient to be educated and then this should replace the time that you would typically spend explaining all of these things to patients. So it should actually improve I guess your timing in dealing with the patient."

- Clinician 4: "Well, what I would do, I would put a big sign in the office, a big poster in the office so everybody becomes aware that mammography screening is something that is in place, and it helps women. And second, that there is a tool that can be accessed in the privacy your own home, and that obviously allows you to understand your own matter better so you can have a discussion with a physician."

- Subject Matter Expert 5: You have a decision aid that is highly discouraging of getting a mammogram before age 50…that will limit its acceptance. [Third,] the decision aid clashes with today's insurance coverage and federal requirements under the Affordable Care act. Congress essentially nullified the 2009 guidelines in favor of the 2002 guidelines…that was unfortunate, since their motivations were based on sentiment and public opinion, but there is no discussion in your decision aid about the controversy. This has been the approach of the US Preventive Services Task Force as well, essentially, "we're evidence based, everyone else isn't (or is less so), and so you should just take a deep breath and adjust to the new thinking about screening before age 50." Probably addressing the controversial issues is not as easy as it may seem, but I suspect if you asked women if they feel they should be made aware of differing interpretations of the data, they would say "yes."

***Length of the Decision aid:***

- Subject Matter Expert 1: "I think it's long, I think it's long and I think it's too long.

- Subject Matter Expert 5: "First, I think it takes too much time. Do what you can to streamline the information.

*Content:*

- Confusing calculations with 1000 women – Subject matter expert 2 said this – "Yeah, I know.  This is why – I mean, I get confused, too.  I'm getting confused, too.  That's why I think it's a little bit tricky when that 1,000 number keeps coming up in multiple places 'cause I think in some cases you're talking about a different – you're talking about 1,000 women over ten years being screened, and then –in that algorithm section where it talks about the outcome of your mammogram, that would actually be in one screening cycle because it should be like ten percent of the screens are positive, and then of those, ten percent are biopsied, approximately, which is basically how your numbers play out "

## Conclusion

The qualitative analysis of the transcribed interviews of the five clinicians and five subject matter experts concluded that 9 out of the 10 interviewees would recommend the Decision Aid to their patients and friends. All of them strongly felt that the language in the Decision Aid had to be simplified so it could help women with an 8th grade education make better decisions about their Breast health.

# Appendix I

Mammography Decision Aid Feedback

1.  Did you find the exit path for ineligible women to be sensitive and supportive of further follow-up?
    - o  Yes
    - o  No

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?
    - o  No
    - o  Yes
6.  Was the information in the Decision Aid presented in a *biased* or *unbalanced* fashion?
    - o  No
    - o  Yes
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 or patient?
    - o  No
    - o  Yes
9.  What would be the ideal way for a woman to access this Decision Aid?
    - o  Through her personal health record.
    - o  Through a web-based interface independent of her personal or medical record.
    - o  Through a computer system in her doctor's waiting room
    - o  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?
    - o  No
    - o  Yes
12. Did you feel that the Decision Aid pushes a woman to have or not have a mammogram?
    - o  Yes, I feel it pushes a woman *to have* a mammogram.
    - o  Yes, I feel it pushes a woman *not to have* a mammogram.
    - o  No, I don't feel it pushes a woman in one direction or the other.

# Appendix II
Themes used in Group coding

1. Access

2. Add testimonials

3. Buy in from stakeholders

4. Certification

5. Challenge existing notions

6. Changes to output

7. Content Add

8. Content changes

9. Content exclude

10. DA(Decision Aid) -Biased or unbalanced

11. DA- Offensive or distasteful

12. DA-Usability

13. DA-Pushes to screen or not to screen

14. DA-Usability

15. Layout

16. Positive feedback

17. Questions women won't answer truthfully

18. Recommend to others

19. Risks vs benefits

20. Sensitivity to ineligible women

21. Browser compatibility

# Appendix III

a. Lengths of the pages seem to vary, causing the illusion that the bottom arrows are at a different spot each time. This can get weary on the eyes. Keeping page length the same may be a good option.
b. Change the combo box to radio buttons Yes, Unsure or No



**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? [Select ▲▼]
Do you know the benefits of each option? [Select ▲▼]
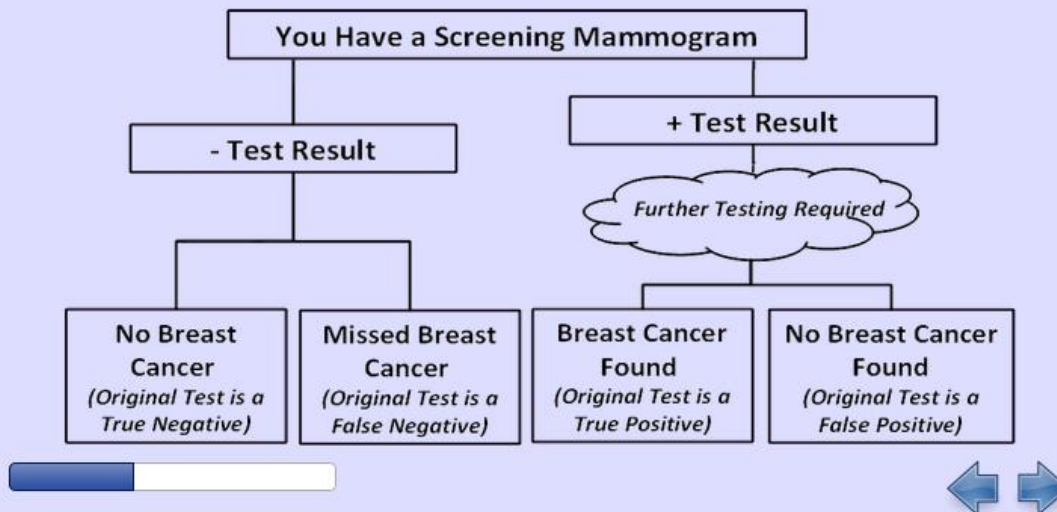Are you clear about which benefits matter most to you? [Select ▲▼]
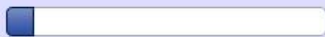
c. Arrows at the bottom are too big
d. In this screen make the options linkable
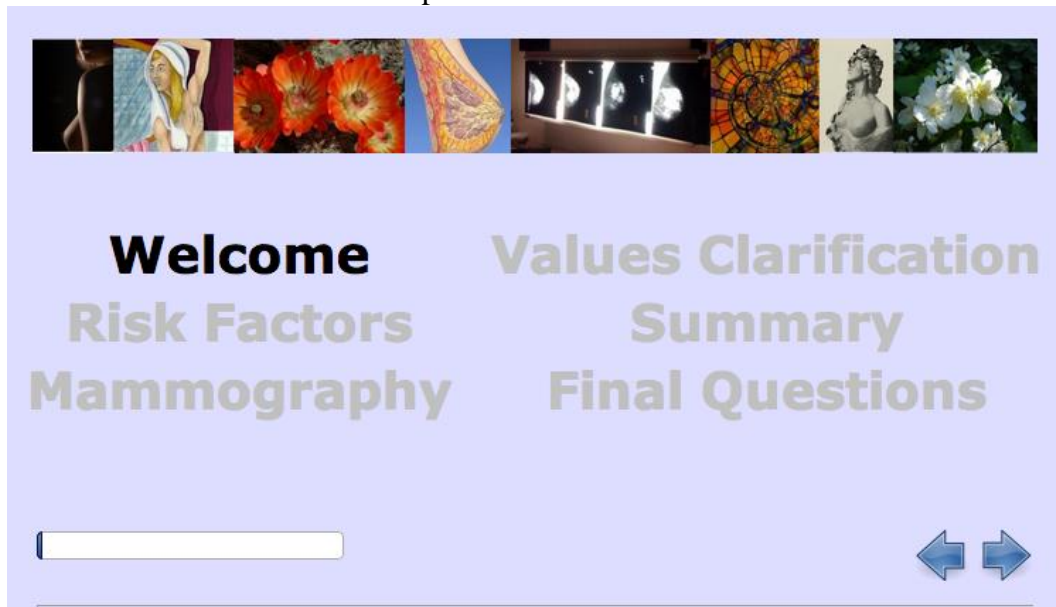


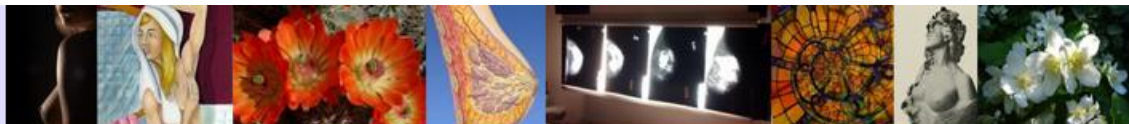e. Explain the terms True Negative , False Negative, True Positive and False Positive
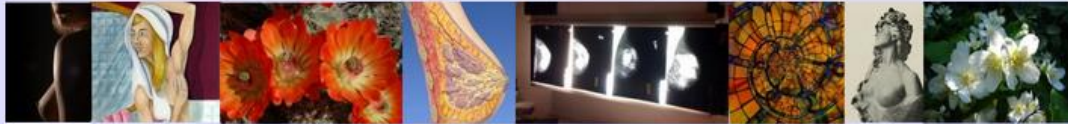
Possible Outcomes of Breast Cancer Screening

f. "Who" should be screened question never answered



Who should be screened?

g. Probability hard concept for people to understand. The second decimal place is not valuable to the audience.
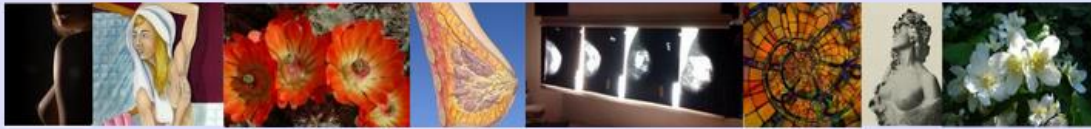


| If your current age is... | For women like you the probability of developing breast cancer in the next 10 years is: | or 1 in: |
|---|---|---|
| 20 | 0.06% | 1760 |
| 30 | 0.44% | 229 |
| 40 | 1.44% | 69 |
| 50 | 2.39% | 42 |
| 60 | 3.40% | 29 |
| 70 | 3.73% | 27 |
| Lifetime Risk | 12.08% | 8 |

h. Mammography screening options What are the possible options? Have one or don't have one?



**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? [Select ÷]
Do you know the benefits of each option? [Select ÷]
Are you clear about which benefits matter most to you? [Select ÷]

i. Explain mature tools

## 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.

j. Change the words "Digest" to summarize or review or process



**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.

# References

[1] Scariati, P. , Making choices about breast cancer screening: A Decision Aid for women between the ages of 38 and 48, Oregon: Oregon Health and sciences university; November 2011

[2] User-friendly hand book for mixed method evaluations [Internet] National science foundation. 1997, August. Available from:

http://www.nsf.gov/pubs/1997/nsf97153/chap_4.htm

[3] Saldana J, The coding manual for qualitative researchers, SAGE Publications, Inc., 2013. Available from: http://www.sagepub.com/upm-data/24614_01_Saldana_Ch_01.pdf

[4] nVivo software - http://www.qsrinternational.com/products_nvivo.aspx

[5] Lavrakas, PJ. *Encyclopedia of Survey Research Methods.* Thousand Oaks, CA: SAGE Publications, Inc., 2008. *SAGE knowledge.* Web. 24 Feb. 2013

# Educational Materials

Pope C, Mays N, Qualitative research in health care. 3rd Edition, BMJ books, 2006

YouTube video on coding - http://www.youtube.com/watch?v=7X7VuQxPfpk&feature=list_related&playnext=1&list=SP14E49EDF20613008