Factors predicting \textit{BRCA1} and \textit{BRCA2} mutation carriers’ preference for communication of risk estimates.

THESIS

Presented in Partial Fulfillment of the Requirements for the Degree Master of Science in the Graduate School of The Ohio State University

By

Sophie Crowdes

Graduate Program in Genetic Counseling

The Ohio State University

2016

Thesis Committee:

Shelly Hovick, PhD, Advisor
Leigha Senter-Jamieson, MS, LGC
Kevin Sweet, MS, LGC
Abstract

Women with hereditary breast and ovarian cancer syndrome (HBOC), caused by mutations in BRCA1 or BRCA2, have increased lifetime risks of certain cancers, including breast and ovarian cancers. Lifetime cancer risks are presented to BRCA mutation carriers during genetic counseling, often with the addition of statistical figures and graphs. This study examines how factors such as demographic characteristics, health numeracy, graph literacy, and HBOC knowledge affect BRCA mutation carriers’ preferences for and understanding of different cancer risk estimate formats, including line graph, bar graph, icon array, and text-only. An anonymous online survey was completed by 82 BRCA mutation carriers that assessed attitudes, comprehension of, and preferences for the cancer risk estimate formats. Participants best understood lifetime cancer risks when presented using the text-only format, but preferred their lifetime cancer risk be presented graphically. The line graph was the most preferred and most easily understood graphical format for presenting lifetime cancer risks. Increased comprehension of the line graph was associated with higher graph literacy (p<.05), while increased comprehension of the bar graph and icon array were associated with higher health numeracy (p<.05). Results suggest that when presented with lifetime cancer risks in genetic counseling, BRCA mutation carriers may benefit most from text and graphic displays, particularly a line or bar graph, to help describe their risks. Line graphs may be more effective for
patients with higher graph literacy, whereas bar graph may be more effective for patients with higher health numeracy.
Acknowledgements

I would like to thank Shelly Hovick for lending her time, wealth of knowledge, and constant encouragement to this project and The Ohio State University Genetic Counseling Program for providing me with the opportunity to pursue my dreams and to gain valuable research experience, as well as for providing partial funding for this project. Additionally, partial funding for this project was provided by the National Society of Genetic Counselors Education Special Interest Group, whom I would like to thank for believing in this project.
Vita

May 2010 ..................................................Blue Springs High School

May 2014 ..........................................................B.S. Biology, The University of Kansas

Fields of Study

Major Field: Genetic Counseling
# Table of Contents

Abstract......................................................................................................................................................... ii

Acknowledgements........................................................................................................................................ iv

Vita.................................................................................................................................................................. v

List of Tables .................................................................................................................................................. viii

Chapter 1: Background and Rationale ........................................................................................................ 1

Previous Research Surrounding *BRCA* Mutation Carriers ................................................................. 2

The Visual Representation of Risk in Genetic Counseling ............................................................... 3

Graphic Formats for Presenting Risk ....................................................................................................... 4

Line Graph Format ...................................................................................................................................... 6

Bar Graph Format ....................................................................................................................................... 6

Icon Array Format ...................................................................................................................................... 6

Factors Impacting Graphic Preferences .................................................................................................. 7

Chapter 2: Methods .................................................................................................................................. 12

Survey Measures ......................................................................................................................................... 14

Data Analysis ................................................................................................................................................ 18
Chapter 3: Results ........................................................................................................... 21
Demographic Characteristics ......................................................................................... 21
Risk Presentation Preferences and Comprehension ....................................................... 22
Risk Communication Preferences ............................................................................... 22
Risk Estimate Comprehension ...................................................................................... 22
Attitudes Towards Risk Estimates ............................................................................... 23
Chapter 4: Discussion .................................................................................................... 27
Cancer Risk Perceptions .............................................................................................. 30
Limitations ................................................................................................................... 31
Conclusions .................................................................................................................. 33
References .................................................................................................................... 35
Appendix A: Survey Questions ..................................................................................... 44
List of Tables

Table 1. Pearson Correlations for Model Variables .......................................................... 20
Table 2. Demographic Characteristics, BRCA Mutation Details, and Cancer Status ..... 25
Table 3. Factors Predicting Comprehension and Attitudes ................................................. 26
Chapter 1: Background and Rationale

Hereditary breast and ovarian cancer syndrome (HBOC) is caused by mutations in the \textit{BRCA1} and \textit{BRCA2} genes. It is estimated that 350,000 adults in the United States carry a germline mutation in the \textit{BRCA1} or \textit{BRCA2} gene (Drohan, Roche, Cusack, & Hughes, 2012). Associated lifetime breast cancer risk estimates vary widely, ranging from 52\% to 90\% for \textit{BRCA1} mutation carriers and 41\% to 84\% for \textit{BRCA2} mutation carriers (Antoniou et al., 2003; Chen & Parmigiani, 2007; Ford, Easton, Bishop, Narod, & Goldgar, 1994; Ford et al., 1998; King, Marks, Mandell, & New York Breast Cancer Study Group, 2003; Levy-Lahad & Friedman, 2007; Mavaddat et al., 2013; Milne et al., 2008; Risch et al., 2006). Lower lifetime breast cancer risk estimates tend to be from population-based studies, while higher lifetime breast cancer risk estimates tend to come from retrospective studies that used families ascertained based on the presence of multiple affected individuals (Mavaddat et al., 2013).

A meta-analysis of ten eligible studies found the lifetime breast cancer risk to be 57\% for \textit{BRCA1} mutation carriers and 49\% for \textit{BRCA2} mutation carriers (Chen & Parmigiani, 2007). A more recent prospective analysis of 1,887 \textit{BRCA} mutation carriers in the United Kingdom found the lifetime breast cancer risk to be 60\% for \textit{BRCA1} mutation carriers and 55\% for \textit{BRCA2} mutation carriers (Mavaddat et al., 2013); this is in line with estimates from Antoniou et al. (2003), which found the lifetime breast cancer
risk to be 65% for BRCA1 mutation carriers and 45% for BRCA2 mutation carriers (Antoniou et al., 2003).

Women with BRCA mutations are typically presented with this wide lifetime breast cancer risk estimate range during genetic counseling. Nearly one third of people in the United States are likely to have problems understanding both numerically and graphically displayed information (Galesic & Garcia-Retamero, 2011), and nearly half of the United States’ adult population has deficiencies in either reading or computation skills (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993); thus, some BRCA mutation carriers may have difficulty understanding risk estimates. In this thesis I examine BRCA mutation carriers’ preferences for the visual presentation of cancer risk in genetic counseling and investigate how health numeracy, graph literacy, and the patient’s knowledge of HBOC influence preferences for and understanding of various risk estimate formats. Although visual depictions of risk estimates, such as various graphical formats like line graphs, are often used in genetic counseling, to our knowledge previous studies have not evaluated their effectiveness in this setting based on these factors. Data from this study may help to improve the effectiveness of genetic counseling and women’s understanding of cancer risks associated with BRCA mutations. This may ultimately lead to the development of risk presentation formats that women of all health numeracies, graph literacies, and HBOC knowledge levels can understand and retain.

Previous Research Surrounding BRCA Mutation Carriers

Because BRCA mutation carriers are relatively rare within the general population, they are an understudied population in the realm of risk communication. Research to date
on these individuals has looked primarily at topics such as decision-making regarding testing and cancer prevention behaviors, family considerations after testing positive for a mutation, and the psychosocial effects of testing (Bosch et al., 2012; Culver et al., 2011; Douglas, Hamilton, & Grubs, 2009; Friedman & Kramer, 2005; Rowland & Metcalfe, 2014; Rupert et al., 2013). To our knowledge, no previous studies have examined the format in which BRCA mutation carriers prefer to receive cancer risk estimates associated with HBOC during their genetic counseling appointments; therefore, this study fills an important gap in the literature.

Previous research has examined the cancer risk communication preferences within the general population (Dolan & Iadarola, 2008; Fortin, Hirota, Bond, O'Connor, & Col, 2001; Schapira, Nattinger, & McAuliffe, 2006), but it cannot be safely assumed that BRCA mutation carriers will have the same preferences since their cancer risks are significantly increased. The perceived threat of cancer may be higher among BRCA mutation carriers, due to the high risk conferred by their mutation status, as well as their cancer worry or concern (Di Prospero et al., 2001; Werner-Lin, 2007); thus, the needs and preferences for information among female BRCA mutation carriers may differ from other women (Di Prospero et al., 2001). Additionally, genetic risk information is often complex.

The Visual Representation of Risk in Genetic Counseling

Cancer risk estimates are generally provided to BRCA mutation carriers during a genetic counseling session, typically before and/or after genetic testing, and many genetic counselors present this risk with the addition of visual aids, using graphs or pictures to
supplement their verbal description of the risk. There is no gold standard for risk visual aids displaying cancer risks of BRCA mutation carriers. The National Society of Genetic Counselors recommends that when counseling patients about their genetic testing options and obtaining informed consent in a cancer genetic counseling setting, information should be presented to the patient in a way that the patient can easily understand (Riley et al., 2012). It is also stated that assessing the patient’s educational level and knowledge of medical genetics can be useful for the counselor when determining how to most effectively provide informed consent (Riley et al., 2012).

Genetic counselors tend to counsel based on their training and experiences, not based on research findings or the risk communication literature (Henneman, Marteau, & Timmermans, 2008). On average, a familial breast cancer genetic counseling session will present four risk estimate figures to the patient (Butow & Lobb, 2004). Genetic counselors tend to frame the risks associated with genetic disorders in negative terms, meaning that the chance that a particular condition or symptom will develop is given more often than the chance that a particular condition or symptom will not develop (Fransen, Meertens, & Schrander-Stumpel, 2006). Many genetic counselors assess comprehension of the risk estimates presented during a session based on the patient’s nonverbal cues (Henneman et al., 2008). Although some genetic counselors desire to know if their risk communication strategies are “right,” many genetic counselors also do not believe that they need to be formally trained in risk communication (Henneman et al., 2008).

Graphic Formats for Presenting Risk
Presenting risk information in graphical formats has been shown to have many positive outcomes on risk perception and the management of one’s risk. Representation of risk in a graphical format has been shown to improve patient understanding (Bogardus, Holmboe, & Jekel, 1999; Lipkus, 2007). Graphs can also reveal data patterns that may otherwise be missed (Julian-Reynier et al., 2003; Lipkus & Hollands, 1999). Individuals have been shown to become more risk-averse when shown a graph in addition to being told the numerical risk alone, which may improve screening uptake and affect management decisions (Lipkus & Hollands, 1999). Graphical presentation of risk has also been shown to affect perceived helpfulness of information, perceived risk, and mitigation intentions (Johnson & Slovic, 1995; Kaplan, Hammel, & Schimmel, 1985; Lipkus & Hollands, 1999; Sandman, Weinstein, & Miller, 1994). Interestingly enough, preferences for a particular graphical format do not always equate to the performance of the graph in terms of understanding (Brown et al., 2011), so it is important to assess and analyze both preference for and understanding of each graphical format. In this study we evaluate three of the more common graphical formats including line graphs, bar graphs, and icon arrays and compare their effectiveness to risk estimates presented using only text. When presented in simple forms, such as a line graph, bar graph, or icon array, health care data has been shown to improve patient understanding (Brundage et al., 2005; Burke et al., 2000; Schapira, Nattinger, & McHorney, 2001). When presenting multiple graphs to individuals, as we did in this study, it has been recommended to use distinctive legends and to keep each variable’s color consistent across graphs (Lipkus & Hollands, 1999).
**Line Graph Format**

Because line graphs depict multiple data points in one visual display, viewers can more easily assess rates of change (Ancker, Senathirajah, Kukafka, & Starren, 2006), and line graphs easily depict data trends (Hollands & Spence, 1992; Lipkus & Hollands, 1999). Line graphs in particular were the most easily comprehended graphical format by cancer patients when depicting quality of life information (Brundage et al., 2005). In addition, the same study found that participants rated the line graph as the most helpful and most easily understood graphical format (Brundage et al., 2005).

**Bar Graph Format**

In the context of breast cancer, bar graphs have been shown to be helpful for the comparison of multiple risks and for improving the accuracy of self-described risk (Schapira et al., 2001). One study found that vertical bar graphs were preferred over icon arrays (Brown et al., 2011). Another study found that bar graphs were vastly preferred over both line graphs and icon arrays (Fortin et al., 2001). Similarly, bar graphs were preferred over icon arrays when presenting multiple risk estimates (Schapira et al., 2006).

**Icon Array Format**

Icon arrays have been well researched in terms of both effectiveness and design. Icon arrays provide both verbatim and gist knowledge, especially for those of low numeracy (Hawley et al., 2008; Zikmund-Fisher et al., 2014). Individuals of all numeracy levels tend to trust the information displayed on icon arrays (Hawley et al., 2008), though individuals with less education tend to perceive their breast cancer risk as erroneously high when presented in an icon array compared to presentation in a bar graph (Brown et
Multiple studies have shown the icon array to be the preferred presentation format, especially for depicting percentages (Hawley et al., 2008; Lautenbach, Christensen, Sparks, & Green, 2013). This format directly translates percentages into discrete visual units and helps to communicate the part-to-whole ratio (Lautenbach et al., 2013). Icon arrays can also reduce the influence of anecdotal information on risk information interpretation (Lautenbach et al., 2013).

In terms of design, icon arrays are best understood with a denominator of 100 individuals, and with a shaded background, horizontal arrangement, and multiple risks shown on one icon array (Lautenbach et al., 2013; Price, Cameron, & Butow, 2007). Using anthropomorphic icons, such as gendered restroom symbols, has also been shown to improve recall of risk estimates displayed using the icon array for individuals of higher numeracy and graph literacy (Zikmund-Fisher et al., 2014). Anthropomorphic icons have also been shown to be more meaningful and easier to understand when compared to other icon types (Ancker et al., 2006). While random arrangement of shaded figures has been shown to improve the understanding of chance (Ancker et al., 2006; Baty et al., 1997), this type of arrangement reduces the accuracy of proportion estimation from the icon array (Ancker et al., 2006; Feldman-Stewart, Kocovski, McConnell, Brundage, & Mackillop, 2000). To better compare the icon array to other graphical formats in terms of readability and accuracy, we did not use a random arrangement.

Factors Impacting Graphic Preferences

In this study, we examine how health numeracy, graph literacy, and knowledge of HBOC and its genetics influence BRCA mutation carriers’ preferences for and
understanding of these various graphical formats compared to risk estimates using text only. Health numeracy has been defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, graphical, biostatistical, probabilistic health information needed to make effective health decisions” (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005) and is a vital part of health literacy. Not all individuals are able to equally understand and apply numeric information (Reyna & Brainerd, 2008); however, health numeracy has been increasingly recognized as an important factor in medical decision-making and risk communication, which includes the domain of genetics (Lea, Kaphingst, Bowen, Lipkus, & Hadley, 2011). Those of low numeracy have been shown to make mistakes in answering very simple questions and to have distorted perceptions of their risk, typically overestimation (Keller, Siegrist, & Visschers, 2009; Keller & Siegrist, 2009; Lipkus & Hollands, 1999; Lipkus, Samsa, & Rimer, 2001; Miron-Shatz, Hanoch, Graef, & Sagi, 2009; Peters, Hart, & Fraenkel, 2011; Reyna, Nelson, Han, & Dieckmann, 2009).

To our knowledge, there has been no research on the topic of health numeracy in regards to the \textit{BRCA} mutation carrier population; however, standard numeracy has been shown to facilitate learning about HBOC in literate individuals (Portnoy, Roter, & Erby, 2010). This study found that numeracy does not impact the learning ability of individuals with literacy deficits (Portnoy et al., 2010). Additionally, individuals of higher numeracy were more likely to correctly interpret uninformative or ambiguous \textit{BRCA} genetic test results (Hanoch, Miron-Shatz, Rolison, & Ozanne, 2014). There is a need to determine if individuals of lower health numeracy have differences in preferences for and
understanding of the various risk estimate formats, as widely-distributed risk estimate formats should be understood and liked by individuals all health numeracy levels.

Graph literacy has been defined as “the ability to understand graphically presented information”, and is essential in everyday life, as graphs are present in all forms of media (Galesic & Garcia-Retamero, 2011). Graph literacy involves three levels of graph understanding: reading the data (finding specific information on a graph), reading between the data (finding relationships in the data presented), and reading beyond the data (making inferences/predictions from the data) (Galesic & Garcia-Retamero, 2011). Research on graph literacy has not yet been applied to the BRCA mutation carrier population. Analyzing BRCA mutation carriers’ risk estimate format preferences based on graph literacy will help us to select the risk estimate format(s) most effective across graph literacy levels, so they can be understood by all BRCA mutation carriers.

HBOC knowledge level is another important factor to consider in this study. Knowledge about genetics and its relationship with breast cancer risk is shown to be low within women in the general population and may influence screening decisions and informed decision making (Katapodi & Aouizerat, 2005; Portnoy et al., 2010), although BRCA mutation carriers may be expected to have higher knowledge than other segments of the population as a result of their experiences with genetic counseling. Women in families affected by HBOC tend to draw on their female relatives’ cancer experiences for knowledge about cancer and the impact that it may have on their own life should they be diagnosed (Etchegary & Perrier, 2007; Hallowell, 2006). One’s knowledge level about a
topic may influence his or her perceptions of information as well as the attention paid to the information. Additionally, those with more knowledge may have an easier time understanding graphs than those with less knowledge. All BRCA mutation carriers in this study have previously had genetic counseling and have been presented with similar risk estimates to what was shown to them in this study; thus, we would presume they are a more knowledgeable population. If women in our study, who have gone through the genetic counseling process and presumably have higher levels of knowledge, have difficulty comprehending graphical risk estimates, it may be particularly difficult for those seeing the cancer risk estimates for the first time.

Additionally, there are many barriers to accurate risk perception for women with elevated cancer risks. Women tend overestimate their breast cancer risk and have excessive worry about their risk, especially in the context of a positive family history (Braithwaite, Emery, Walter, Prevost, & Sutton, 2006; Croyle & Lerman, 1999; Durfy, Bowen, McTiernan, Sporleder, & Burke, 1999; Hallowell, Statham, & Murton, 1998; Lerman et al., 1995; Mouchawar, Byers, Cutter, Dignan, & Michael, 1999). These excessive worries may deter women from breast cancer screening or lead to excessive screening (Alagna, Morokoff, Bevett, & Reddy, 1987; Epstein et al., 1997). When the cancer in the family seems to be relentless and is perceived to be the cause of suffering and death, women tend to feel more hopeless and out of control; conversely, when the cancer in the family responds well to treatments and intervention, women tend to feel as though cancer is survivable (Etchegary & Perrier, 2007; Hallowell, 2006). Similarly, in a phenomenon called pre-selection, which is common in families affected by Huntington’s
disease, an individual may define his or her risk of developing a certain condition by
determining how similar he or she is to the individual(s) in the family that have been
affected by the condition (Evers-Kiebooms & Decruyenaere, 1998; Kessler & Bloch,
1989).

In conclusion, though BRCA mutation carriers have been researched in many
regards, we do not know the formats that are preferred or best understood for displaying
cancer risk information in genetic counseling. We also do not know how factors such as
HBOC knowledge, health numeracy, and graph literacy impact BRCA mutation carriers’
preferences for and understanding of risk communication formats. In this study we
compare four of the most common risk estimate formats used in genetic counseling (line
graph, bar graph, icon array, and text only). Being presented with easy-to-understand risk
estimates in genetic counseling may consequently aid in accurate risk estimate retention,
perhaps helping to combat barriers to accurate risk perception. This may in turn assist the
patient in accurately conveying the risk information to at-risk family members, which is
an important first step towards appropriate management and potential pursuit of genetic
testing for these individuals. Ultimately, a visual aid that presents risk estimates for
BRCA mutation carriers in a way that is well understood by carriers of all health
numeracies, graph literacies, and HBOC knowledge levels has the potential to positively
impact mutation carriers and assist them in decision-making regarding prevention
behaviors to manage their cancer risks.
Chapter 2: Methods

A cross-sectional (non-experimental) study design was used for this research project. Potential participants were identified through a query of The Ohio State University’s Clinical Cancer Genetics Program database containing all individuals that have received hereditary cancer genetic testing and genetic counseling through this clinic. The database was queried based on the eligibility criteria of: female gender, age 18 or older, and having a molecularly confirmed pathogenic or likely pathogenic $BRCA1$ or $BRCA2$ mutation. The query identified 230 eligible participants that met the inclusion criteria and had an email address on file.

Eligible individuals were sent an email invitation to participate in the study from The Ohio State University’s Clinical Cancer Genetics Program email address. To protect the privacy of these $BRCA$ mutation carriers, individual, personalized emails were sent to eligible participants. The decision to send email invitations from the Clinical Cancer Genetics Program’s email account (rather than a personal email account) was made so that the eligible participants could see that the study invitation was sent from the genetics clinic at which they underwent genetic testing. The invitation email contained a link that directed interested participants to an anonymous online survey hosted by Qualtrics, Inc. The first question of this survey was the informed consent for the study, which participants completed before being able to access additional survey questions.
Participants then completed questions assessing demographic characteristics, *BRCA* mutation status, cancer status, cancer risk perception, HBOC knowledge, health numeracy, graph literacy, and health information orientation. Participants then viewed each risk estimate format individually and answered questions about their attitudes towards and comprehension of the risk figure. Additional questions assessed their overall preferences for and understanding of the risk estimate formats and their cancer risk perception prior to viewing the risk estimate formats. The complete survey, including the risk estimate formats presented in this study, is available in Appendix A. All participants received a $10 Target gift card as compensation for participating in the study.

We chose to use bar graph, line graph, and icon array graphical formats in our study, as well as a text-only format that described the *BRCA*-associated lifetime breast cancer risk estimate without the use of a graphical display. The text-only format was the last format presented to study participants since it plainly spelled out the lifetime breast cancer risk estimates. By presenting this format last, study participants were forced to interpret the graphical displays, eliminating elevated comprehension scores from recall of the risk estimate information presented in the text-only format.

For the design of the particular graphical formats used in this study, age-related breast cancer penetrance figures for *BRCA1* and *BRCA2* carriers were taken from Narod et al. (1995) and Ford et al. (1998) respectively. The age-related breast cancer penetrance estimates for *BRCA1* carriers used in this study are 18% by age 40, 64% by age 60, and 71% by age 70 (Ford et al., 1998; Narod et al., 1995). The age-related breast cancer penetrance estimates for *BRCA2* carriers used in this study are 12% by age 40, 50% by
age 60, and 83% by age 70 (Ford et al., 1998). While newer age-related breast cancer penetrance estimates are available, these estimates are in line with what BRCA mutation carriers would have been told in a genetic counseling session, as it is common for genetic counselors to state that the lifetime breast cancer risk associated with a BRCA mutation is between 50% and 85%. Presenting estimates at the highest or lowest end of the range was avoided so as not to alarm any BRCA mutation carriers with risk estimates that could be perceived as new or different information from that received in their genetic counseling sessions. Additionally, these risk estimates presented us with breast cancer penetrance estimates at singular ages versus an age range format; this allowed us to reduce the amount of numerical information presented in the legend of the graphs, thereby increasing the simplicity, without having to alter the data from its original age range form.

Invitation emails were sent in batches of approximately 40 per week. Of the invitation emails sent, 23 were undeliverable. If a participant did not respond to the initial email, one study invitation reminder email was sent (n=53) to eligible participants. Study accrual was met before additional reminder emails were needed for other eligible participants. In total, 82 of the 230 eligible participants completed the survey either in part or in whole, equaling a response rate of 35.7%.

Survey Measures

Demographics. Measures included age, race/ethnicity, education level (never attended (coded as 1) to college four or more years (coded as 6)), income (less than $10,000 (coded as 1) to more than $200,000 (coded as 8)), and health care coverage
We also measured self-reported health (i.e. “in general, would you say your health is…?”) on a scale from 1 (poor) to 5 (excellent). All measures were based on the 2011 and 2013 Behavioral Risk Factor Surveillance Survey (Centers for Disease Control and Prevention (CDC), 2011; Centers for Disease Control and Prevention (CDC), 2013).

**BRCA Mutation Status.** Measures included confirmation of being mutation positive, as well as which ***BRCA*** gene was mutated (**BRCA1** or **BRCA2**). The question confirming that the participant was a mutation carrier served as an eligibility checkpoint. If the participant answered that they were not mutation positive, they were directed to the end of the survey and informed that they did not meet eligibility criteria. We also assessed whether any family members had been tested for the familial mutation (1=yes, 0=no) and if any family members had testing and had tested positive (1=yes, 0=no). Participants were given the option of disclosing relatives who had undergone testing and/or tested positive (e.g. mother, sister). All questions were original to this study.

**Cancer Status.** Participants were asked if they had previously been diagnosed with a cancer. If a participant answered ‘yes’ to this question, they were then asked the type of cancer they had been diagnosed with, the age cancer was diagnosed, and the date the diagnosis occurred. For the purposes of analyzing the data, a binary cancer status variable was created (1=previous cancer, 0=no previous cancer).

**Cancer Risk Perceptions.** Measures assessed perceived severity (i.e. “if you were to get cancer/another cancer, how serious would it be?”) and susceptibility (i.e. “how likely are you to get cancer/another cancer in your lifetime?”) to cancer or another cancer
on a 1-5 Likert scale (Kahlor, 2010), ranging from not likely/not serious (1) to definitely/very serious (5). Risk perception was measured at baseline and after viewing the risk estimates. As is the usual practice, the mean of the two items was used in the analyses. The mean baseline risk perception score was 3.53 (SD=0.75, range: 1-5); the mean follow up risk perception score was 3.71 (SD=0.66, range: 1-5).

_HBOC Knowledge Scale._ This scale assesses HBOC knowledge via 11 true/false questions about HBOC (e.g. “A father can pass down an altered breast cancer gene to his children” and “Early onset breast cancer is more likely due to an altered breast cancer gene than is late onset breast cancer”). This HBOC knowledge scale is widely used and is previously validated (Vadaparampil et al., 2010). All 11 items were scored as either correct (1) or incorrect (0); individuals therefore received a score of 0-11 based on the number of questions answered correctly, with higher scores indicating greater knowledge of HBOC. The mean HBOC knowledge score was 8.18 (SD=1.77, range: 2-11).

_Health Numeracy._ Health numeracy was assessed using the short form of the Numeracy Understanding in Medicine Scale (Schapira et al., 2014). This scale consists of 8 questions that assess health numeracy (e.g. “James has diabetes. His goal is to have his blood sugar between 80 mg/dL and 150 mg/dL in the morning. Which of the following blood sugar readings is within his goal?”). All of the items were scored as correct (1) or incorrect (0). Individuals received a score of 0-8 based on the number of questions answered correctly, with higher scores indicating higher health numeracy. The mean health numeracy score was 6.29 (SD=1.40, range: 1-8).
Graph Literacy. Graph literacy was assessed using a previously validated scale consisting of 6 questions assessing one’s ability to read and interpret graphical information (e.g. participants were shown a graph indicating disease prevalence over a certain timespan and asked “Between 1980 and 1990, which disease had a higher increase in the percentage of people affected?” (Zikmund-Fisher et al., 2014). All of the items were scored as correct (1) or incorrect (0). Individuals were given a score of 0-6 based on the number of questions answered correctly, with higher scores indicating higher graph literacy. This scale is a shortened version of the original graph literacy measure (Galesic & Garcia-Retamero, 2011). Across the sample, mean graph literacy score was 4.91 (SD=1.18, range: 1-6).

Attitudes Towards Risk Estimate Formats. Attitudes towards each risk estimate format were assessed using a 10-point semantic differential scale whereby participants identified how valuable (versus worthless), good (versus bad), beneficial (versus harmful), helpful (versus not helpful), useful (versus not useful), relevant (versus not relevant) applicable (versus not applicable), and clear (versus unclear) each format was (Azjen, 2006). As is standard practice with this attitudes scale, the mean of the items was used in analysis. Scale reliability was determined using Cronbach’s Alpha for the text-only (Cronbach’s α=.98), line graph (Cronbach’s α=.97), bar graph (Cronbach’s α=.96), and icon array attitudes scale (Cronbach’s α=.98). Attitudes were assessed after exposure to each risk estimate format (line graph M=8.84, SD=1.61, range: 1-10; bar graph M=8.82, SD=1.42, range: 4-10; icon array M=7.02, SD=2.82, range: 1-10; text-only M=9.53, SD=1.15, range: 5-10).
Comprehension of Risk Estimate Formats. Comprehension was assessed by asking participants to answer multiple choice factual questions about the risk estimates presented in each risk estimate format (e.g. “Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA1 carrier?” and “Based on the risk estimate you just saw, how much more likely is a woman with a BRCA2 mutation to get breast cancer in her lifetime than a woman without a BRCA mutation?”). The same set of questions was asked after exposure to each risk estimate format. Each item was scored as correct (1) or incorrect (0) and a total score was summed to provide an indicator of overall comprehension (line graph $M=5.39$, $SD=1.18$, range: 1-6; bar graph $M=5.48$, $SD=1.21$, range: 0-6; icon array $M=5.34$, $SD=1.29$, range: 0-6; text-only $M=5.61$, $SD=1.13$, range: 0-6). All questions were original to this study.

Risk Estimate Format Preference. Three single item questions assessed the (1) risk estimate format the participant liked best (i.e. “Of the four risk estimate formats that you just saw, which one did you like the most?”), (2) risk estimate format that was the easiest to understand (i.e. “Of the four risk estimate formats that you just saw, which one did you find the easiest to understand?”), and (3) risk estimate format that was the most difficult to understand (i.e. “Of the four risk estimate formats that you just saw, which one did you find the most difficult to understand?”). Descriptive statistics were used to calculate frequencies for analysis of preferences for and understanding of the risk estimate formats. All three questions were original to this study.

Data Analysis
All analysis was conducted in SPSS version 23. Descriptive statistics were first calculated to examine the dataset including the demographics, *BRCA* mutation status, cancer characteristics, health numeracy, graph literacy, HBOC knowledge, and risk estimate format preferences of participants. Table 1 provides correlations for major continuous model variables to provide additional information regarding sample characteristics. Independent samples t-tests were also used to examine differences in cancer risk perceptions (continuous) based on cancer status and *BRCA* mutation status.

In this study we aimed to determine which of the four risk estimate formats used (line graph, bar graph, icon array, and text-only) were preferred and easiest for *BRCA* mutation carriers to understand. Participants’ mean comprehension and attitudes were computed for each risk estimate format. Paired samples t-tests and Analysis of Variance (ANOVA) were used to examine differences in risk perceptions, comprehension, and attitudes between risk estimate formats. Multiple linear regression analyses were also used to examine predictors of comprehension and attitudes towards each risk estimate format.
Table 1

*Pearson Correlations for Model Variables*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
<td>—</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Education</td>
<td>-.16</td>
<td></td>
<td>—</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Income</td>
<td>-0.03</td>
<td>.09</td>
<td>—</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Cancer status(^a)</td>
<td>-.45**</td>
<td>.10</td>
<td>-.14</td>
<td>—</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Cancer risk perception</td>
<td>.09</td>
<td>.01</td>
<td>-0.03</td>
<td>.28</td>
<td>—</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. HBOC(^b) knowledge</td>
<td>.03</td>
<td>-.02</td>
<td>.07</td>
<td>.04</td>
<td>.00</td>
<td>—</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Health numeracy</td>
<td>-.12</td>
<td>.26*</td>
<td>.05</td>
<td>.13</td>
<td>-.32**</td>
<td>.25*</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>8. Graph literacy</td>
<td>.24*</td>
<td>.07</td>
<td>.24</td>
<td>.01</td>
<td>.07</td>
<td>.14</td>
<td>.30*</td>
<td>—</td>
</tr>
</tbody>
</table>

Notes. \(^a\)1=previous cancer, 0=no previous cancer; \(^b\)HBOC = hereditary breast and ovarian cancer syndrome

**\(p < .01\); *\(p < .05\).
Chapter 3: Results

Demographic Characteristics

In total, 82 of the 230 eligible participants completed the survey either in part or in whole, equaling a response rate of 35.7%. Demographic characteristics, BRCA mutation details, and cancer status of study participants are reported in Table 2. The majority of the women surveyed were under the age of 50 (57%), with the oldest study participant being 73 years of age. Most participants were white (91.1%), had at least 4 years of college education (72.2%), and an annual household income of more than $50,000 (85.9%). Nearly all participants were covered by health insurance (97.5%).

Of the 78 respondents that chose to reveal the BRCA gene in which they have a mutation, 40 women (51.3%) had a mutation in BRCA1 and 38 women (48.7%) had a mutation in BRCA2. More than half of study participants reported a previous personal cancer diagnosis (54.4%), with the majority of cancer diagnoses occurring before age 50 (74.4%). The oldest reported age of cancer diagnosis was 62 years. The majority of participants with a previous cancer diagnosis reported having breast cancer (80.9%), but there were also reports of ovarian cancer (12.8%), fallopian tube cancer (2.1%), melanoma (2.1%), and thyroid cancer (2.1%). Women who had not been previously diagnosed with a cancer had higher cancer risk perceptions than those women who had been previously diagnosed with a cancer ($M$ of 3.76 vs. 3.34; $p=.01$, range: 1-5). Cancer
risk perceptions did not differ between *BRCA1* versus *BRCA2* mutation carriers (*M*=3.53 in both groups, *p*>.05, range: 1-5).

**Risk Presentation Preferences and Comprehension**

**Risk Communication Preferences**

The majority of participants (59.7%; *n*=37) preferred their lifetime breast cancer risk estimates displayed graphically (in either line graph, bar graph, or icon array format) to using only text; however, the text-only format was preferred over any individual graphical format alone. Of the participants who preferred a graphic display, the line graph format was most preferred (56.8%), followed by bar graph (32.4%) and icon array (10.8%). ANOVA showed that risk perceptions were unrelated to the risk estimate format the participant preferred (*p*=.97).

Despite a majority of participants preferring their risk be presented graphically, most participants (62%; *n*=44) thought lifetime breast cancer risk estimates were easiest to understand when presented using only text (versus any graphical format). Of those participants who thought the breast cancer risk estimates were easier to understand when presented graphically, the majority thought that the line graph was easiest to understand (55.6%), followed by the bar graph (37%) and icon array (7.4%).

**Risk Estimate Comprehension**

Comprehension of lifetime breast cancer risk estimates was high for each format, although it was higher for certain graphs than others. Paired samples t-tests showed that comprehension of text-only (*M*=5.61, range: 0-6) was significantly higher than icon array (*M*=5.34, range: 0-6, *t*(58)=−2.51, *p*=.02). Comprehension was also significantly higher
for bar graph \((M=5.48, \text{range: 0-6})\) than icon array \((M=5.34, \text{range: 0-6}, t (58)=1.99, p=.05)\). No other significant comprehension differences were found.

Comprehension of each risk estimate format (continuous variable) also was examined based on HBOC knowledge, health numeracy, graph literacy, age, income, education, and cancer status using multiple linear regression (Table 3). Greater comprehension of the line graph was associated only with higher graph literacy \((p=.03)\), whereas greater comprehension of the bar graph was associated only with higher health numeracy \((p=.03)\). Greater comprehension of the icon array was associated with higher health numeracy \((p<.01)\) as well as increasing age \((p=.04)\). For text only, greater comprehension was associated only with higher income \((p=.04)\).

**Attitudes Towards Risk Estimates**

Attitudes towards all of the risk estimate formats, in general, were positive. However, results of paired samples t-tests showed that participants had significantly more positive attitudes towards text-only \((M=9.53, \text{range: 5-10})\) than they did bar graph \((M=8.82, \text{range: 4-10}, t (70)=-5.14, p=.00)\), line graph \((M=8.84, \text{range: 1-10}, t (70)=-3.72, p=.00)\), or icon array \((M=7.03, \text{range: 1-10}, t (70)=-7.65, p=.00)\). In contrast, for icon array, attitudes towards bar graph \((M=8.82, t (71)=6.00, p=.00)\) and line graph \((M=8.84, t (71)=5.42, p=.00)\) were significantly more positive. No attitudinal differences were found between line graph and bar graph formats \((p>.05)\).

As with comprehension, attitudes were examined based on HBOC knowledge, health numeracy, graph literacy, age, income, education, and cancer status using multiple linear regression (Table 3). None of these factors were significantly associated with
attitudes for the icon array or line graph formats. However, higher health numeracy was associated with more positive attitudes for the bar graph \((p=.03)\), and higher education was associated with more positive attitudes for text-only \((p<.01)\).
<table>
<thead>
<tr>
<th>Age (n=78)</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 years</td>
<td>45</td>
<td>57.0</td>
</tr>
<tr>
<td>50-59 years</td>
<td>13</td>
<td>16.4</td>
</tr>
<tr>
<td>60-69 years</td>
<td>18</td>
<td>24.1</td>
</tr>
<tr>
<td>70+ years</td>
<td>2</td>
<td>2.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/Ethnicity (n=78)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic white</td>
<td>72</td>
<td>91.1</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>8.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest Education (n=79)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 12 or GED</td>
<td>5</td>
<td>6.3</td>
</tr>
<tr>
<td>1-3 years of college</td>
<td>17</td>
<td>21.5</td>
</tr>
<tr>
<td>4+ years of college</td>
<td>57</td>
<td>72.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annual Household Income (n=64)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$50,000</td>
<td>9</td>
<td>14.1</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>26</td>
<td>40.6</td>
</tr>
<tr>
<td>&gt;$100,000</td>
<td>29</td>
<td>45.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Insurance (n=78)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Insured</td>
<td>77</td>
<td>97.6</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1</td>
<td>1.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BRCA Gene Mutation (n=78)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>BRCA1</td>
<td>40</td>
<td>51.3</td>
</tr>
<tr>
<td>BRCA2</td>
<td>38</td>
<td>48.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Previous Cancer Diagnosis (n=79)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>43</td>
<td>54.4</td>
</tr>
<tr>
<td>No</td>
<td>36</td>
<td>45.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age at Cancer Diagnosis (n=43)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 years</td>
<td>32</td>
<td>74.4</td>
</tr>
<tr>
<td>&gt;50 years</td>
<td>11</td>
<td>26.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer Type (n=47)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>38</td>
<td>80.9</td>
</tr>
<tr>
<td>Ovarian</td>
<td>6</td>
<td>12.8</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Fallopian tube</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Thyroid</td>
<td>1</td>
<td>2.1</td>
</tr>
</tbody>
</table>
### Table 3

**Factors Predicting Comprehension and Attitudes**

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Line graph</th>
<th></th>
<th></th>
<th>Bar graph</th>
<th></th>
<th></th>
<th>Icon array</th>
<th></th>
<th></th>
<th>Text-only</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Attitudes</td>
<td>B</td>
<td>SE B</td>
<td>Attitudes</td>
<td>B</td>
<td>SE B</td>
<td>Attitudes</td>
<td>B</td>
<td>SE B</td>
<td>Attitudes</td>
<td>B</td>
<td>SE B</td>
</tr>
<tr>
<td>HBOC&lt;sup&gt;a&lt;/sup&gt; knowledge</td>
<td>.09</td>
<td>.14</td>
<td>.08</td>
<td>.08</td>
<td>.05</td>
<td>.13</td>
<td>.04</td>
<td>.10</td>
<td>.41</td>
<td>.24</td>
<td>.17</td>
<td>.10</td>
</tr>
<tr>
<td>Health numeracy</td>
<td>.08</td>
<td>.19</td>
<td>.15</td>
<td>.11</td>
<td>.34*</td>
<td>.15</td>
<td>.28*</td>
<td>.12</td>
<td>.44</td>
<td>.30</td>
<td>.34**</td>
<td>.12</td>
</tr>
<tr>
<td>Graph literacy</td>
<td>.31</td>
<td>.24</td>
<td>.31*</td>
<td>.14</td>
<td>-.13</td>
<td>.19</td>
<td>.06</td>
<td>.15</td>
<td>-.45</td>
<td>.37</td>
<td>-.05</td>
<td>.15</td>
</tr>
<tr>
<td>Age</td>
<td>.02</td>
<td>.04</td>
<td>.02</td>
<td>.02</td>
<td>.07</td>
<td>.04</td>
<td>.04</td>
<td>.03</td>
<td>.02</td>
<td>.07</td>
<td>.06*</td>
<td>.03</td>
</tr>
<tr>
<td>Income</td>
<td>-.02</td>
<td>.15</td>
<td>.15</td>
<td>.09</td>
<td>-.06</td>
<td>.13</td>
<td>.13</td>
<td>.10</td>
<td>.17</td>
<td>.24</td>
<td>.18</td>
<td>.10</td>
</tr>
<tr>
<td>Education</td>
<td>.40</td>
<td>.44</td>
<td>.10</td>
<td>.26</td>
<td>.26</td>
<td>.37</td>
<td>.08</td>
<td>.30</td>
<td>-.30</td>
<td>.72</td>
<td>.13</td>
<td>.29</td>
</tr>
<tr>
<td>Cancer status&lt;sup&gt;b&lt;/sup&gt;</td>
<td>-.31</td>
<td>.53</td>
<td>.18</td>
<td>.32</td>
<td>.10</td>
<td>.43</td>
<td>.53</td>
<td>.34</td>
<td>-.100</td>
<td>.84</td>
<td>.71</td>
<td>.36</td>
</tr>
</tbody>
</table>

**Note.** Comp=comprehension; <sup>a</sup>HBOC=hereditary breast and ovarian cancer syndrome; <sup>b</sup>1=previous cancer, 0=no previous cancer

*<sup>p</sup> < .05 **<sup>p</sup> < .01
Chapter 4: Discussion

This study aimed to assess which of four common lifetime breast cancer risk estimate formats (line graph, bar graph, icon array, and text-only) are both most preferred and most understood by BRCA mutation carriers. Furthermore, we investigated the potential impact of graph literacy, health numeracy, and HBOC knowledge on BRCA mutation carriers’ preferences for and understanding of these risk estimate formats in hopes of finding one or more risk estimate format that was both well-liked and well-understood by BRCA mutation carriers of varying graph literacy, health numeracy, and HBOC knowledge levels.

Overall, participants stated that they preferred their risk be presented graphically (using either the line graph, bar graph, or icon array format) to using text alone to describe their risk; however, when compared to each graphical format individually rather than all graphical formats collectively, the text-only format was more preferred. The text-only format was also preferred in terms of ease of understanding than any single graphical format alone. These findings may be due to the fact that risk is commonly estimated verbally during genetic counseling, but it may also suggest that the easiest to understand format (in this case, text-only) is not necessarily best, particularly among BRCA mutation carriers with higher education, health numeracy, and graph literacy. Furthermore, our results suggest that BRCA mutation carriers could derive the most
benefit if they are presented with a graphical risk estimate format in addition to being given a written and/or verbal description of their cancer risk.

While attitudes were positive towards all of the graphical formats, the line graph was most preferred by participants. One reason our participants may have preferred the line graph is that it was also the most easily understood graphical format. These results were surprising, as they are in conflict with previous studies. One study showed icon arrays to be the best risk estimate format for depicting percentages (Hawley et al., 2008), while another showed that bar graphs were preferred over both line graphs and icon arrays (Fortin et al., 2001); however, these studies employed different study designs and methods, which could contribute to our conflicting results. While the bar graph format was the second most preferred graphical format in this study, the icon array was the least preferred. These findings may be due to higher health literacy levels among our participants, particularly since icon arrays have been found to be most helpful to those of low numeracy (Hawley et al., 2008; Zikmund-Fisher et al., 2014), with another possible explanation being that the icon array does not depict a change in risk over time. The findings nonetheless illustrate the complexity of BRCA mutation carriers’ preferences for risk formats in genetic counseling.

In general, participants had positive attitudes and high comprehension of all formats and few differences were found across formats. For text-only, no differences in comprehension or attitudes were found based on factors including graph literacy, health numeracy, or HBOC knowledge; these findings suggest that text-only is a suitable risk estimate format for BRCA mutation carriers of all levels. Attitudes towards text-only
were more positive with increasing education levels; thus, individuals with more education had more positive attitudes towards text-only. Attitudes were also more positive towards text-only than any of the graphical formats.

Greater comprehension of the line graph, the most preferred graphical format by participants, was associated with higher graph literacy. Those with higher graph literacy had an easier time comprehending the information in the line graph. Because line graphs are most useful in depicting data trends over time, which likely contributed to their popularity among BRCA mutation carriers in this study, properly interpreting a line graph requires the viewer to both find specific information on the graph and to find relationships in the data presented. Because text-only and icon array formats did not depict cancer risk over time, the skill of finding relationships in the data was not required to the same degree; however, the bar graph format did depict cancer risk over time and was not found to be associated with graph literacy. More research is needed to determine the difference between line graph and bar graph associations with graph literacy and comprehension. One potential clue is the significant association found between health numeracy and bar graph comprehension and attitudes, which suggests comprehension of bar graphs depends more on people’s ability to use numbers than to understand graphs. Whereas the line graph depicts change in risk horizontally and utilizes the slope of the line to depict the rate of change, the bar graph depicts change in risk vertically and does not provide a simple way to interpret the rate of change of the risk. Individuals therefore have to rely more heavily on their numeracy skills to interpret the rate of change from the stacked, age-dependent risk estimates. The bar graph was also the only graphical format
in which the legend depicted age categories rather than \textit{BRCA} carrier status categories, which may require individuals to think about the information presented in a slightly different way than with the other graphical formats.

Increasing health numeracy was also associated with increased comprehension of the icon array; thus, individuals of higher health numeracy had an easier time comprehending the information presented in the icon array. Icon arrays have been shown to provide both verbatim and gist knowledge even for individuals of low numeracy levels (Hawley et al., 2008; Zikmund-Fisher et al., 2014), though our results suggest that \textit{BRCA} mutation carriers of low health numeracy may have more difficulty interpreting the icon array. One explanation could be that in this study the lifetime breast cancer risk estimates for women in the general population, female \textit{BRCA1}, and female \textit{BRCA2} carriers were all displayed on one icon array, which required more processing and numeracy skills to separate out these populations in order to answer the comprehension questions. Due to the nature of the graphs, the other risk estimate formats displayed lifetime breast cancer risk estimates more separated based on an individual’s \textit{BRCA} mutation status.

Comprehension of both the text-only and bar graph formats were also significantly higher than that of the icon array. Attitudes towards both the line graph and bar graph were significantly more positive than those towards the icon array. These findings further suggest that the icon array is not the best graphical risk estimate format to use when counseling \textit{BRCA} mutation carriers about their cancer risk.

\textbf{Cancer Risk Perceptions}
While not a central focus of our research, we did examine differences in cancer risk perception based on *BRCA* mutation details and cancer status. Cancer risk perceptions were not significantly different between *BRCA1* and *BRCA2* mutation carriers although cancer risk estimates do vary depending on which gene there is a mutation. For example, although *BRCA2* mutation carriers have a higher risk of pancreatic cancer than *BRCA1* mutation carriers (Risch et al., 2006; Thompson, Easton, & Breast Cancer Linkage Consortium, 2002; van Asperen et al., 2005), *BRCA2* mutation carriers did not have an overall increased cancer risk perception based on this difference. However, women in this study without a previous cancer diagnosis had significantly higher cancer risk perceptions than women with a previous cancer diagnosis. Women that have already successfully battled a cancer diagnosis may feel less at risk and may have a reference point for what another cancer may be like. Women that have already had cancer may feel as though they have already dealt with their share of cancer despite the fact that there is an increased risk for a second cancer (especially breast), particularly in women with HBOC that have not had risk-reducing surgeries.

Limitations

While this study represents an important first step in understanding how certain factors such as graph literacy, health numeracy, and HBOC knowledge impact *BRCA* mutation carriers’ preferences for and understanding of different graphical formats for presenting cancer risk estimates, there are certain limitations that must be considered. First, our sample consisted of only *BRCA* mutation carrier women that had received their genetic counseling and testing through The Ohio State University’s Clinical Cancer
Genetics program and may not be representative of BRCA mutation carriers in different settings. More research is needed to determine if these results are generalizable to other BRCA mutation carrier populations.

Additionally, the women in our study were also mostly white and of high socioeconomic status; consequently, their preferences may not be representative of BRCA mutation carriers of other ethnicities and/or socioeconomic statuses. Similarly, the women in our study were also generally of high graph literacy, health numeracy, and HBOC knowledge. It is possible that the risk estimate formats may perform differently in a population of women with lower graph literacy, health numeracy, and HBOC knowledge; more research on these topics is warranted. Regarding the comprehension questions used to assess understanding of each risk estimate format, some study participants may remember more risk estimate information from their genetic counseling session than others, and may therefore perform better on the comprehension questions. This higher performance may actually be a result of their prior HBOC knowledge rather than the information that they actually gleaned from the risk estimate format itself.

Despite asking women what their lifetime risk of breast cancer is prior to seeing any risk estimate formats, we were unable the accurately assess their baseline risk estimate knowledge. Upon completion of the survey, several study participants reached out to inform us that they had answered this question based on their lifetime breast cancer risk estimate after undergoing one or more prophylactic surgeries that dramatically reduce lifetime breast cancer risk estimates. Because we did not ask if women had previously had any prophylactic surgeries, we had no way to determine which women
may have answered this question based on the lower risk estimates provided to women post-prophylactic surgeries. Measuring baseline cancer risk knowledge in future studies has the potential to provide more insight into both comprehension of risk estimate formats and cancer risk perception.

Finally, there was self-selection bias to be expected with this study design. Individuals who responded to the survey elected to do so and may have been driven by numerous possible motivations, including their personal interest in the research topic, an altruistic desire to help further research surrounding BRCA mutation carriers, or the incentive of receiving the gift card as compensation. Women that chose not to respond to the survey may have been disinterested in the study or topic or had other priorities for their time. Similarly, the survey was distributed via email, which may select for individuals that are younger and/or more tech-savvy with access to a computer or smartphone. This self-selection bias may have been contributory to some of the participant demographic findings and characteristics, such as income, graph literacy levels, health numeracy levels, and HBOC knowledge levels. Future studies are needed to determine how generalizable these results are to other BRCA mutation carrier populations.

Conclusions

While BRCA mutation carriers in this study best understood their lifetime breast cancer risk estimate when presented using only text, they also preferred to have this information be presented graphically. Of the graphical formats examined in this study, the line graph was found to be the most preferred and easily understood. The lack of significant difference between the line graph and bar graph in terms of attitudes and
comprehension suggests that the bar graph also is a well-liked and well-understood graphical format for presenting risk estimates to *BRCA* mutation carriers. However, our data suggest that line graphs may be more effective when used with patients who have higher graph literacy, whereas bar graphs may be more effective for those patients who have higher health numeracy.

The results of this study further suggest that the standard practice of providing cancer risk estimates to *BRCA* mutation carriers verbally or using text to describe the risk should be continued, but that supplementing the verbal description of cancer risk with a graphical presentation of the risk estimate (line graph or bar graph) would be beneficial to these individuals. Our findings represent a critical first step in determining how to best include graphical formats into genetic counseling and how factors such as graph literacy, health numeracy, and HBOC knowledge impact *BRCA* mutation carriers’ preference for and understanding of various risk estimate formats.
References


among a multiethnic group of hispanic women with a personal or family history of cancer. *Genetic Testing and Molecular Biomarkers, 14*(1), 99-106.


Appendix A: Survey Questions

What is your current age?
[Responses are a check list from 50 to 100 that includes “less than 50 years old” (first) and “greater than 100 years old” and “prefer not to answer” (last)]

Are you Hispanic, Latino or Spanish Origin?
   □ Yes
   □ No
   □ Don’t know
   □ Prefer not to answer

What is the highest degree or year of school you have completed?
   □ Never attended school or only attended kindergarten
   □ Grades 1-8 (Elementary)
   □ Grades 9-11 (Some high school)
   □ Grade 12 or GED (High school graduate)
   □ College 1 year to 3 years (Some college or technical school)
   □ College 4 years or more
   □ Prefer not to answer

What is your annual household income from all sources?
   □ Less than $10,000
   □ $10,000 to less than $25,000
   □ $25,000 to less than $35,000
   □ $35,500 to less than $50,000
   □ $50,000 to less than $75,000
   □ $75,000 to less than $100,000
   □ $100,000 to less than $200,000
   □ More than $200,000
   □ Prefer not to answer
Do you currently have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare or Indian Health Services?

- □ Yes
- □ No
- □ Don’t Know
- □ Prefer not to answer

Please indicate your current family structure. Children may live in or outside your home.

- □ Single without children
- □ Single with children
- □ Married without children
- □ Married with children
- □ Life partner without children
- □ Life partner with children
- □ Prefer not to answer

In general, would you say that in general your health is….?

- □ Poor
- □ Fair
- □ Good
- □ Very Good
- □ Excellent
- □ Don’t know
- □ Prefer not to answer

Are you a *BRCA1* or *BRCA2* carrier?

- □ Yes
- □ No
- □ Prefer not to answer

In which gene do you have a mutation?

- □ *BRCA1*
- □ *BRCA2*
- □ Prefer not to answer
Have any of your family members been tested for the *BRCA1* or *BRCA2* mutation?

- □ Yes
- □ No
- □ Prefer not to answer

[If “yes” to family member testing] Which of your family members was tested? If you prefer not to answer, you may leave this question blank.
[Text box with open response]

[If “yes” to family member testing] Did any of your relatives test positive for the *BRCA1* or *BRCA2* mutation?

- □ Yes
- □ No
- □ Prefer not to answer

[If “yes” to family member testing positive] Which of your family members tested positive? If you prefer not to answer, you may leave this question blank.
[Text box with open response]

Have you ever been diagnosed as having cancer?

- □ Yes
- □ No
- □ Don't know
- □ Prefer not to answer

[If “yes” to cancer diagnosis] What type(s) of cancer were you diagnosed with? Check all that apply.

- □ Breast Cancer
- □ Ovarian Cancer
- □ Colorectal Cancer
- □ Cervical Cancer
- □ Prostate Cancer
- □ Lung Cancer
- □ Melanoma
- □ Other [includes text box for optional elaboration]
- □ Don’t know
☐ Prefer not to answer

[If “yes” to cancer diagnosis] At what age were you diagnosed with this cancer? [Responses are a check list from 50 to 100 that includes “less than 50 years old” (first) and “greater than 100 years old” and “prefer not to answer” (last)]

[If “yes” to cancer diagnosis] When was this cancer diagnosed? If you prefer not to answer, you may leave this question blank. [Text box with open response for month and year]

How likely are you to get [cancer/another cancer] in your lifetime?

1 2 3 4 5 [6] [prefer not to answer]

Not likely Definitely

If you were to develop [cancer/another cancer], how serious would it be?

1 2 3 4 5 [6] [prefer not to answer]

Not likely Definitely

How likely are you to get [cancer/another cancer] compared to other women without a BRCA mutation?

1 2 3 4 5 [6] [prefer not to answer]

Not likely Definitely

How likely are you to get [cancer/another cancer] compared to other women with a BRCA mutation?

1 2 3 4 5 [6] [prefer not to answer]

Not likely Definitely

What is your lifetime risk of developing breast cancer?

☐ 0-25%
☐ 26-49%
☐ 50-85%
☐ 86-100%
1 in 10 women with breast cancer has an altered breast cancer gene.

- True
- False
- Don’t know
- Prefer not to answer

One half of all breast cancer cases occur in women who have an altered breast cancer gene.

- True
- False
- Don’t know
- Prefer not to answer

A father can pass down an altered breast cancer gene to his children.

- True
- False
- Don’t know
- Prefer not to answer

The sister of a woman with an altered breast cancer gene has a 50% risk of having the altered gene.

- True
- False
- Don’t know
- Prefer not to answer

A woman who does not have an altered breast cancer gene can still get breast or ovarian cancer.

- True
- False
- Don’t know
- Prefer not to answer
Early onset breast cancer is more likely due to an altered breast cancer gene than is late onset breast cancer.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer

A woman who has an altered breast cancer gene has a higher ovarian cancer risk.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer

All women who have an altered breast cancer gene get cancer.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer

A woman who has her breasts removed can still get breast cancer.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer

Ovarian cancer screening tests often do not detect cancer until after it spreads.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer

Having ovaries removed will definitely prevent ovarian cancer.

☐ True
☐ False
☐ Don’t know
☐ Prefer not to answer
James has diabetes. His goal is to have his blood sugar between 80 mg/dL and 150 mg/dL in the morning. Which of the following blood sugar readings is within his goal?

- □ 55 mg/dL
- □ 140 mg/dL
- □ 165 mg/dL
- □ 180 mg/dL
- □ Prefer not to answer

Nathan has a pain rating of 5 on a scale of 1 (no pain) to 10 (worst possible pain). One day later Nathan still has pain but not as much. Now, what pain rating might Nathan give?

- □ 3
- □ 5
- □ 7
- □ 9
- □ Prefer not to answer

Frank has a test done to look for blockages in the arteries of his heart. The doctor said that a person with a higher percent (%) blockage has a high chance of having a heart attack. Which percent (%) blockage has the highest chance of a heart attack?

- □ 33%
- □ 50%
- □ 75%
- □ 99%
- □ Prefer not to answer

Natasha started a new medicine that may cause the side effects listed below. Which side effect is Natasha least likely to have?

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Chance of Occurring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dizziness</td>
<td>1 in 5 people</td>
</tr>
<tr>
<td>Nausea</td>
<td>1 in 10 people</td>
</tr>
<tr>
<td>Stomach pain</td>
<td>1 in 100 people</td>
</tr>
<tr>
<td>Allergic reaction</td>
<td>1 in 200 people</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
</tr>
</tbody>
</table>
James starts a new blood pressure medicine. The chance of a serious side effect is 0.5%. If 1000 people take this medicine, about how many would be expected to have a serious side effect?

- 1 person
- 5 people
- 50 people
- 500 people
- Prefer not to answer

The PSA (prostate specific antigen) is a blood test that looks for prostate cancer. The test has false alarms so about 30% of men who have an abnormal test turn out not to have prostate cancer. John has an abnormal test. What is the chance that John has prostate cancer?

- 0%
- 30%
- 70%
- 100%
- Prefer not to answer

A study found that a new diabetes medicine led to control of blood sugar in 8% more patients than the old medicine. The difference was statistically significant (p=0.05). The likelihood that the finding was due to chance alone is best described as less than:

- 1 in 5
- 1 in 10
- 1 in 15
- 1 in 20
- Prefer not to answer

A nutrition label is shown below. How many calories did Mary eat if she had 2 cups of food?

- 140 calories
- 280 calories
- 560 calories
- 680 calories
- Prefer not to answer

*Percent Daily Values are based on a 2,000 calorie diet. Your Daily Values may be higher or lower depending on your calorie needs.

<table>
<thead>
<tr>
<th>Nutrition Facts</th>
<th>Serving Size: 1 cup (228g)</th>
<th>Servings per Container: 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amount per Serving</strong></td>
<td>Calories 280</td>
<td>Calories from Fat 120</td>
</tr>
<tr>
<td>Total Fat 13g</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Saturated Fat 5g</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>Trans Fat 2g</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholesterol 2mg</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Sodium 660mg</td>
<td>28%</td>
<td></td>
</tr>
<tr>
<td>Total Carbohydrate 31g</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Dietary Fiber 3g</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Sugars 5g</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protein 5g</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin A 4%</td>
<td>Vitamin C 2%</td>
<td></td>
</tr>
<tr>
<td>Calcium 15%</td>
<td>Iron 4%</td>
<td></td>
</tr>
</tbody>
</table>
Here is some information about an imaginary disease called Adeolitis.

![Graph showing percentage of people with Adeolitis over years]

Approximately what percentage of people had Adeolitis in the year 2000? Please respond with a only number between 0-100 without the percentage sign.
[Text box for response]

When was the increase in the percentage of people with Adeolitis higher?

- □ From 1975 to 1980
- □ From 2000 to 2005
- □ Increase was the same in both intervals
- □ Prefer not to answer

The following figure shows the number of men and women among patients with disease X. The total number of circles is 100.

![Figure showing number of men and women with disease X]

Of 100 patients with disease X, how many are women?
[Text box for response]

How many more men than women are there among 100 patients with disease X?
[Text box for response]
In a magazine you see two advertisements, one on page 5 and another on page 12. Each is for a different drug for treating heart disease, and each includes a graph showing the effectiveness of the drug compared to a placebo (sugar pill).

Compared to the placebo, which treatment leads to a larger decrease in the percentage of patients who die?

- ■ Crosicol
- ■ Hertinol
- ■ They are equal
- ■ Can’t say
- ■ Prefer not to answer

Here is some information about the imaginary disease Coliosis and Tiosis.
Between 1980 and 1990, which disease had a higher increase in the percentage of people affected?

- □ Coliosis
- □ Tiosis
- □ The increase was equal
- □ Can’t say
- □ Prefer not to answer

When I’m dealing with health concerns…
I like to gather as much info as I can before making a decision.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
I like to review information multiple times before making a decision.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
After I’ve made a decision, I continue to look for related information.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
I like to make decisions quickly.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
I have difficulty making sense of information from multiple sources.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]
When I’m dealing with health concerns…
I fear I might find out something I don’t want to know.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
I feel overwhelmed by the amount of information available.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

When I’m dealing with health concerns…
I think it’s the doctor’s job to deal with information, not mine.

1 2 3 4 5 [6]
Not at all true Very True [prefer not to answer]

Please review the risk information presented in the line graph below and answer the following questions based on your interpretation of this information. If you are taking this survey on a mobile device, it may help to hold the phone horizontally so that the entire question fits on the page.
The information presented in this risk estimate is...

| Worthless | 1 2 3 4 5 6 7 8 9 10 | Valuable |
| Bad       | 1 2 3 4 5 6 7 8 9 10 | Good    |
| Harmful   | 1 2 3 4 5 6 7 8 9 10 | Beneficial |
| Not Helpful | 1 2 3 4 5 6 7 8 9 10 | Helpful |
| Not Useful | 1 2 3 4 5 6 7 8 9 10 | Useful |
| Irrelevant | 1 2 3 4 5 6 7 8 9 10 | Relevant |
| Not Applicable | 1 2 3 4 5 6 7 8 9 10 | Applicable |
| Unclear   | 1 2 3 4 5 6 7 8 9 10 | Clear |

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA1 carrier?

- □ 18%
- □ 65%
- □ 71%
- □ 84%
- □ Prefer not to answer

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA2 carrier?

- □ 13%
- □ 59%
- □ 71%
- □ 84%
- □ Prefer not to answer

Based on the risk estimate you just saw, what percentage of women without a BRCA1 or BRCA2 mutation will get breast cancer in their lifetime?

- □ 7%
- □ 12%
- □ 23%
- □ 31%
- □ Prefer not to answer
Based on the risk estimate you just saw, how much more likely is a woman with a *BRCA1* mutation to get breast cancer in her lifetime than a woman without a *BRCA* mutation?

- □ Approximately 10%
- □ Approximately 20%
- □ Approximately 40%
- □ Approximately 60%
- □ Prefer not to answer

Based on the risk estimate you just saw, how much more likely is a woman with a *BRCA2* mutation to get breast cancer in her lifetime than a woman without a *BRCA* mutation?

- □ Approximately 10%
- □ Approximately 30%
- □ Approximately 50%
- □ Approximately 70%
- □ Prefer not to answer

Based on the risk estimate you just saw, what percentage of women with a *BRCA2* mutation will get breast cancer in their lifetime?

- □ Approximately 20%
- □ Approximately 35%
- □ Approximately 60%
- □ Approximately 85%
- □ Prefer not to answer

Please review the risk information presented in the bar graph below and answer the following questions based on your interpretation of this information. If you are taking this survey on a mobile device, it may help to hold the phone horizontally so that the entire question fits on the page.
The information presented in this risk estimate is...

Worthless
Bad
Harmful
Not Helpful
Not Useful
Irrelevant
Not Applicable
Unclear

Valuable
Good
Beneficial
Helpful
Useful
Relevant
Applicable
Clear

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA1 carrier?

- [ ] 18%
- [ ] 65%
- [ ] 71%
- [ ] 84%
Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA2 carrier?

- □ 13%
- □ 59%
- □ 71%
- □ 84%
- □ Prefer not to answer

Based on the risk estimate you just saw, what percentage of women without a BRCA1 or BRCA2 mutation will get breast cancer in their lifetime?

- □ 7%
- □ 12%
- □ 23%
- □ 31%
- □ Prefer not to answer

Based on the risk estimate you just saw, how much more likely is a woman with a BRCA1 mutation to get breast cancer in her lifetime than a woman without a BRCA mutation?

- □ Approximately 10%
- □ Approximately 20%
- □ Approximately 40%
- □ Approximately 60%
- □ Prefer not to answer

Based on the risk estimate you just saw, how much more likely is a woman with a BRCA2 mutation to get breast cancer in her lifetime than a woman without a BRCA mutation?

- □ Approximately 10%
- □ Approximately 30%
- □ Approximately 50%
- □ Approximately 70%
- □ Prefer not to answer
Based on the risk estimate you just saw, what percentage of women with a \textit{BRCA2} mutation will get breast cancer in their lifetime?

- [ ] Approximately 20%
- [ ] Approximately 35%
- [ ] Approximately 60%
- [ ] Approximately 85%
- [ ] Prefer not to answer

Please review the risk information presented in the icon array below and answer the following questions based on your interpretation of this information. If you are taking this survey on a mobile device, it may help to hold the phone horizontally so that the entire question fits on the page.

The information presented in this risk estimate is...

| Worthless | 1 2 3 4 5 6 7 8 9 10 | Valuable       |
| Bad       | 1 2 3 4 5 6 7 8 9 10 | Good          |
| Harmful   | 1 2 3 4 5 6 7 8 9 10 | Beneficial    |
| Not Helpful | 1 2 3 4 5 6 7 8 9 10 | Helpful       |
Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a \textit{BRCA1} carrier?

- □ 18%
- □ 65%
- □ 71%
- □ 84%
- □ Prefer not to answer

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a \textit{BRCA2} carrier?

- □ 13%
- □ 59%
- □ 71%
- □ 84%
- □ Prefer not to answer

Based on the risk estimate you just saw, what percentage of women without a \textit{BRCA1} or \textit{BRCA2} mutation will get breast cancer in their lifetime?

- □ 7%
- □ 12%
- □ 23%
- □ 31%
- □ Prefer not to answer

Based on the risk estimate you just saw, how much more likely is a woman with a \textit{BRCA1} mutation to get breast cancer in her lifetime than a woman without a \textit{BRCA} mutation?

- □ Approximately 10%
- □ Approximately 20%
- □ Approximately 40%
Based on the risk estimate you just saw, how much more likely is a woman with a BRCA2 mutation to get breast cancer in her lifetime than a woman without a BRCA mutation?

- Approximately 10%
- Approximately 30%
- Approximately 50%
- Approximately 70%
- Prefer not to answer

Based on the risk estimate you just saw, what percentage of women with a BRCA2 mutation will get breast cancer in their lifetime?

- Approximately 20%
- Approximately 35%
- Approximately 60%
- Approximately 85%
- Prefer not to answer

Please review the risk information below and answer the following questions based on your interpretation of this information. If you are taking this survey on a mobile device, it may help to hold the phone horizontally so that the entire question fits on the page.

**Risk of Developing Breast Cancer**

The lifetime risk that a woman without a BRCA1 or BRCA2 mutation will develop breast cancer is 12%. The lifetime risk that a BRCA1 mutation carrier will develop breast cancer is 71%. The lifetime risk that a BRCA2 mutation carrier will develop breast cancer is 84%.

The information presented in this risk estimate is...

Worthless 1 2 3 4 5 6 7 8 9 10 Valuable
Bad 1 2 3 4 5 6 7 8 9 10 Good
Harmful 1 2 3 4 5 6 7 8 9 10 Beneficial
Not Helpful 1 2 3 4 5 6 7 8 9 10 Helpful
Not Useful 1 2 3 4 5 6 7 8 9 10 Useful
Irrelevant 1 2 3 4 5 6 7 8 9 10 Relevant
Not Applicable 1 2 3 4 5 6 7 8 9 10 Applicable
Unclear 1 2 3 4 5 6 7 8 9 10 Clear

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA1 carrier?

☐ 18%
☐ 65%
☐ 71%
☐ 84%
☐ Prefer not to answer

Based on the risk estimate you just saw, what is the lifetime breast cancer risk estimate of a BRCA2 carrier?

☐ 13%
☐ 59%
☐ 71%
☐ 84%
☐ Prefer not to answer

Based on the risk estimate you just saw, what percentage of women without a BRCA1 or BRCA2 mutation will get breast cancer in their lifetime?

☐ 7%
☐ 12%
☐ 23%
☐ 31%
☐ Prefer not to answer
Based on the risk estimate you just saw, how much more likely is a woman with a *BRCA1* mutation to get breast cancer in her lifetime than a woman without a *BRCA* mutation?

- [ ] Approximately 10%
- [ ] Approximately 20%
- [ ] Approximately 40%
- [ ] Approximately 60%
- [ ] Prefer not to answer

Based on the risk estimate you just saw, how much more likely is a woman with a *BRCA2* mutation to get breast cancer in her lifetime than a woman without a *BRCA* mutation?

- [ ] Approximately 10%
- [ ] Approximately 30%
- [ ] Approximately 50%
- [ ] Approximately 70%
- [ ] Prefer not to answer

Based on the risk estimate you just saw, what percentage of women with a *BRCA2* mutation will get breast cancer in their lifetime?

- [ ] Approximately 20%
- [ ] Approximately 35%
- [ ] Approximately 60%
- [ ] Approximately 85%
- [ ] Prefer not to answer

Of the four risk estimate formats that you just saw, which one did you like the most?

- [ ] Words only
- [ ] Line graph
- [ ] Bar graph
- [ ] Icon array
- [ ] Prefer not to say

Of the four risk estimate formats that you just saw, which one did you find the easiest to understand?

- [ ] Words only
Of the four risk estimate formats that you just saw, which one did you find the most difficult to understand?

- □ Words only
- □ Line graph
- □ Bar graph
- □ Icon array
- □ Prefer not to say

How likely are you to get [cancer/another cancer] in your lifetime?

1 2 3 4 5 [6] [prefer not to answer]

- Not likely
- Definitely

If you were to develop [cancer/another cancer], how serious would it be?

1 2 3 4 5 [6] [prefer not to answer]

- Not likely
- Definitely

How likely are you to get [cancer/another cancer] compared to other women without a BRCA mutation?

1 2 3 4 5 [6] [prefer not to answer]

- Not likely
- Definitely

How likely are you to get [cancer/another cancer] compared to other women with a BRCA mutation?

1 2 3 4 5 [6] [prefer not to answer]

- Not likely
- Definitely