SUPPLEMENTAL MATERIAL

Preferences for Return of Genetic Results among Participants in the Jackson and Framingham Heart Studies

Supplemental Methods

Methods

Participants

The FHS and JHS are prospective longitudinal cohort studies that examine the natural history, risk factors (including genetic factors), and prognosis of cardiovascular and other diseases in primarily European-American and African-American populations, respectively.[1, 2] Since the 1950s, FHS has enrolled three generational cohorts; members of subsequent generations are related to members of the first generation as offspring, spouses of offspring or grandchildren. Because Framingham residents were almost entirely of European origin when the study began, the legacy FHS cohorts are primarily white. To increase the diversity of the participant sample, FHS therefore enrolled two additional "Omni" cohorts in 1994 and 2003. By the time the survey mailings began, all FHS participants who had attended recent exams had received consent forms that included information and check-box options about participating in genetic studies, about DNA and cell line collections, and about permission to be notified of genetic results with important health and treatment implications (the relevant items read, "I agree to provide a blood sample from which genetic material…can be obtained. I agree to allow my data and blood samples to be used in the genetic studies of factors contributing to heart and blood vessel diseases, lung and blood diseases, stroke, memory loss, cancer, and other diseases and health conditions"; "I

agree to allow my data and blood samples to be used in genetic studies of reproductive conditions, and mental health conditions such as alcohol use and depressive symptoms"; and "If a genetic condition is identified that may have important health and treatment implications for me, I agree to allow the FHS to notify me, and then with my permission to notify my physician"). Over 99% of the FHS participants who had been invited to participate in genetic research had agreed to do so.[3] For the present study, surveys were mailed in late 2011 to a randomly selected subset (n=1308) of the over 7000 FHS Generation 2 and 3 participants, as well as to all 226 African-American members of the Omni cohorts, who had previously agreed to participate in genetic research. To avoid biasing results, surveys were sent to FHS participants regardless of whether they had agreed to or declined return of genetic results.

JHS is an outgrowth of the Atherosclerosis Risk in Communities study, which helped establish that cardiovascular disease morbidity and mortality are substantially higher among African-Americans throughout the U.S., particularly among those in Mississippi. At its inception, the study enrolled a representative, population-based cohort of 5301 self-described African-American persons aged 35-84 years from the three counties in the Jackson Metropolitan Statistical Area.[2] A layered consent process gave participants clear choices regarding the use of their genetic materials. For example, participants could withhold permission for family studies or the isolation of genomic DNA. Similarly, participants could limit the use of their genetic material to the study of cardiovascular disease or allow its use for any major disease or health condition. Of 5301 enrollees, 87% agreed to participate in genetic research ("I agree to participate in the genetic (inheritance/DNA) studies, and provide a blood sample from which DNA will be extracted";

the contemporaneous JHS consent form did not mention return of genetic results). For this study, surveys were mailed in late 2011 to a randomly selected subset (n=1426) of the JHS participants who had consented to participate in genetic research.

Survey Instrument

We developed a draft questionnaire, and we then conducted in-person cognitive debriefing interviews to assess the clarity of the vignettes and the questionnaire items and the format of the survey booklets.[4] A convenience sample of 27 individuals completed the in-person debriefing interviews; 12 were participants in the JHS, whereas at the request of the FHS, 16 individuals from communities around Framingham who were demographically similar to FHS participants were identified by a commercial recruitment firm. The sample was stratified by age and level of education.

During a debriefing session, each respondent completed one of two versions of the survey booklet (each booklet had two vignettes) at the beginning of each session. Then, using retrospective probing techniques, interviewers asked the respondent to 1) discuss their reasons for choosing each response; 2) comment on the clarity of the vignette; and 3) rephrase each sentence in the scenario in their own words. The interviews were recorded and transcribed.

Using thematic analysis[5], we examined responses related to degree of understanding of concepts covered in the vignettes, reasoning behind the desire for return of results, and comments about the survey format and design. Results suggested while respondents in both study locations generally understood the vignette scenarios, it was important to use a

pictogram to illustrate the concept of risk, and to avoid an overload of numeric information, the vignettes were revised so that the relative risk was implicit in the pictograms rather than explicit in text. Second, to avoid framing bias, we modified the risk statements to present both the numbers of individuals who would and would not develop the relevant phenotype. Third, because interviews suggested that numeracy might be associated with judgments, we added the Subjective Numeracy Scale to the survey. Finally, question ordering was modified so that the vignettes followed the attitudinal questions, in order to avoid the former influencing the latter.

The survey instrument included two types of vignettes (see online Appendix 2 for an example of a survey booklet). The first was generated using the factorial survey method, a social science technique that combines the advantages of experimental designs (e.g., ability to incorporate orthogonal factors) and survey research (e.g., ability to incorporate real-world complexity).[6-10] Each vignette, which was approximately 125 words long and had a Flesch-Kincaid Grade Level of approximately 7.1, described a hypothetical genetic variant identified during the course of research. Each vignette specified five phenotypic characteristics associated with the hypothetical variant: 1) its severity (four levels, varying from a painless rash to death); 2) its preventability; 3) its reproductive implications; 4) the relative risk of developing the phenotype among those with, compared to those without, the variant; and 5) the absolute risk of developing the phenotype among those with the variant. In order to explore the extent to which factors that are important to experts match those that are salient to research participants, we chose these five factors based on their inclusion among the criteria articulated by NHLBI guideline panels for deciding when to offer return of genetic research test results.[11, 12]

There were 64 possible vignettes (i.e., 4x2x2x2x2=64 factor combinations; see online Appendix 3 for the full set of 64 factorial vignettes). To balance the desire for multiple data points per person with respondent burden while ensuring factor orthogonality, each survey included three vignettes randomly selected from among the 64 possible combinations. To ensure variation in vignette factors within respondents, the selection of vignettes was constrained such that each level of the 2-level factors appeared at least once and each of the 4 severity descriptors appeared at most once. Each unique combination of five factors appeared in 1.33% to 1.80% of vignettes. Appendix Table 1 shows the factors and their levels used for the analysis reported here.

Respondents were asked whether, given these characteristics, they would want the researchers to inform them if they carried the variant described in each vignette. Respondents could choose from among five response options: definitely tell me, probably tell me, probably not tell me, definitely not tell me, and prefer not to answer. A pilot test, conducted using 129 participants from JHS and 97 participants randomly sampled from a town in metropolitan Boston that is demographically similar to Framingham , resulted in several changes to the vignette design: 1) use of "chronic arthritis (pain and swelling of joints)" rather than "chronic diarrhea" as a phenotype; 2) modification of the levels of absolute and relative risk; 3) use of titles for the pictograms that state the numbers of individuals with the variant ("X/1000") who will develop the disease; and 4) a statement of the relative risk following the pictograms (e.g., "This means that the risk of the disease is X times as high among people who have the mutation"). Based on the results of the pilot test, we also added four items related to knowledge of genetic testing and refined the sociodemographic items included in the survey instrument.

In addition to the three vignettes generated from the factorial survey, every survey included two realistic vignettes, identical in all survey booklets. These two vignettes asked respondents to indicate whether or not they would want to be notified of a variant that increased their risk for blood clots (modeled on heterozygosity for Factor V Leiden) and for a variant associated with early-onset Alzheimer's disease (modeled on presenilin 1/2 variants).[13, 14] The vignettes were 183 and 159 words long, respectively, and had Flesch-Kincaid Grade Levels of 5.6 and 9.5. These realistic vignettes, which map onto the design of the factorial survey, were included due to the abstract, decontextualized nature of the factorial vignettes.

Pictograms (icon arrays) accompanied each vignette to enhance comprehension of risk information, particularly among lower-numeracy respondents.[15-17] These showed the numbers of individuals with and without the genetic variant described in the vignette who were expected to develop the phenotype.

Survey Data Collection

Surveys were mailed to JHS and FHS participants by the staff of the respective cohorts using their own study letterhead. Completed surveys were returned to the JHS and FHS headquarters and then forwarded in batches, with participant identification numbers but without direct identifiers, to the coordinating center at Education Development Center. The fielding process followed the method of Dillman, including: 1) a brief pre-notification letter; 2) an initial survey mailing; 3) a follow-up reminder letter; 4) a second survey mailing sent to nonrespondents three weeks after the first survey mailing; and 5) a third survey mailing sent to nonrespondents three weeks after the second.[18] For JHS, the first mailing included a

$10 gift-card incentive; at the request of FHS leadership, no financial incentive was included with the mailings to FHS participants.

Main Outcomes and Covariates

The primary outcomes were the responses to the question, "Would you want the researchers to tell you about your increased risk for this disease?," for each of the three factorial vignettes and the two realistic vignettes in each survey.

Attitude towards genetic testing was assessed using a measure developed by Michie et al.[19] Respondents rated their attitudes to undergoing a genetic test on three 5-point scales: "a bad thing - a good thing," "beneficial - harmful," and "important – not important." The measure is scored by averaging responses across the three items, after reverse-coding the 2nd and 3rd items. Higher scores indicate more favorable attitudes. Internal reliabilities (Cronbach's alpha) were 0.80, 0.87 and 0.83 in the JHS, FHS and FHS-Omni samples, respectively. *Knowledge of genetics and genetic testing* was measured by counting the number of correct responses to a measure combining four questions from Singer et al and three questions from Furr et al.[20, 21] The knowledge questions preceded the vignettes so that the vignettes did not inadvertently cue the correct answers. A single item was used to measure *prior experience with genetic testing.*[22]

Numeracy, the respondent's level of comfort using numbers, was measured using four items from Fagerlin et al's Subjective Numeracy Scale (SNS).[23] The SNS correlates with, and is more acceptable to respondents than, objective numeracy tests. In the pilot, a scale based on four of the eight items was highly correlated (r=0.95) with the full 8-item scale, so

respondent burden was reduced by using only four items. The scale was constructed by averaging the responses to the four questions, each of which used a 1 to 6 scale. Higher SNS scores indicate greater numeracy.

Demographic questions included level of education, work status, marital status, whether the respondent had any children, religious preference, and how frequently the respondent participated in organized religious activities. FHS and JHS provided the age and sex of each respondent.

Statistical Analysis

Regression analyses were carried out to examine the influences of the vignette factors (e.g., severity, preventability) and of respondent characteristics on participants' desire for results, and more generally to evaluate whether respondents' preferences were sensitive to expert-identified criteria. We analyzed the factorial survey data first because the orthogonality of the factor design allowed all factors to be included in the model. Each survey included three of the factorial vignettes. Each response to a factorial vignette was treated as a separate observation, so up to three responses were nested within each respondent. Factorial vignettes in which the response was either skipped or "prefer not to answer" were excluded from the analyses (<5% of responses were excluded for this reason). To take advantage of the ordinal information available in the four responses (definitely tell me, probably tell me, probably not tell me, and definitely not tell me) and to facilitate the use of stepwise methods, we first used standard (ordinary least squares, OLS) regression to describe the contribution of the five vignette factors to the variation in the responses. Stepwise methods were used to explore the additional influence of respondent

characteristics (covariates were included when bivariate $\alpha \leq 0.10$). After initial stepwise selection, remaining variables were retested for inclusion in the regression model. Finally, the factorial vignette responses were then categorized into binary outcomes using an *a priori* selected cut point ('definitely/probably tell' vs. 'definitely/probably not tell') and fitted using generalized linear mixed models ($\alpha < 0.05$). A random intercept was included to account for between-subject heterogeneity arising from the repeated measures data. The final model included all five vignette factors, as well as any respondent covariates that were statistically significant in any of the JHS, FHS, or Omni cohorts, to facilitate examination of the results across the cohorts. All analyses were conducted using SAS/STAT* software version 9.4 (SAS Institute, Cary, NC).

Respondents provided a single response to each of the two realistic vignettes, so no nesting within respondent occurred. Thus, each realistic vignette was analyzed separately using standard logistic regression on the same *a priori* selected cut point as in the factorial vignettes. Stepwise methods were used to explore the influence of respondent characteristics. Covariates were included when bivariate $\alpha \leq 0.10$. The final models included any respondent covariates that were statistically significant in at least one of the three cohorts or in either of the realistic vignettes. We anticipated ample power to detect 'small' regression effect[24] (partial $R^2 = 0.02$) within the JHS and FHS cohorts, assuming moderate within-person correlation ($r = 0.5$), negligible between-person correlation, approximately 900 respondents in each cohort, and no more than 30 covariates. Power in the Omni cohort was limited by the small number of enrolled African-Americans. As prespecified in the study protocol, we analyzed the JHS, FHS and FHS Omni cohorts separately, without conducting statistical comparisons among them.

Ethics Review

The study was approved by the IRBs at the Dana-Farber Cancer Institute, Education Development Center, Jackson State University, and Boston University. Consistent with the requirements of the Common Rule, return of a completed questionnaire was considered evidence of consent.

Data Sharing

The JHS and FHS Coordinating Centers will post their respective data from this study with the NHLBI Biologic Specimen and Data Repository Information Coordinating Center (https://biolincc.nhlbi.nih.gov/home/).

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Supplemental Table 1. Factors and levels used in factorial vignettes*

FACTOR	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4
1. Relative risk of phenotype among those with the variant	15	1.5	--	--
2. Absolute risk of phenotype among those with the variant	300/1000	30/1000	--	--
3. Severity of phenotype	Death	Loss of memory and other mental abilities	Chronic arthritis (pain and swelling in joints)	Painless rash
4. Preventability	Can be prevented by medical treatment	Cannot be prevented by medical treatment	--	--
5. Reproductive risk	There is a 1 in 2 chance	It is unlikely	--	--

* See online Appendix 2 for a representative survey booklet and online Appendix 3 for the full set of 64 factorial vignettes.

20001

SUPPLEMENTAL MATERIAL: EXAMPLE SURVEY BOOKLET

What Do You Think? When Should Researchers Give People Who Take Part in Genetic Research the Results of Their Genetic Tests?

A Project of
Jackson Heart Study,
Education Development Center, Inc.,
and
Dana-Farber Cancer Institute.

Made possible by

The National Human Genome Research Institute
The National Institutes of Health

September 2011

In the following pages, we will ask for your opinions about research on the genetic causes of disease. Our main goal is to understand whether people who take part in genetic research want to know if their research test results indicate an increased risk for disease.

There are advantages and disadvantages to learning about one's genetic risk for disease. As a result, researchers are struggling to decide whether or not to offer the results of genetic tests from research to the people who took part in those studies. Your answers to the questions on this survey will help researchers understand the opinions of people who are involved in studies like the Jackson Heart Study. Although answering this survey will not benefit you directly, your answers will be extremely valuable in helping researchers around the world decide what to do when the research reveals genetic information about the people who are in the study.

There are no right or wrong answers to these questions about your opinions. We just want to know what you think. At the end of the survey, we will also ask you a few questions about yourself.

The survey will take about 15 minutes to complete. For most questions you will be asked to check a box next to your response. For example,

Do you have a pet? ***Please check one.***

☐ No

☐ Yes

☐ Not sure

☐ Prefer not to answer

Your participation in the survey is voluntary. A decision to respond or not respond will not affect your participation in the Jackson Heart Study or any benefits to which you are entitled. You may skip any questions you do not wish to answer. There are no risks to you from answering this survey.

If you have any questions about this survey or research study, please contact Lynette Ekunwe at (601) 979-8728. If you have any questions about your rights as a research subject, please contact Dr. Felix Okojie at (601) 979-2931.

Thank you for your help!

BACKGROUND INFORMATION ABOUT GENETICS

In this survey, we ask you for your opinions about some important questions that genetic researchers face. To help you understand these questions, this page provides some information about genetics and genetic tests. Before you complete the survey, please review this information. This information may help as you consider the questions below.

Genetic tests involve the examination of genes (DNA). Genes are units of information stored inside the cells of our body. They contain the instructions for our growth and development. They are passed on (inherited) from parents to children.

Genetic tests can identify changes in genes called *mutations*. Mutations may contribute to heart disease, cancer, and other diseases.

- A few illnesses, like sickle cell disease, result mainly from mutations in genes.
- More common diseases like diabetes and heart disease also involve mutations in genes.
- Environment and lifestyle also affect your risk of these diseases. Diet, exercise, and smoking are examples of environment and lifestyle factors.

1. Below is a list of words that describe how some people feel about genetics. Please read the list of words. Then check *all* the words that describe how *you* feel about genetics. You may check as many or as few words as you wish.

☐ Enthusiastic	☐ Indifferent	☐ Cautious	☐ Optimistic
☐ Horrified	☐ Confused	☐ Hopeful	☐ Concerned
☐ Mixed feelings	☐ Excited	☐ Pessimistic	☐ Worried

For each of the following items, please check the box that best describes your attitude about having a genetic test.

2. **A bad thing** **A good thing**

☐1 ☐2 ☐3 ☐4 ☐5

3. **Beneficial** **Harmful**

☐1 ☐2 ☐3 ☐4 ☐5

4. **Important** **Not important**

☐1 ☐2 ☐3 ☐4 ☐5

5. Have you ever had a genetic test to find out if you are at increased risk for a disease? ***Please check one.***

☐ No

☐ Yes

☐ Not sure

6. As far as you know, is each of the following statements about genetics true or false, or are you not sure? *Please check one.*

	True	False	Not Sure
a. If a person has a genetic mutation for a disease, the person will always get the disease.	☐1	☐2	☐3
b. Only mothers can pass on genetic diseases.	☐1	☐2	☐3
c. People can be healthy even if they have a genetic mutation for a disease.	☐1	☐2	☐3
d. Genetic testing can be used in adults to find out if they have a greater than average chance of developing certain kinds of cancer.	☐1	☐2	☐3
e. Genetic testing can be used in adults to find out if they have a greater than average chance of developing depression.	☐1	☐2	☐3
f. Genetic testing can be used in adults to predict whether a person will have a heart attack.	☐1	☐2	☐3
g. Genetic testing can be used during pregnancy to find out whether the baby will develop sickle cell disease or cystic fibrosis.	☐1	☐2	☐3

For the next three questions, please imagine that you are taking part in a medical research study. In this study, the researchers run genetic tests on a few cells from each person who takes part. They do these tests to look for mutations in people's genes (DNA). The researchers then study whether people with these mutations in their genes are more likely to get certain diseases.

This research will help scientists and doctors understand the genetic (inherited) causes of disease. This understanding will allow researchers to develop better tests and treatments in the future.

The genetic mutations that affect some diseases are already known. The tests on your genes might show that you have an increased risk for one of those diseases. The questions in this section ask if you would want to know about your increased risk.

Some people might decide that they want to know the results of their genetic tests. Reasons for wanting to know might include

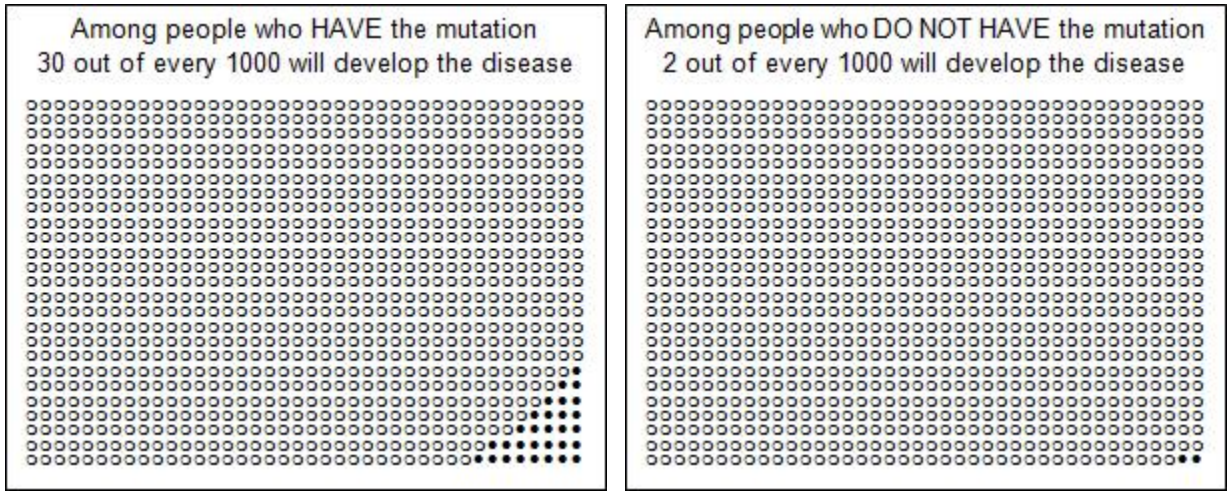
- preparing yourself or your family for an illness;
- helping you to make decisions on having or not having children;
- curiosity;
- the possibility that an effective prevention or treatment might be available;
- the possibility that you might be able to find the disease early if you know you are at risk.

Other people might decide that they do not want to know the results of their genetic tests. Reasons for not wanting to know might include

- worry from knowing about your increased risk;
- worry about your family members who might also have the mutation;
- the possibility that no effective prevention or treatment would be available;
- the possibility that you might need to have additional medical tests;
- the chance that learning about your risk could cause problems with employment, health insurance or life insurance.

7. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

- There is a 1 in 2 chance that the risk for the disease would be passed on to your children.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

☐ Definitely not tell me

☐ Probably not tell me

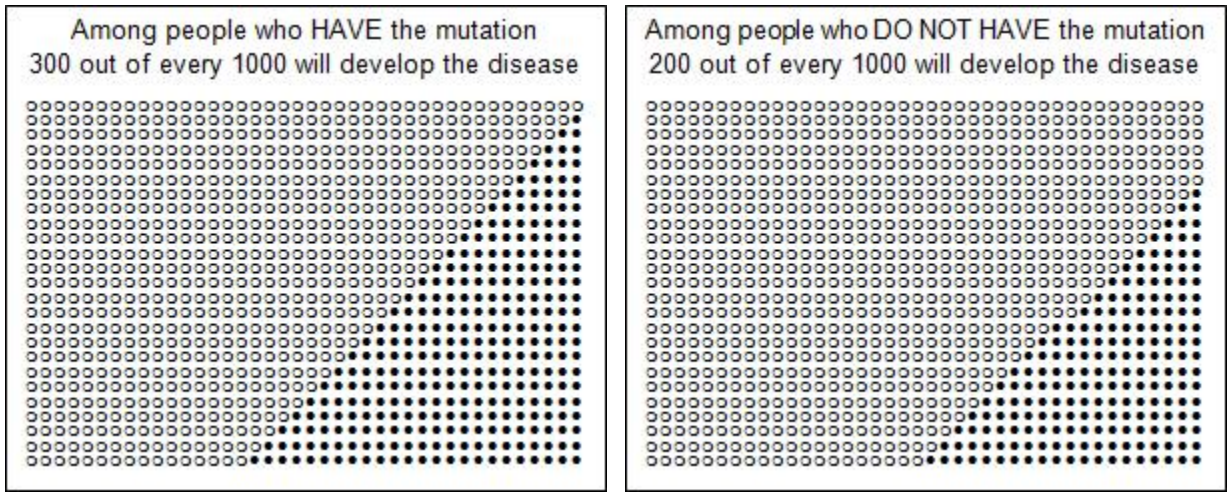
☐ Probably tell me

☐ Definitely tell me

☐ Prefer not to answer

8. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a different disease. Some important facts about this second disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

- It is unlikely that the risk for the disease would be passed on to your children.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

☐ Definitely not tell me

☐ Probably not tell me

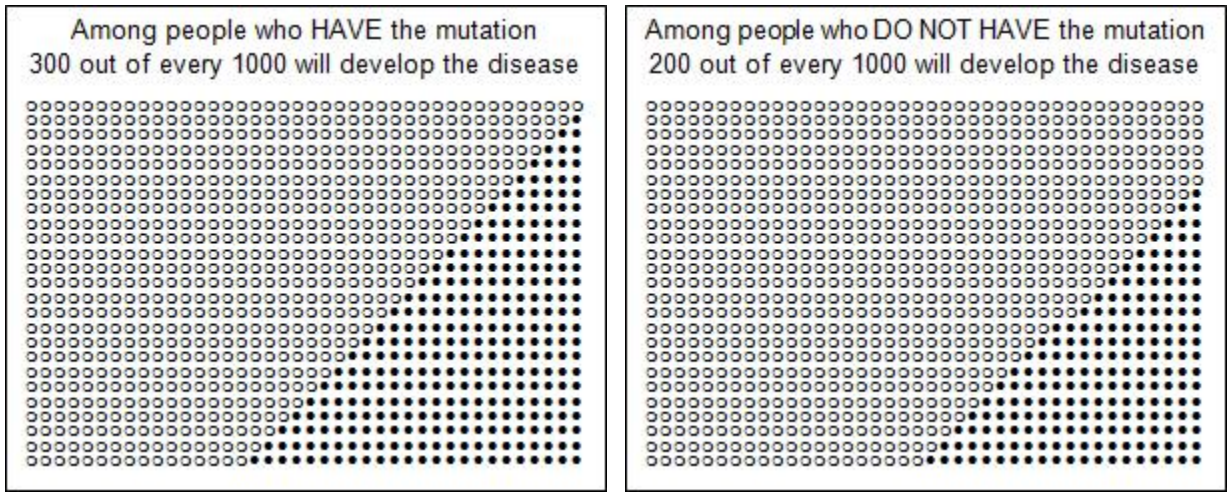
☐ Probably tell me

☐ Definitely tell me

☐ Prefer not to answer

9. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for yet a different disease. Some important facts about this third disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

- There is a 1 in 2 chance that the risk for the disease would be passed on to your children.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

☐ Definitely not tell me

☐ Probably not tell me

☐ Probably tell me

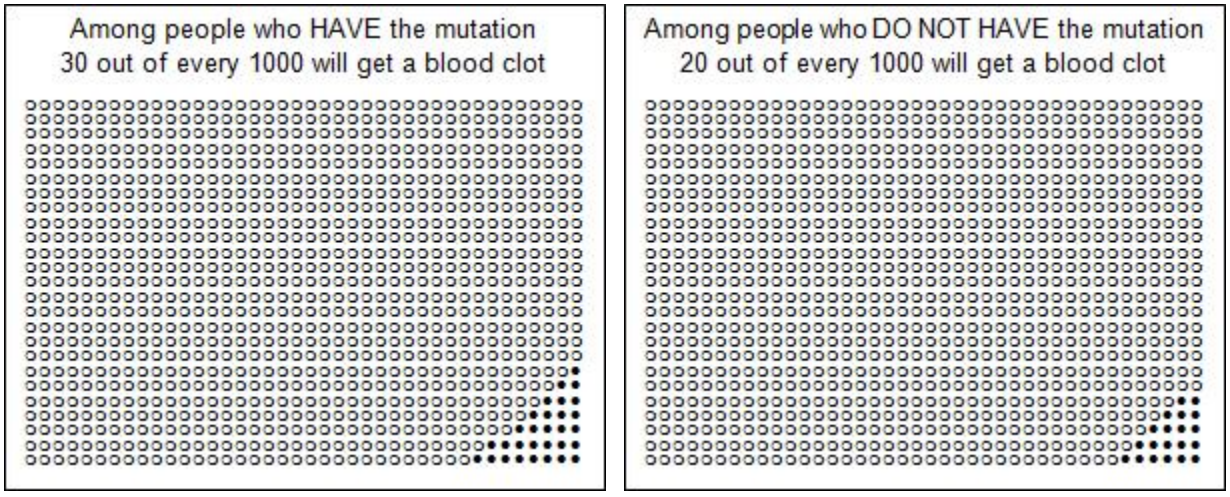
☐ Definitely tell me

☐ Prefer not to answer

Now we are going to ask you a few questions about two specific genetic diseases.

10. Some people have a genetic mutation that can cause the blood to clot too much. This increases the risk of serious blood clots, usually in the veins of the legs. Clots can cause pain and swelling in the affected body part. Also, a piece of the clot can break free and travel through the blood to the lungs. Clots that travel to the lungs can cause chest pain and shortness of breath. In some cases, they can be life-threatening.

The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



❍ Person who WILL NOT get a blood clot

● Person who WILL get a blood clot

This means that the risk of developing a blood clot is 1-½ (one and a half) times as high among people who have the mutation.

Currently, people with this mutation do not receive any medicines to prevent blood clots.

There is a 1 in 2 chance that a person with this mutation will pass the increased risk of blood clots on to their children.

a. Suppose that tests run on your genes as part of a research study show that you have the genetic mutation that can cause the blood to clot too much. Would you want the researchers to tell you about your increased risk of blood clots? *Please check one.*

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

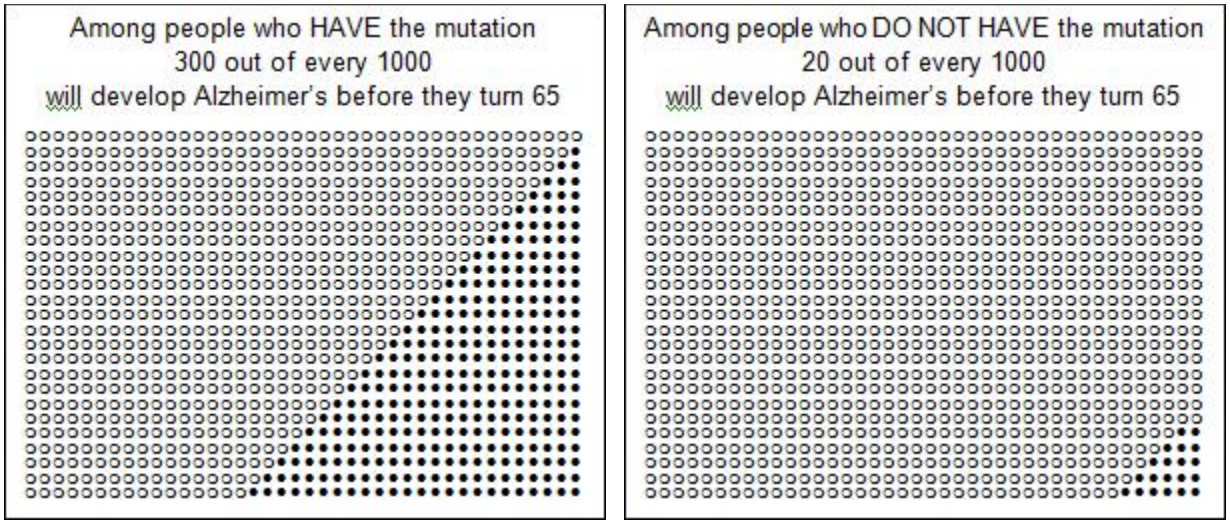
b. Do you personally know anyone who has had a blood clot?

- ☐ No
- ☐ Yes
- ☐ Not sure

11. Alzheimer's disease is a condition that usually affects older adults. It causes dementia (loss of memory and thinking abilities) that gets worse with time.

Some people have a mutation that increases their chance of developing Alzheimer's disease. People with this mutation usually develop Alzheimer's disease at an earlier age (usually before age 65).

The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of developing Alzheimer's disease before they turn 65 is 15 times as high among people who have the mutation.

Currently, there are no treatments that can reduce the risk of getting Alzheimer's disease.

There is a 1 in 2 chance that a person with this mutation will pass the increased risk for early Alzheimer's disease on to their children

a. Suppose that tests run on your genes as part of a research study show that you have the genetic mutation that can cause early Alzheimer's disease. Would you want the researchers to tell you about your increased risk for early Alzheimer disease? *Please check one.*

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

b. Do you personally know anyone who has had Alzheimer's disease?

- ☐ No
- ☐ Yes
- ☐ Not sure

12. Below we have listed four factors that might affect whether or not researchers should offer the results of genetic tests to people who take part in genetic research studies. Please rank the four factors listed below from 1 (most important) to 4 (least important). Place a "1" next to the factor that is most important to you when deciding if you would want to be told that you have a mutation. Place a "2" next to the second most important factor, and so on. Remember, no two factors can have the same ranking.

_____How much higher the risk of disease is among people who have the mutation

_____Whether or not people who have the mutation might pass the risk of the disease on to their children

_____How serious the disease is

_____Whether or not the development of the disease can be prevented by medical treatment

13. We would like to know something about how comfortable you are working with numbers. For each of the following questions, please check the box that best reflects *how good you are at*

	Not at all good					**Extremely good**
a. working with fractions?	☐1	☐2	☐3	☐4	☐5	☐6
b. working with percentages?	☐1	☐2	☐3	☐4	☐5	☐6

For each of the following questions, please check the box that *best reflects your answer*

c. When reading the newspaper, how **helpful** do you find tables and graphs that are parts of a story?

Not at all helpful					**Extremely helpful**
☐1	☐2	☐3	☐4	☐5	☐6

d. When people tell you the chance of something happening, do you prefer that they use **words** ("it rarely happens") or **numbers** ("there's a 1% chance")?

Always prefer words					**Always prefer numbers**
☐1	☐2	☐3	☐4	☐5	☐6

14. What is today's date?

_____/_____/ _____
Month Day Year

15. What is the highest grade or level of school that you have completed? *Please check one*.

- ☐ 8th grade or less
- ☐ Some high school
- ☐ High school graduate or equivalent
- ☐ Some college or technical school
- ☐ College graduate (Associates or Bachelors)
- ☐ Graduate or professional school (for example Masters, PhD, MD, JD/LLB)
- ☐ Prefer not to answer

16. What language do you mainly speak at home? *Please check one.*

- ☐ English
- ☐ Other (*specify*): _____
- ☐ Both English and another language (*please write in other language*):_____
- ☐ Prefer not to answer

17. What is your current marital status? *Please check one.*

- ☐ Single, never married
- ☐ Married or living with a partner
- ☐ Divorced or separated
- ☐ Widowed
- ☐ Other (*specify*): _____
- ☐ Prefer not to answer

18. Do you have any children? ***Please check one.***

- ☐ Yes
- ☐ No
- ☐ No, but I hope to have children in the future
- ☐ Prefer not to answer

19. What is your religious preference?

- ☐ Protestant, Baptist
- ☐ Protestant, Methodist
- ☐ Protestant, Other Denomination (please specify: _____)
- ☐ Catholic
- ☐ Jewish
- ☐ Muslim/Islam
- ☐ None
- ☐ Other (please specify: _____)
- ☐ Prefer not to answer

20. In general, how often do you attend the main service of your place of worship or otherwise participate in organized religion (such as watching services on TV, listening to services on the radio, participating in Bible study groups or other religious study groups, etc.)?

- ☐ Nearly every day
- ☐ At least once a week
- ☐ A few times a month
- ☐ A few times a year
- ☐ Less than once a year
- ☐ Not at all
- ☐ Prefer not to answer

21. What type of health insurance coverage do you have? ***Please check all that apply.***

- ☐ None
- ☐ Private insurance
- ☐ CHAMPUS/Veterans or other military coverage
- ☐ Medicaid
- ☐ Medicare
- ☐ Other (*specify*): _____
- ☐ Prefer not to answer

22. What is your current work status? ***Please check one.***

- ☐ In school
- ☐ Working full time
- ☐ Working part time
- ☐ Homemaker
- ☐ Disabled
- ☐ On medical leave from work
- ☐ Unemployed, looking for work
- ☐ Unemployed, not looking for work
- ☐ Retired
- ☐ Other (*specify*): _____
- ☐ Prefer not to answer

23. Are you Hispanic or Latino(a)? ☐ No ☐ Yes

24. Would you like to be able to look up the results of your genetic tests from the Jackson Heart Study on a password protected website? ***Please check one.***

- ☐ No
- ☐ Yes
- ☐ Not sure

THIS COMPLETES THE SURVEY.

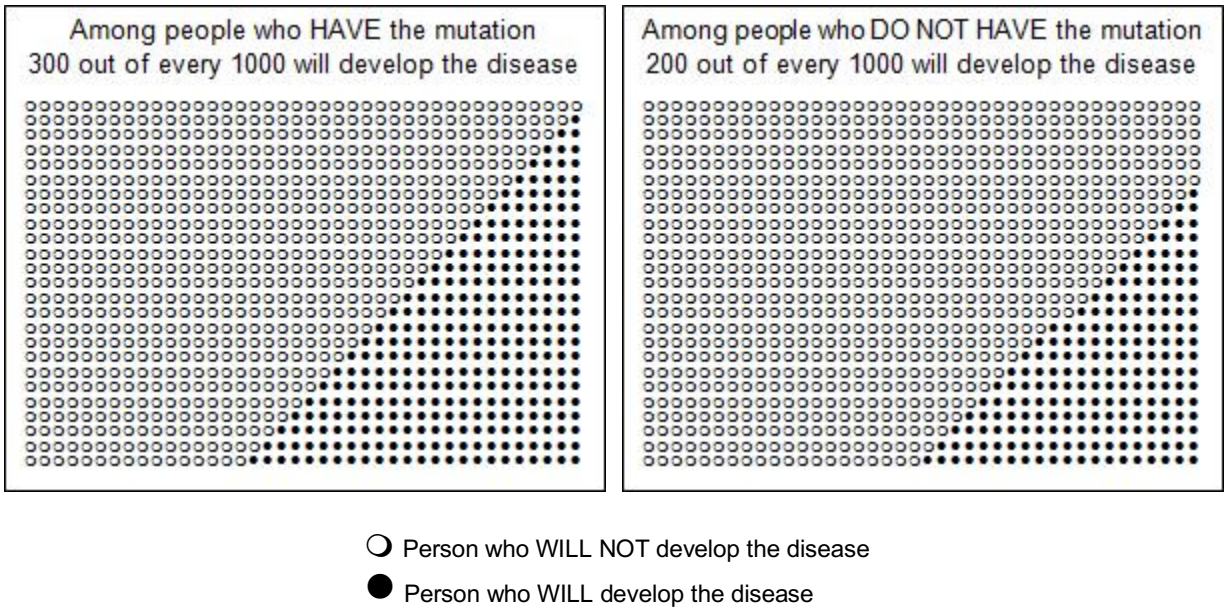
PLEASE RETURN IT IN THE ENVELOPE PROVIDED.

THANK YOU VERY MUCH FOR YOUR HELP.

SUPPLEMENTAL MATERIAL: FULL SET OF 64 FACTORIAL VIGNETTES

1. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

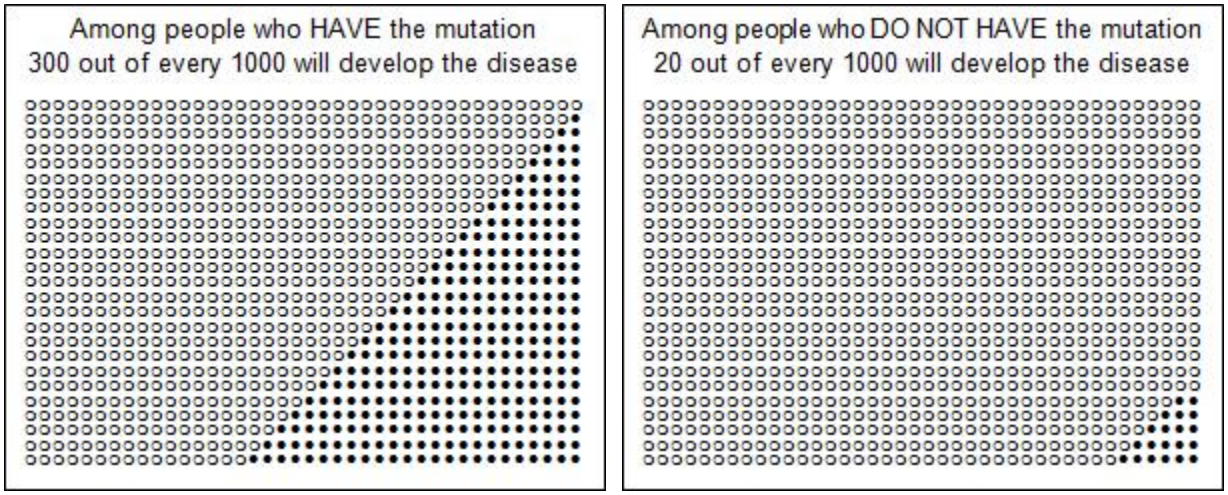
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

2. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

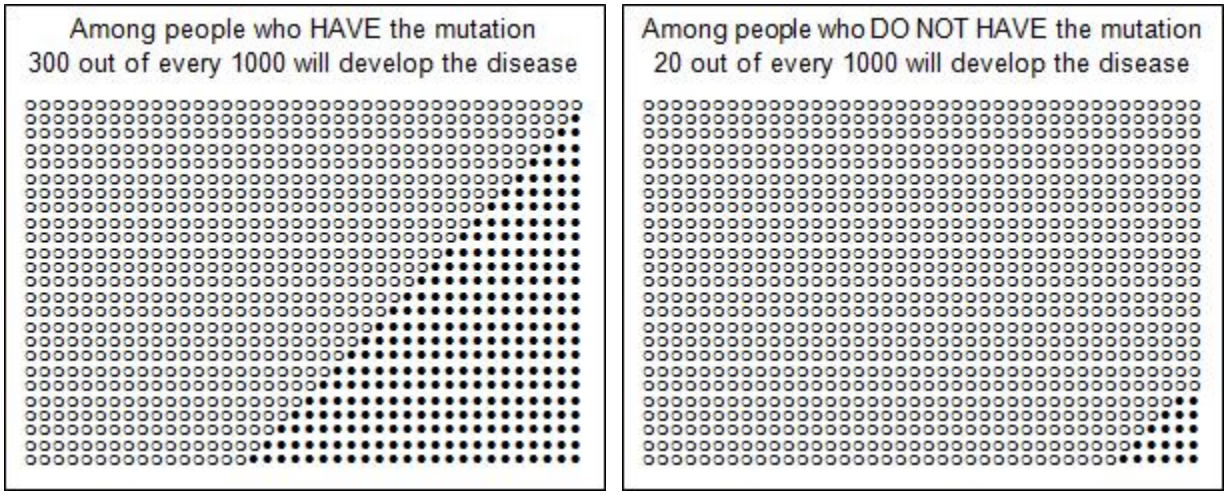
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

3. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

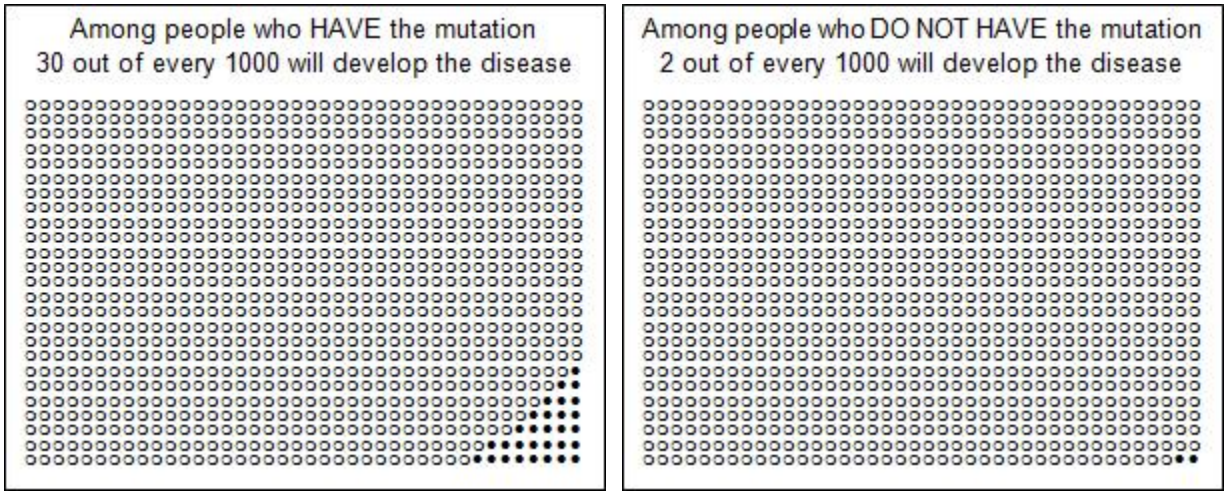
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

4. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



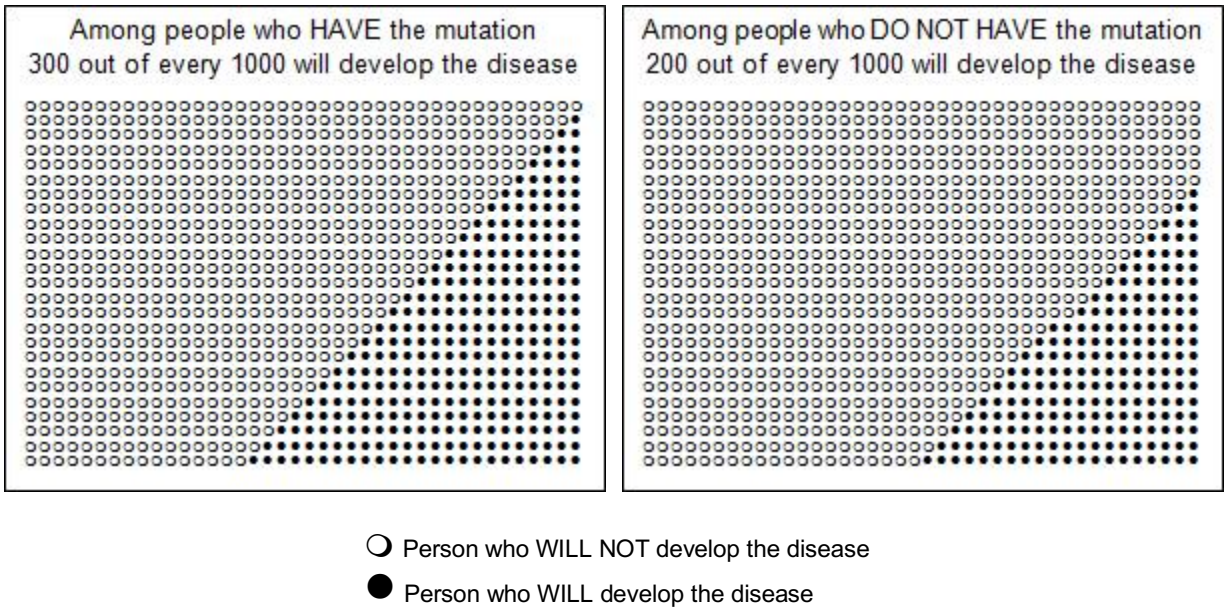
This means that the risk of the disease is 15 times as high among people who have the mutation.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

5. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

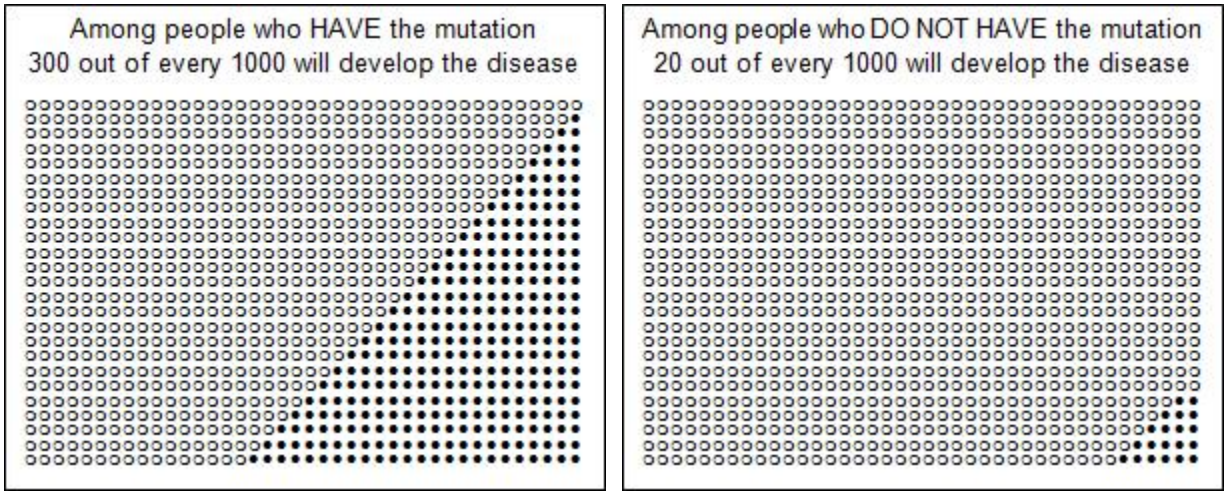
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

6. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

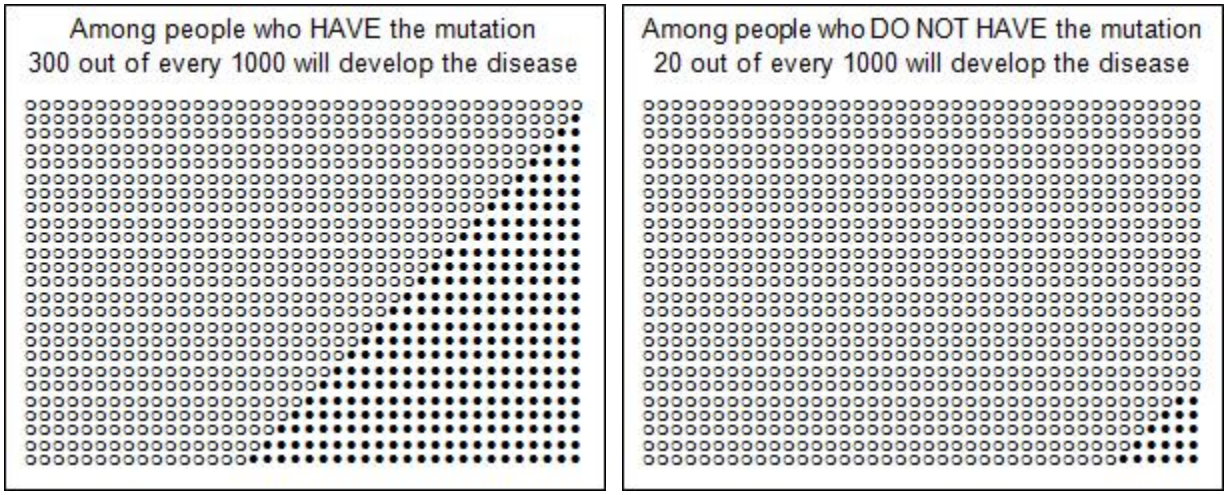
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

7. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

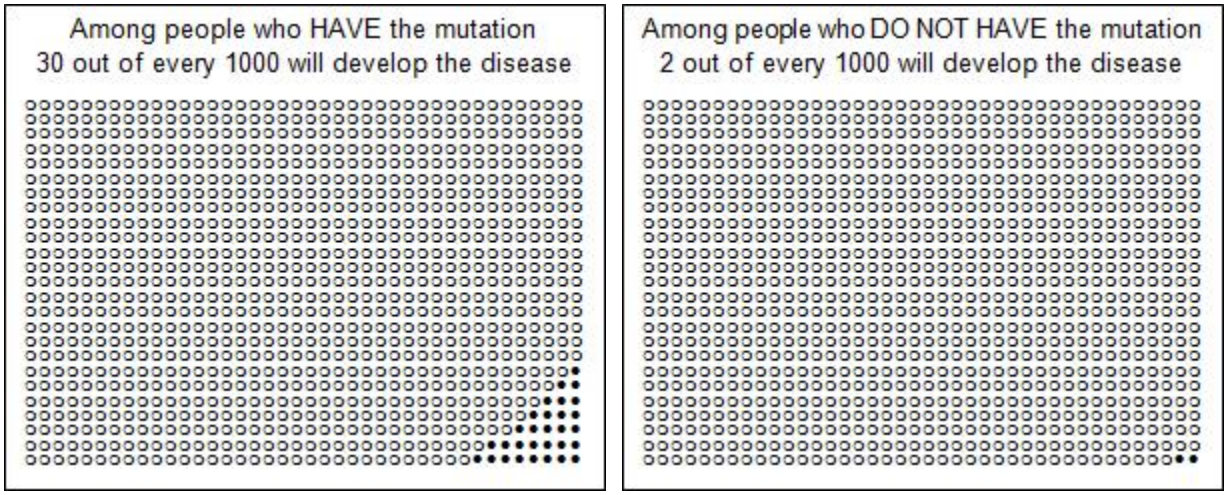
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

8. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

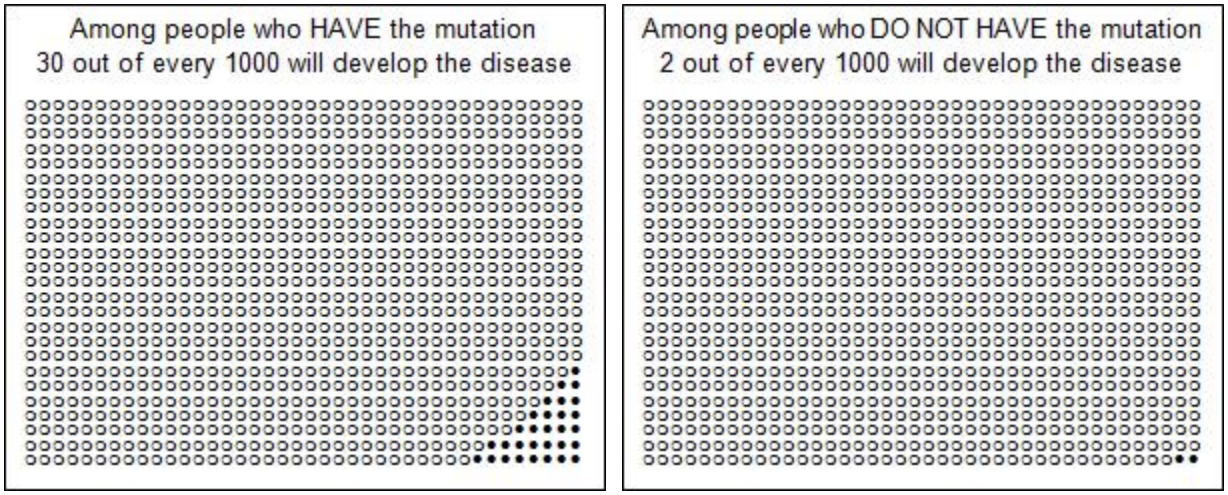
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

9. **Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

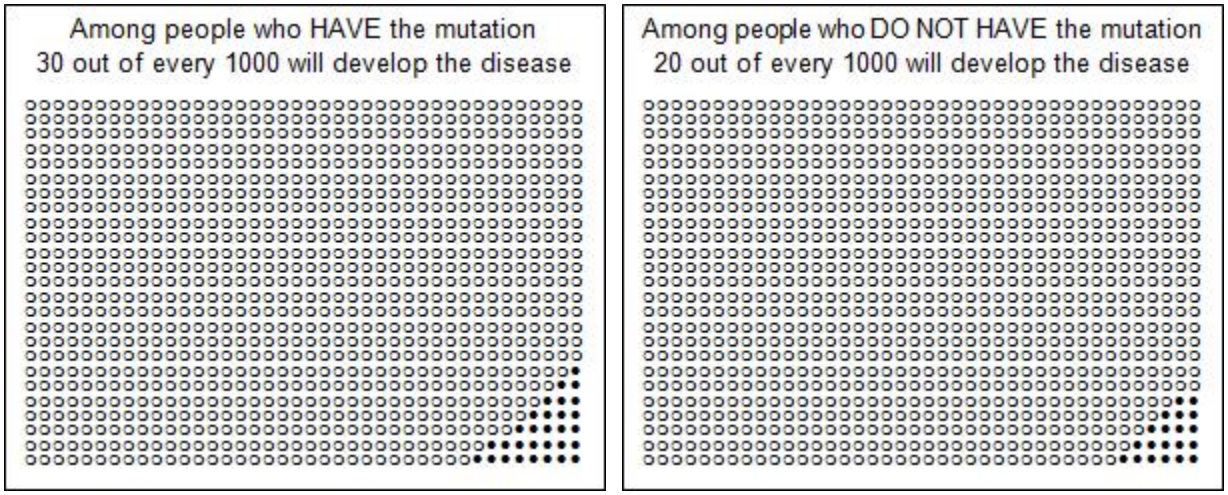
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

10**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

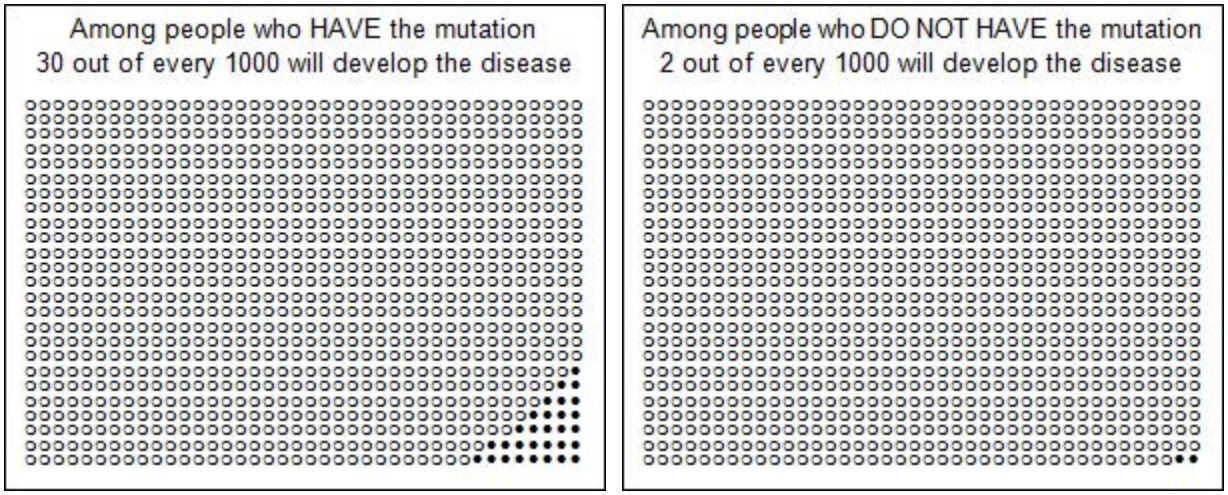
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

11**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

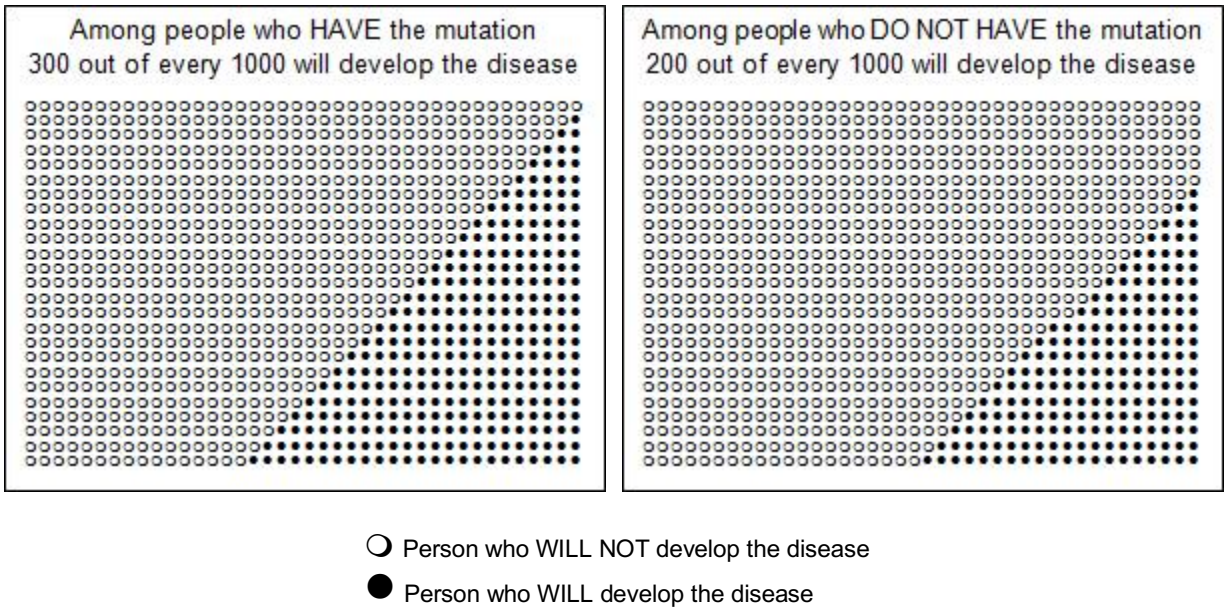
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

12**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

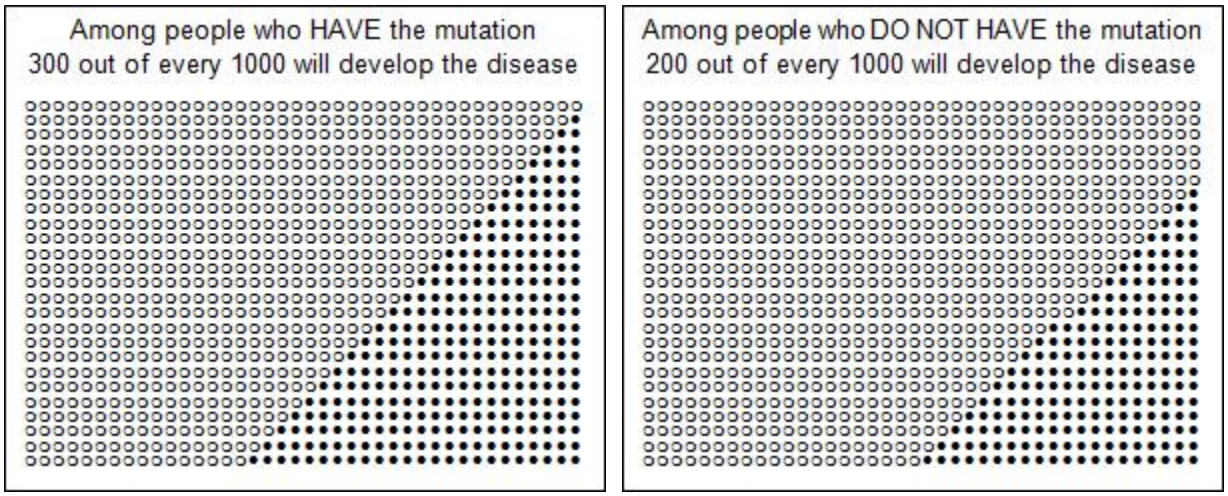
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

13**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

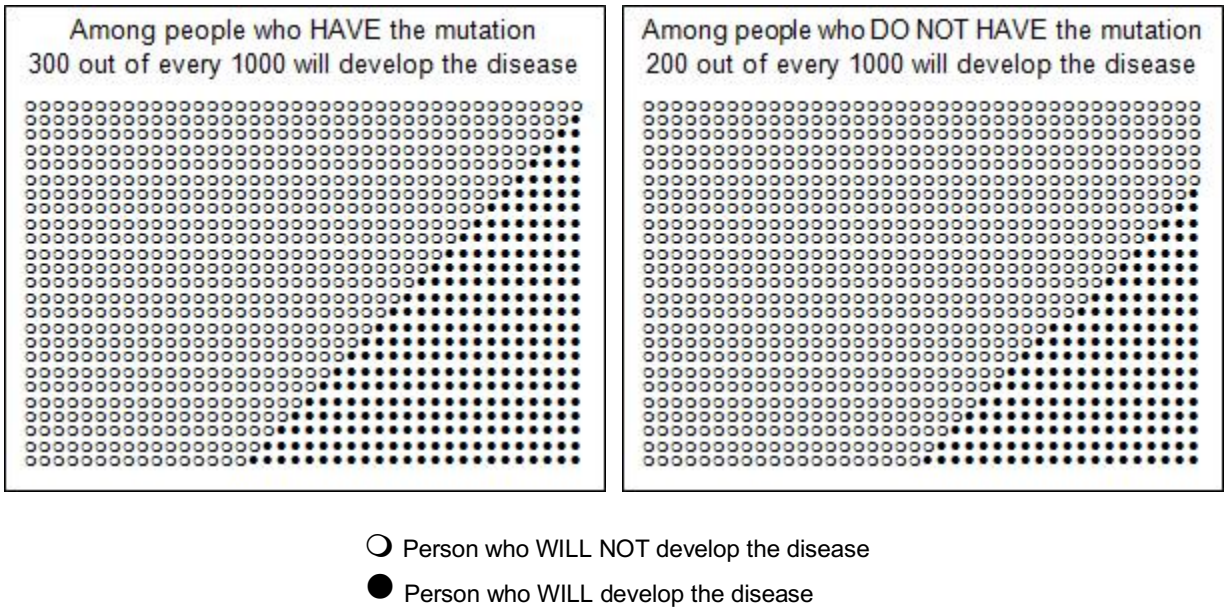
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

14**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

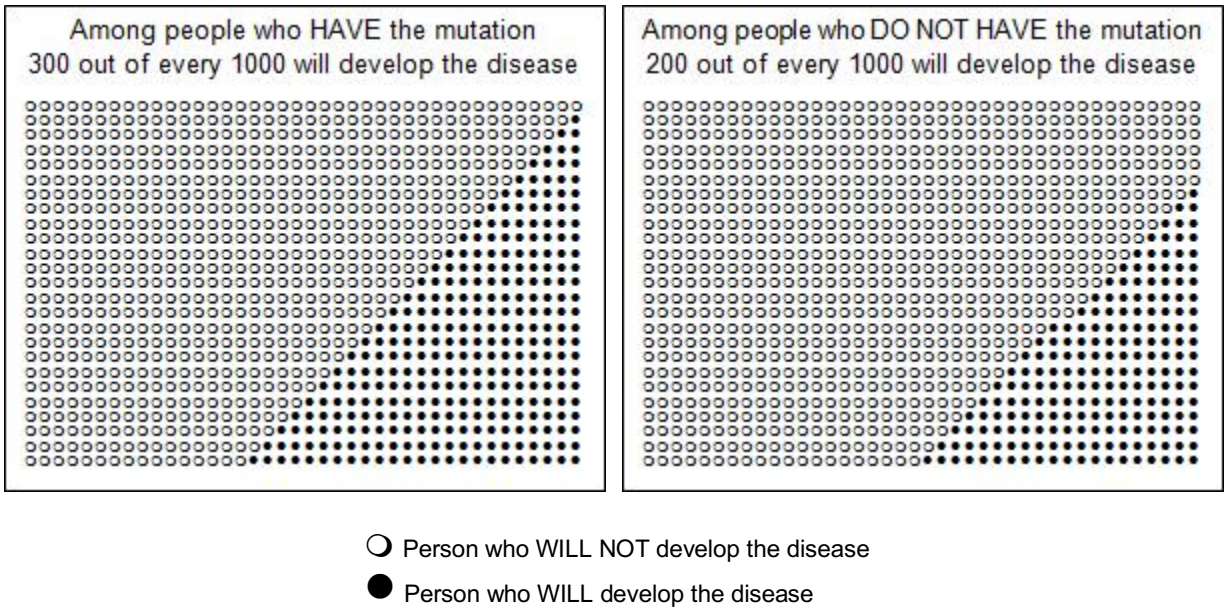
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

15**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

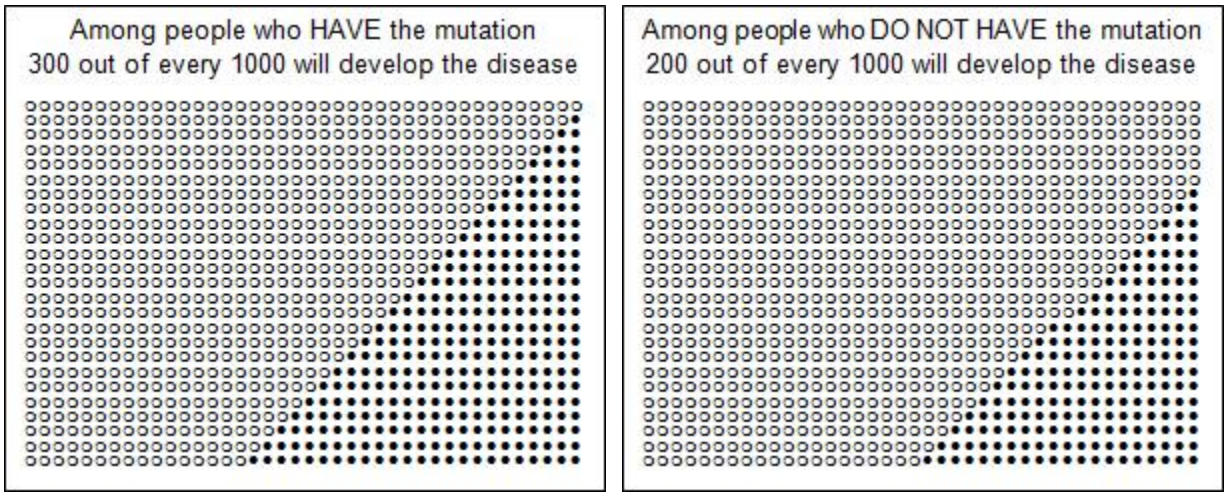
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

16**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

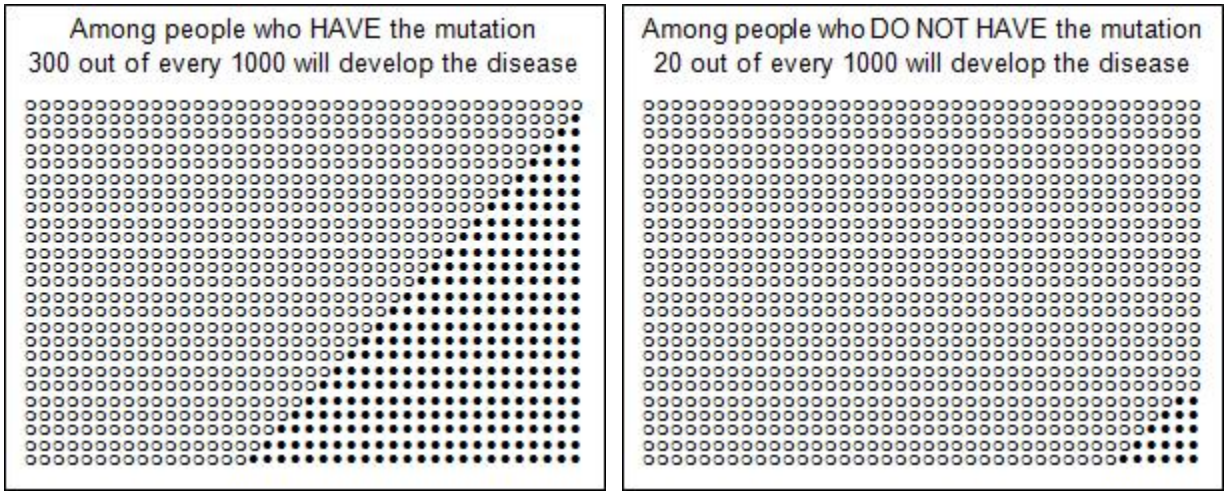
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

17**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

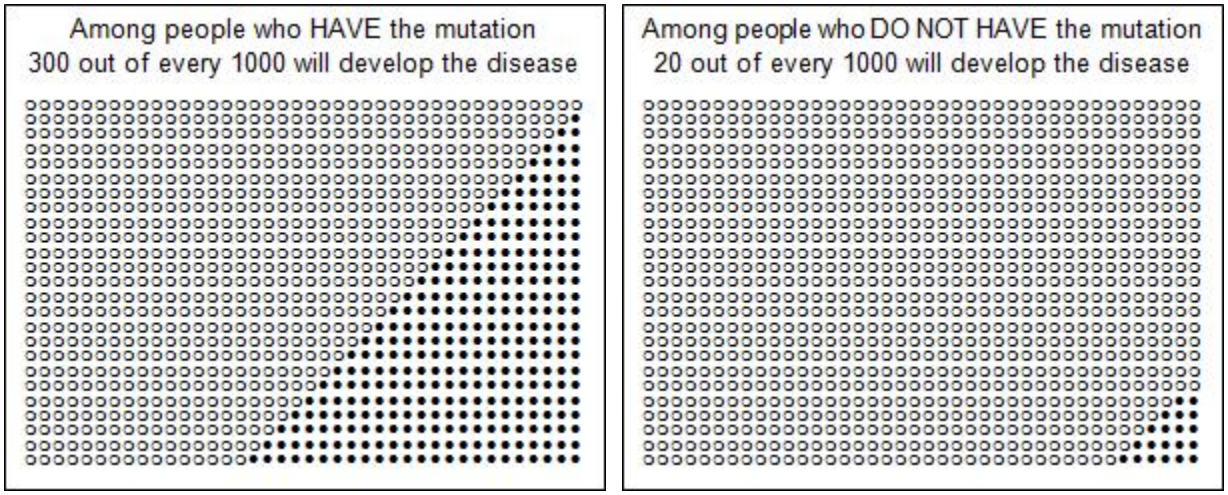
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

18**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

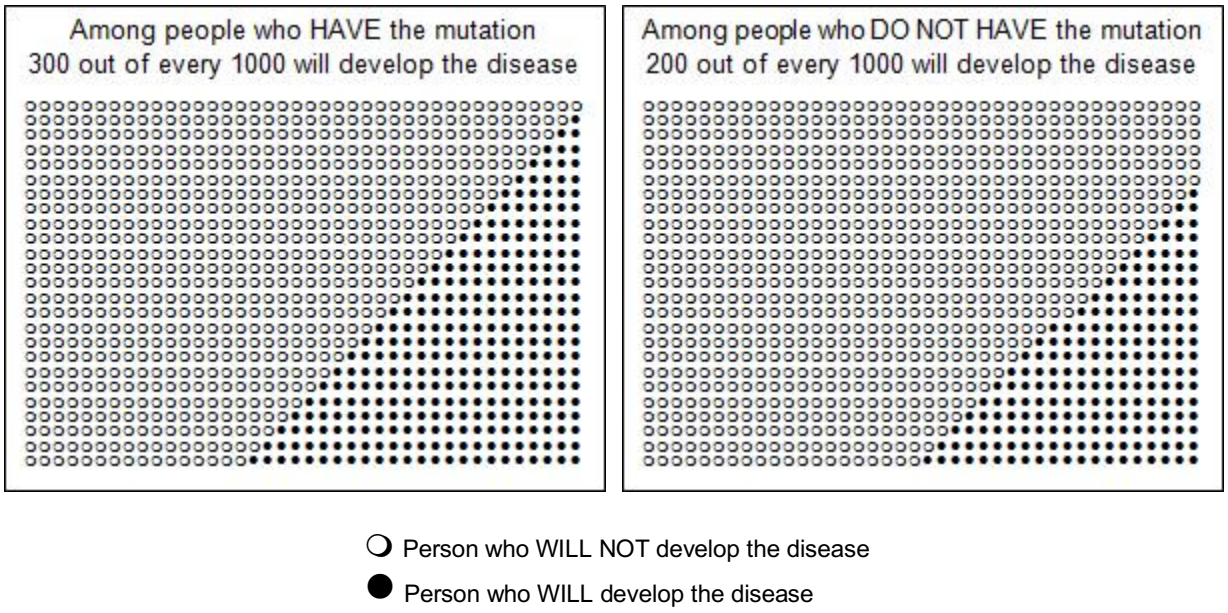
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

19**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

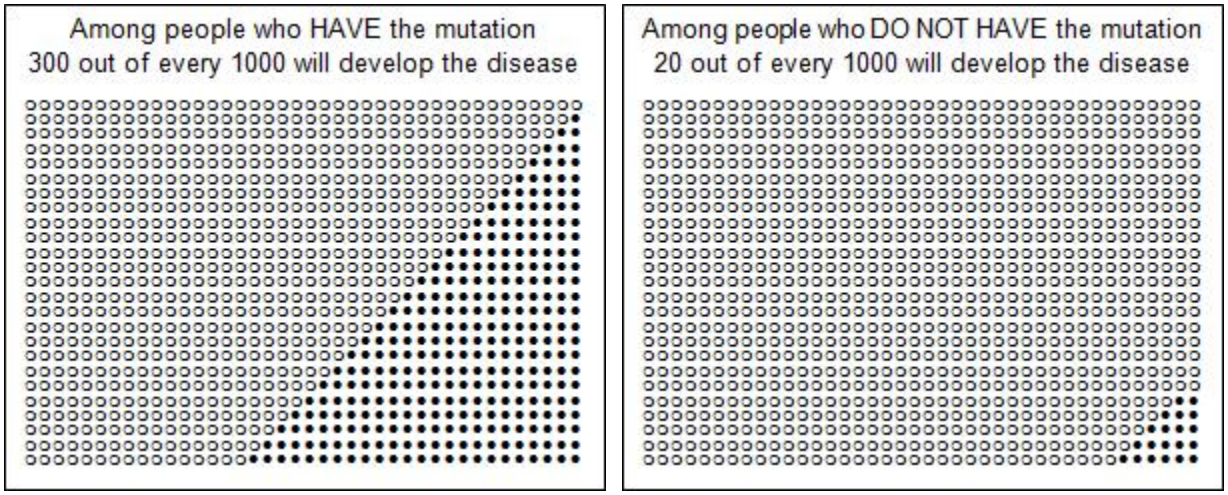
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

20**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

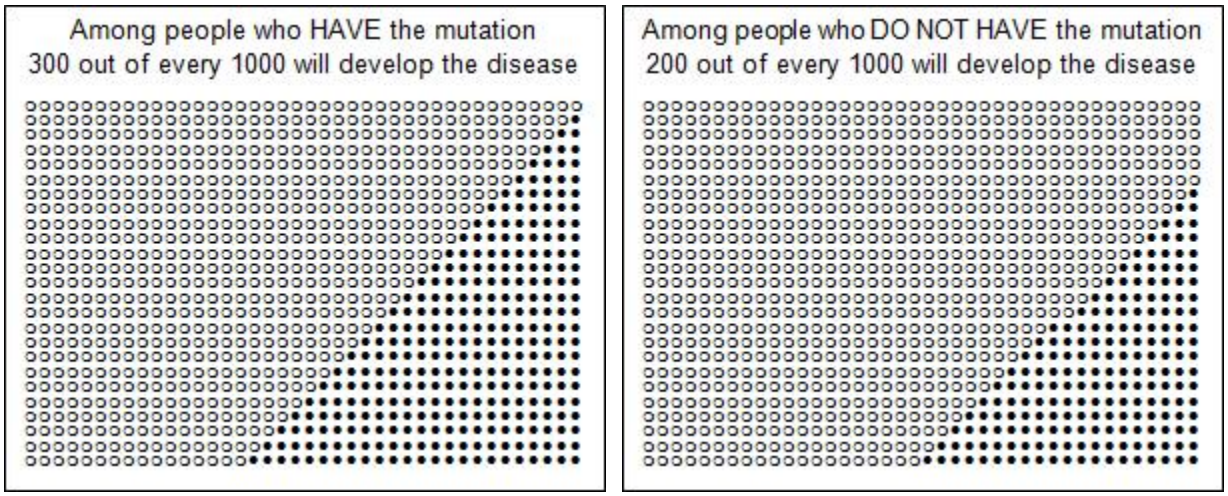
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

21**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

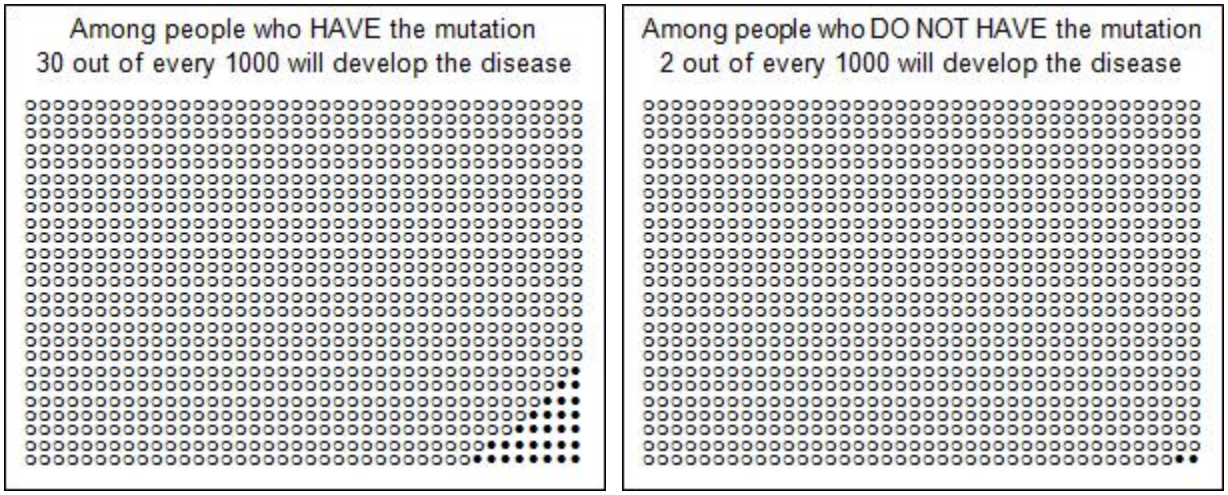
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

22**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

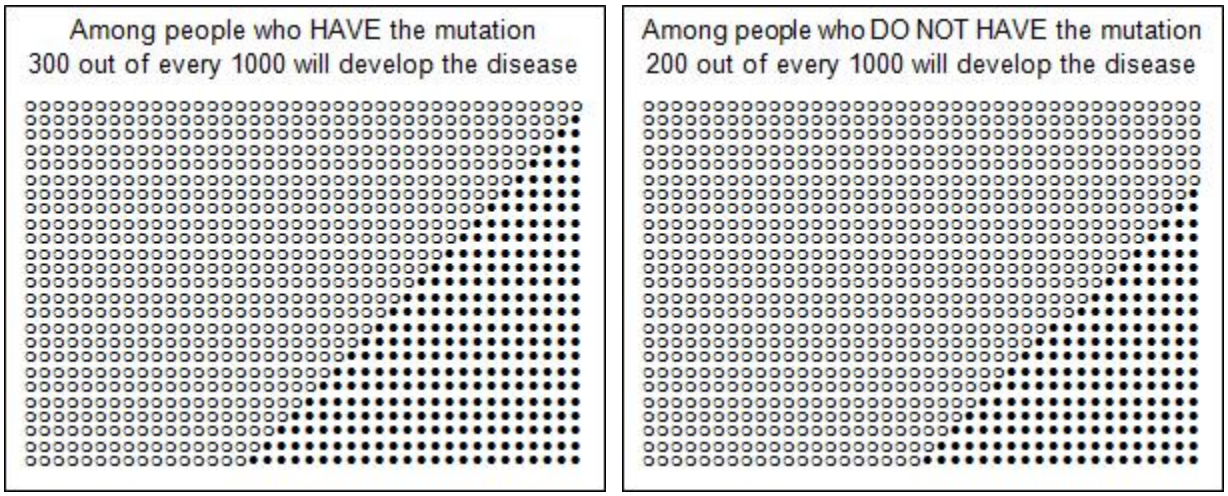
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

23**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

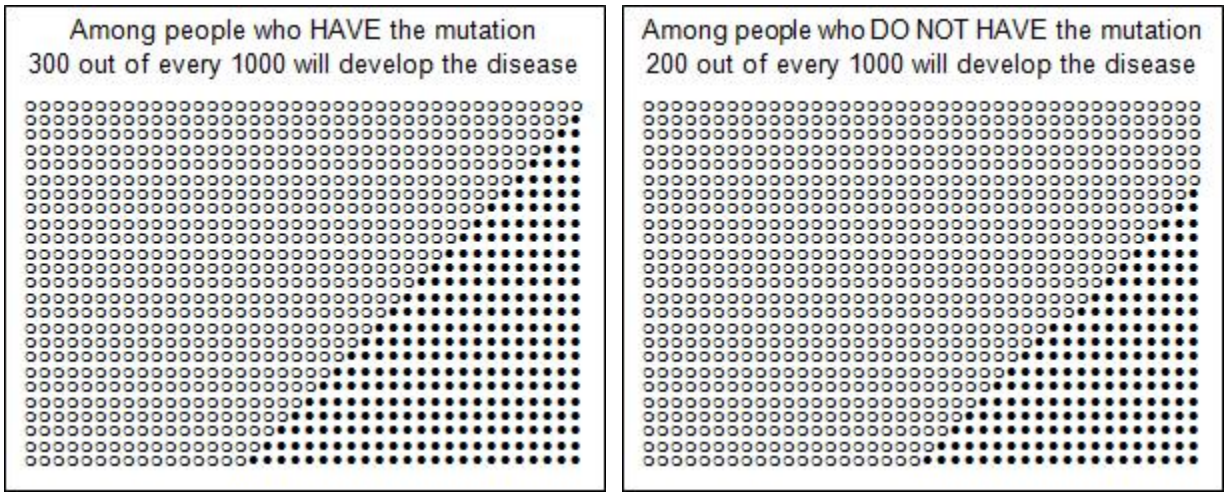
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

24**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

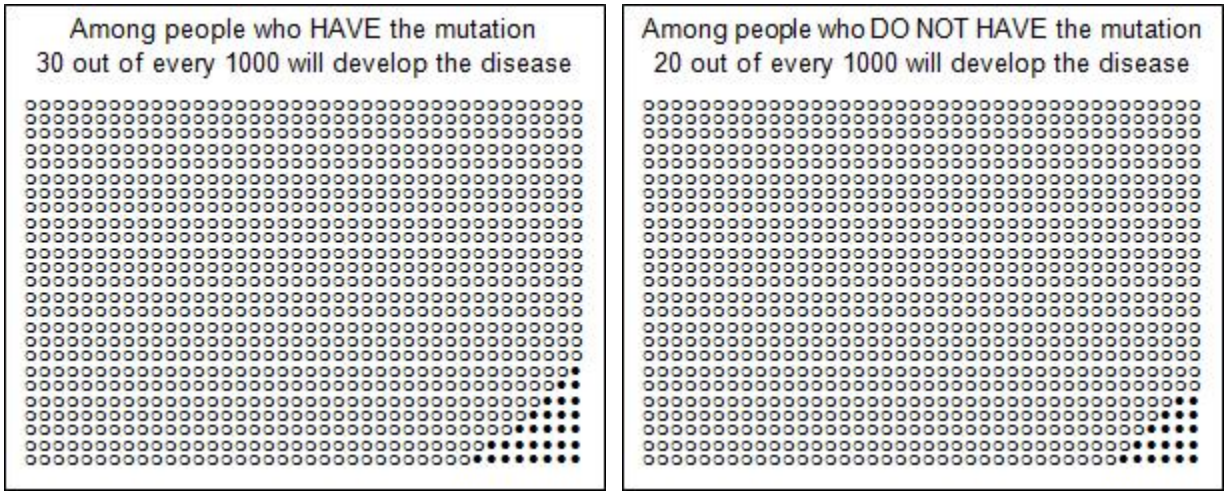
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

25**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

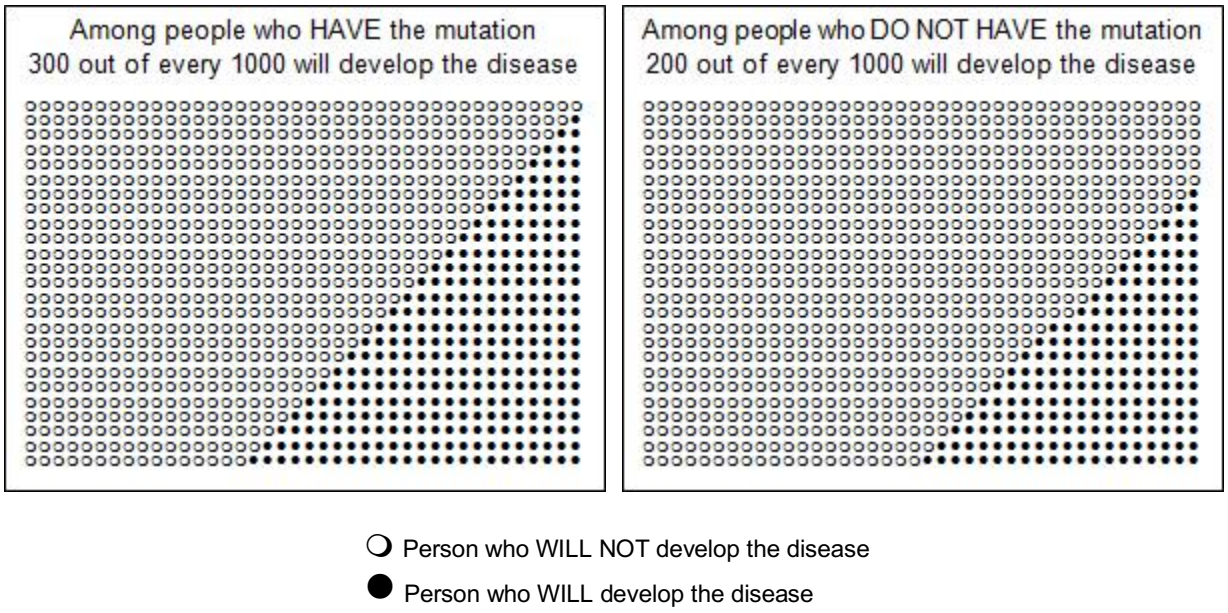
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

26**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

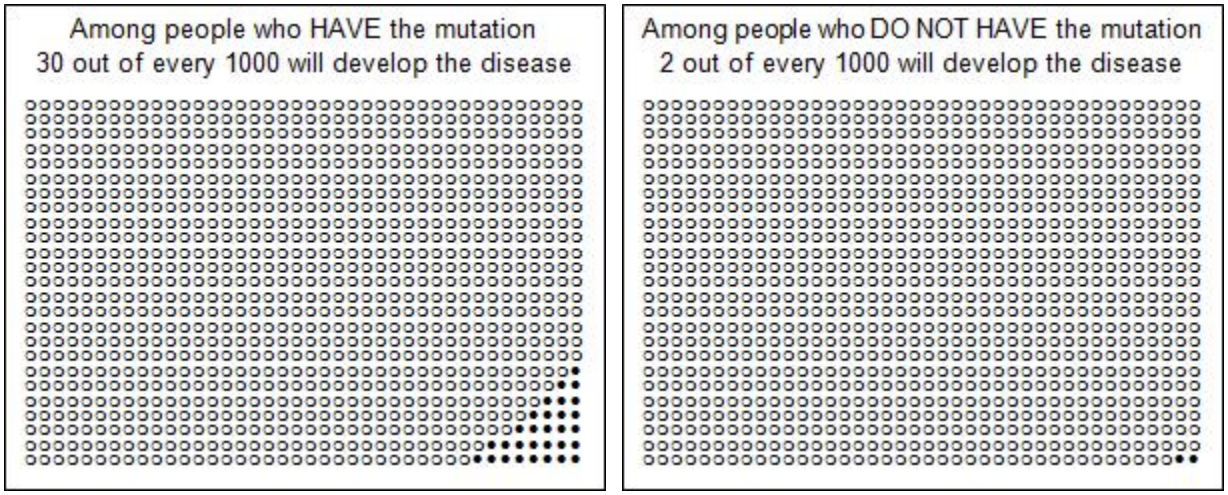
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

27**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

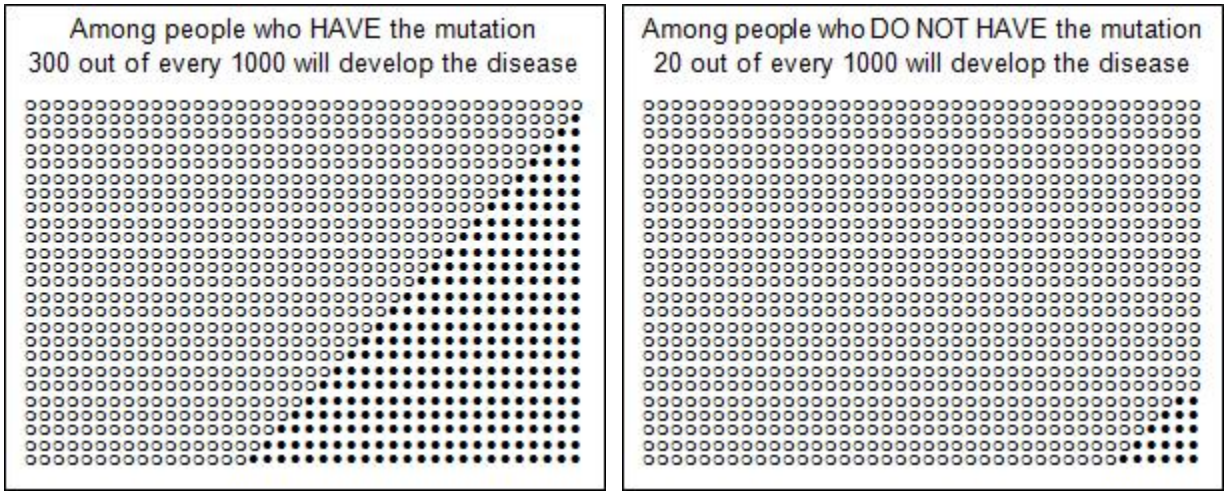
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

28**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

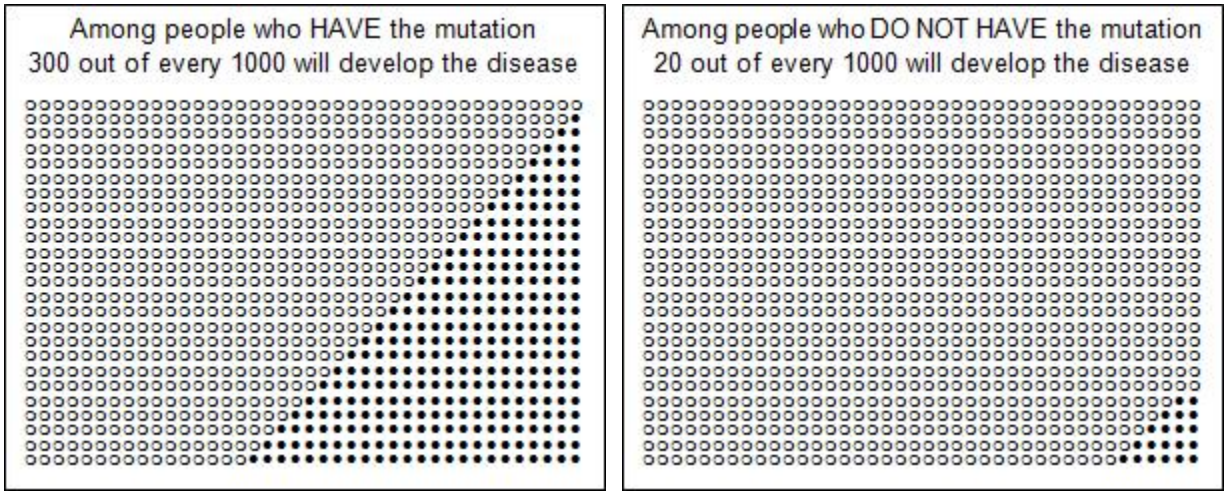
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

29**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

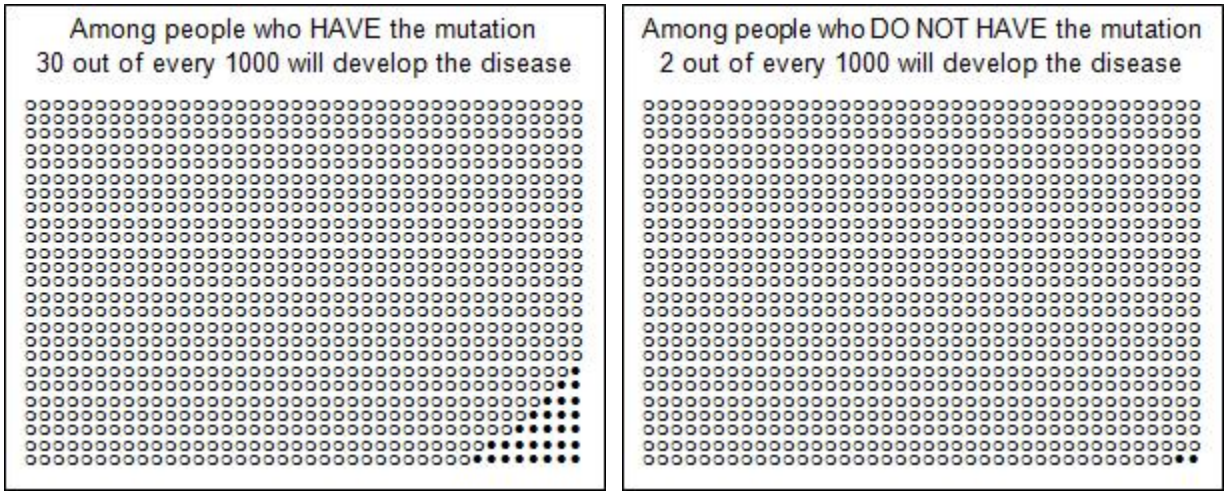
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

30**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

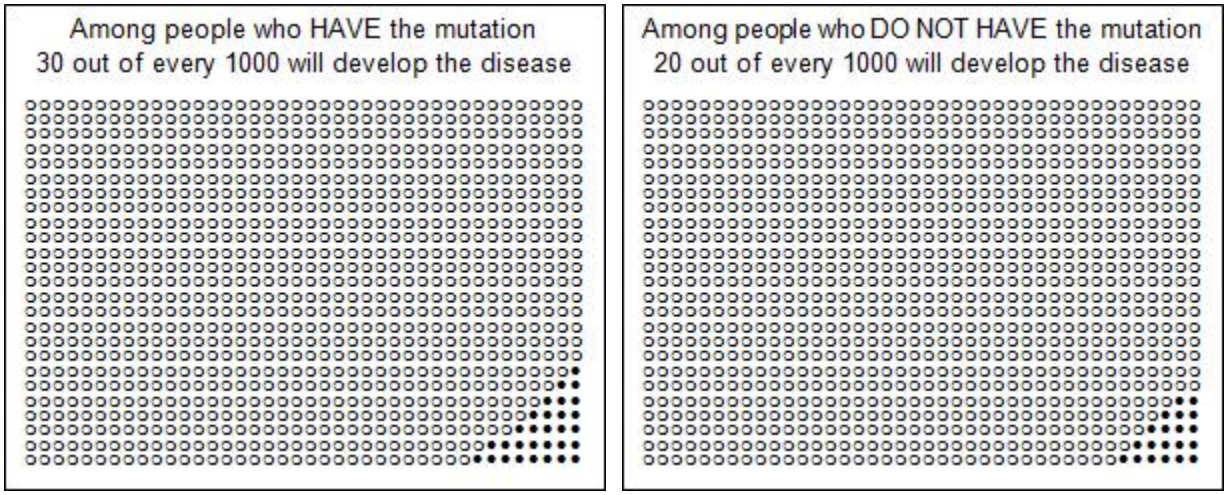
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

31**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

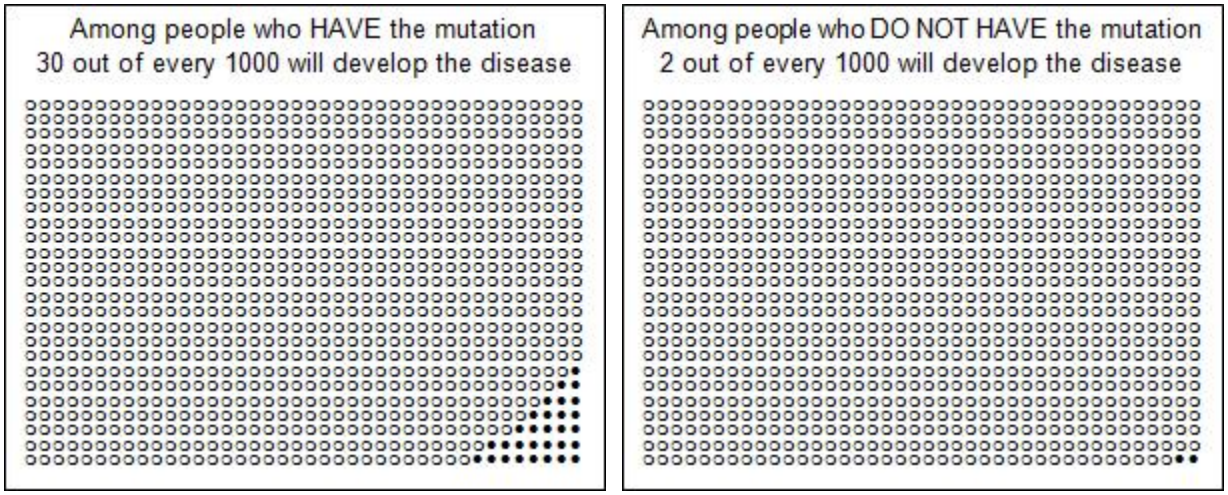
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

32**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

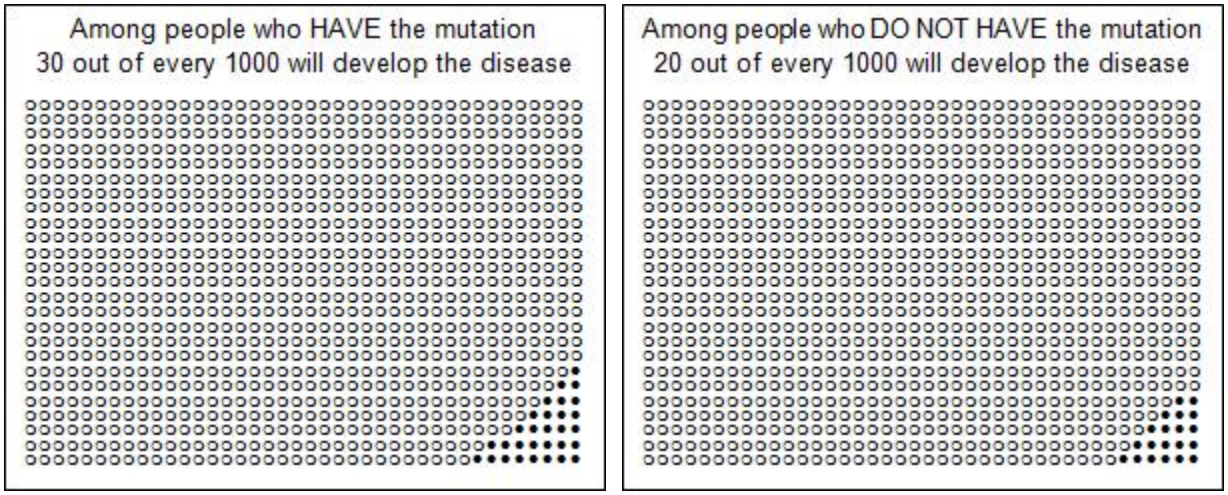
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

33**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

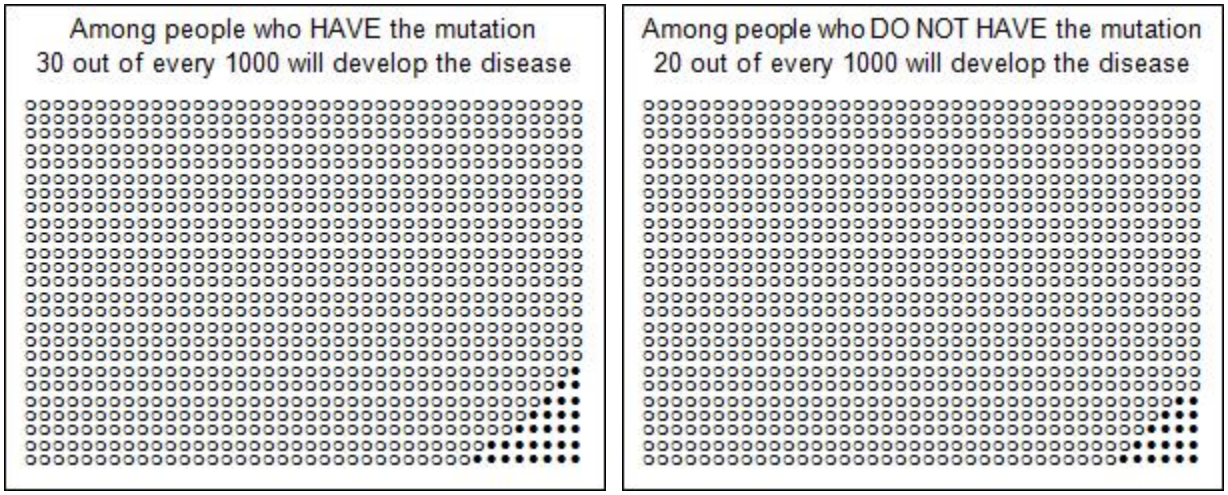
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

34**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

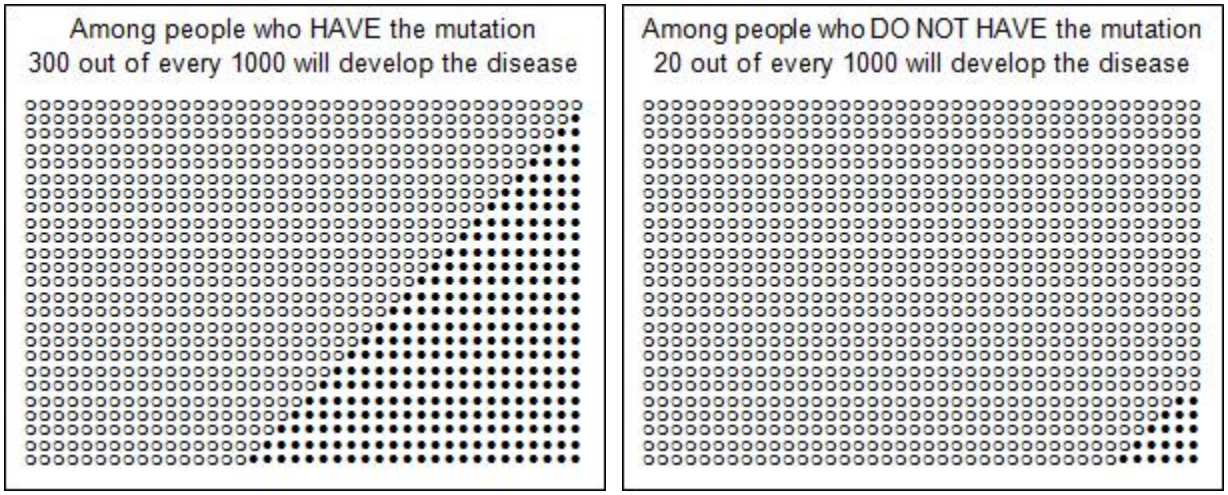
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

35**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

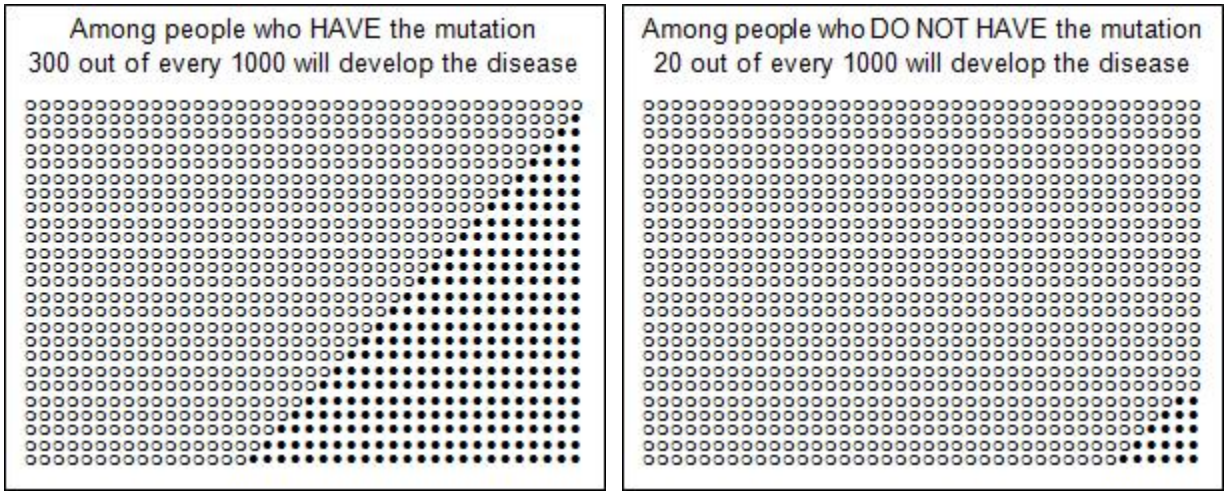
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

36**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

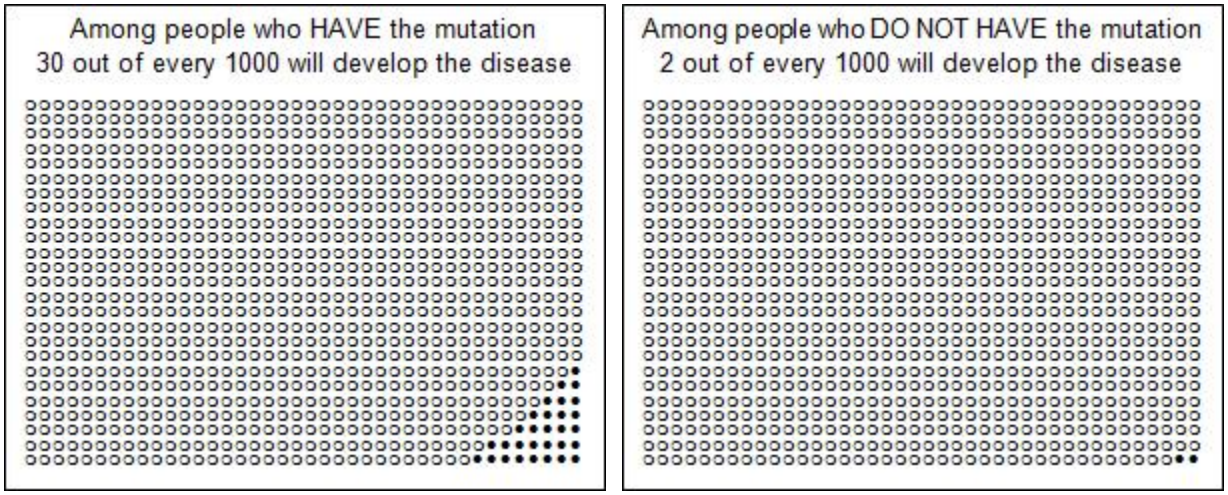
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

37**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



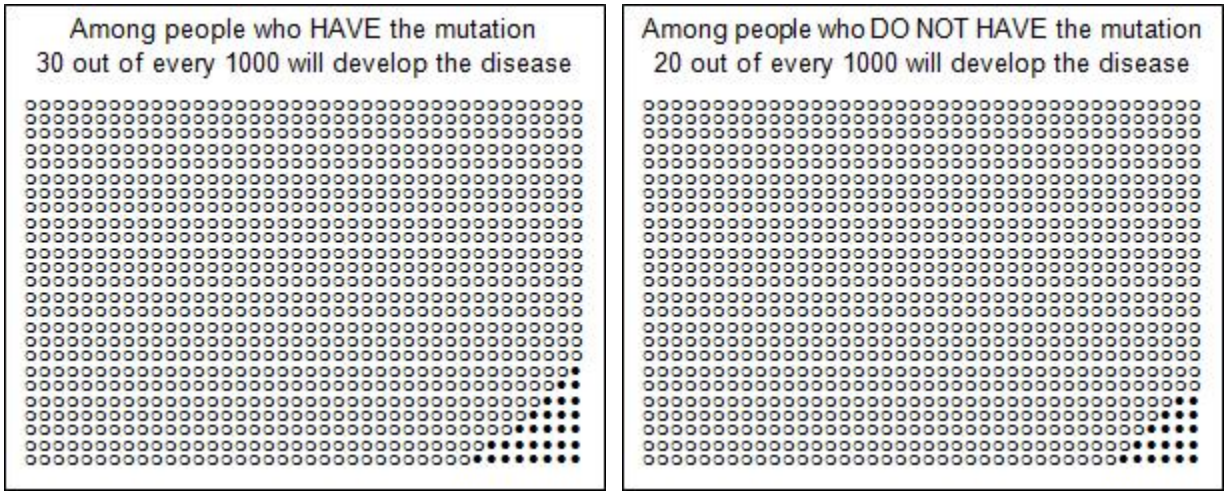
This means that the risk of the disease is 15 times as high among people who have the mutation.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

38**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

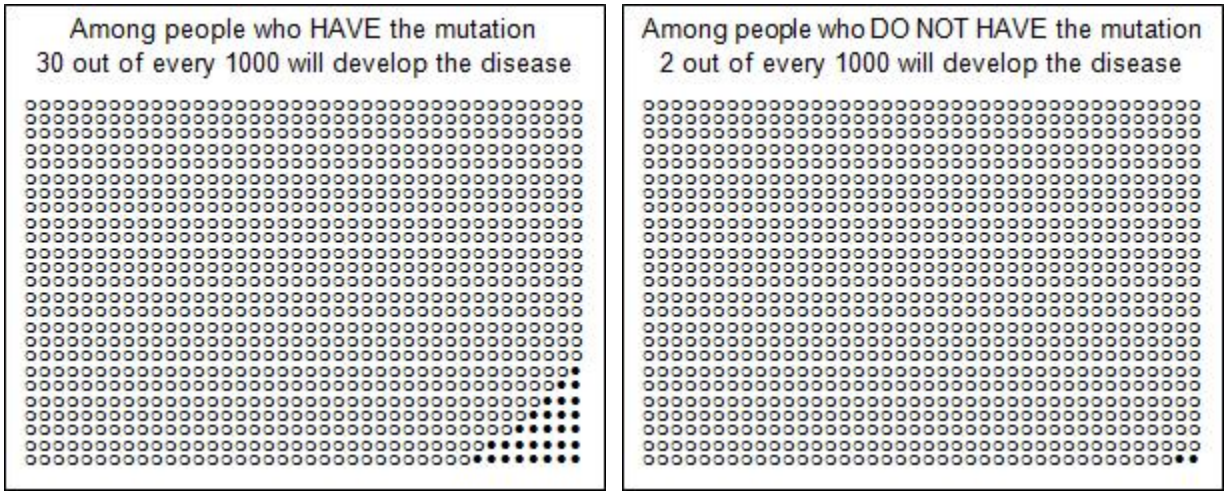
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

39**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

40**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.

This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

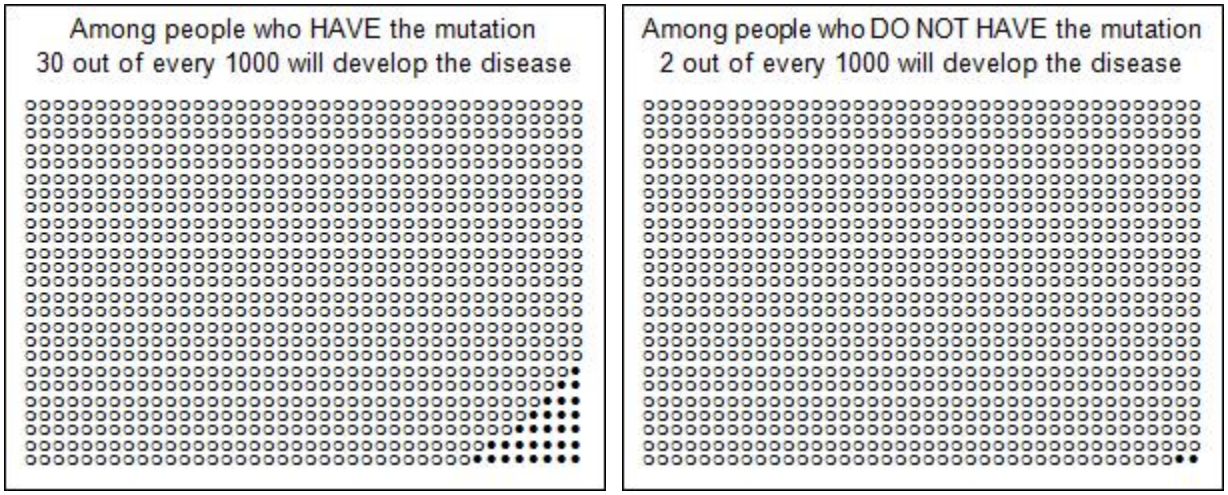
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

41**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

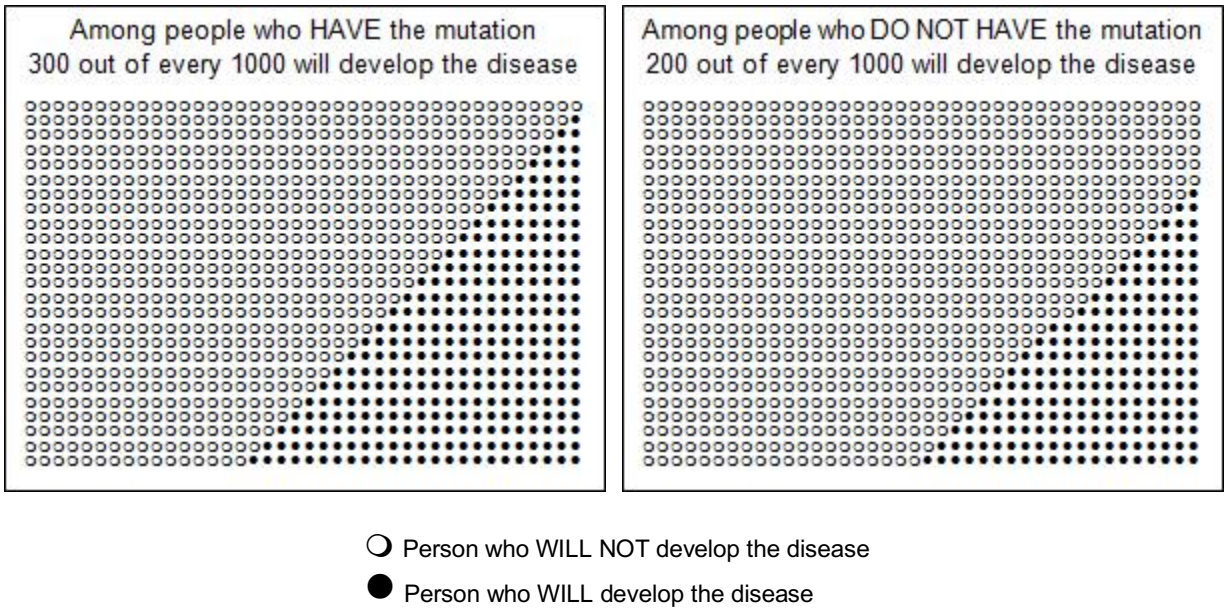
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

42**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

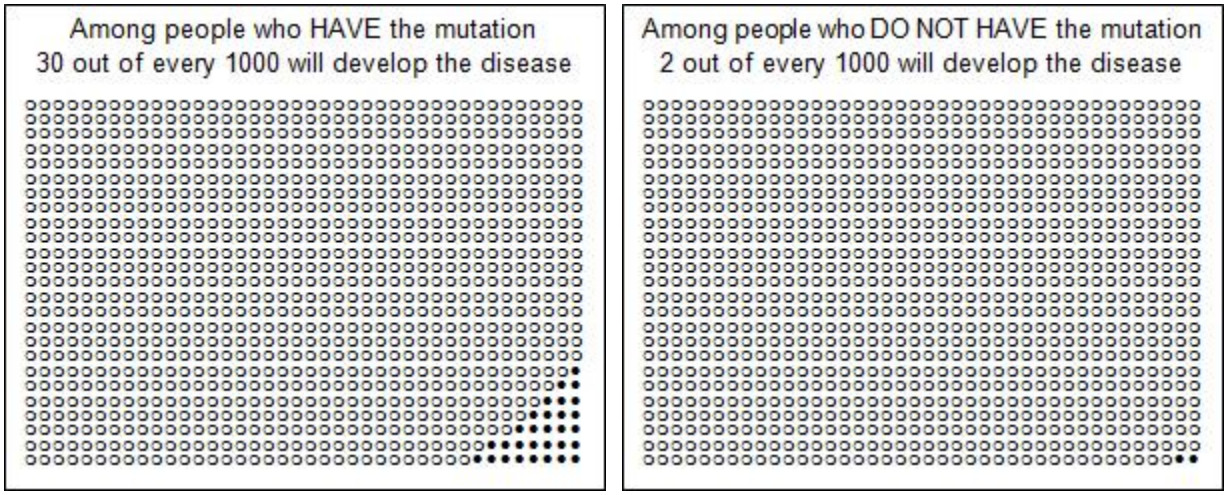
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

43**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

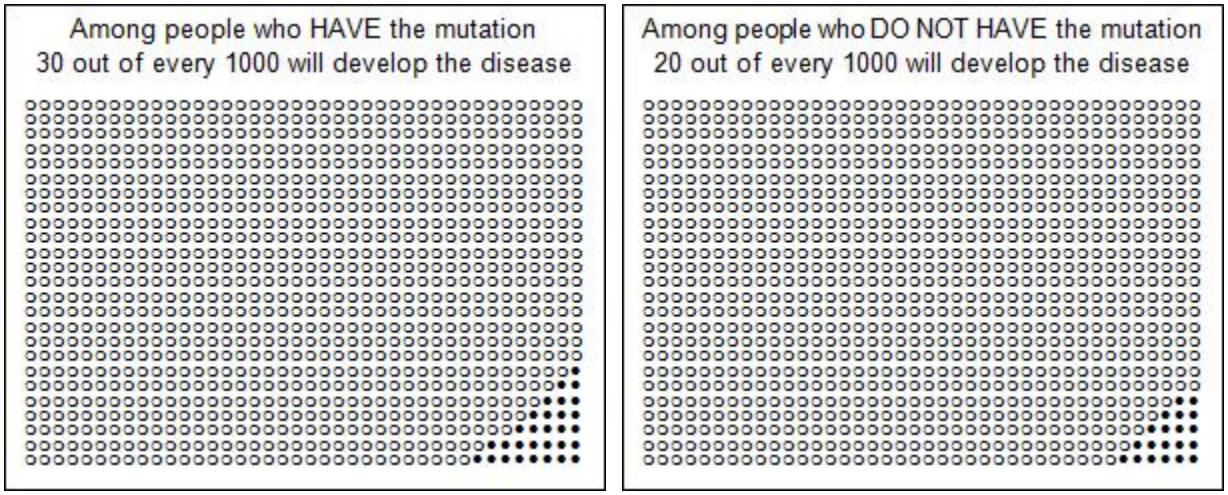
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

44**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

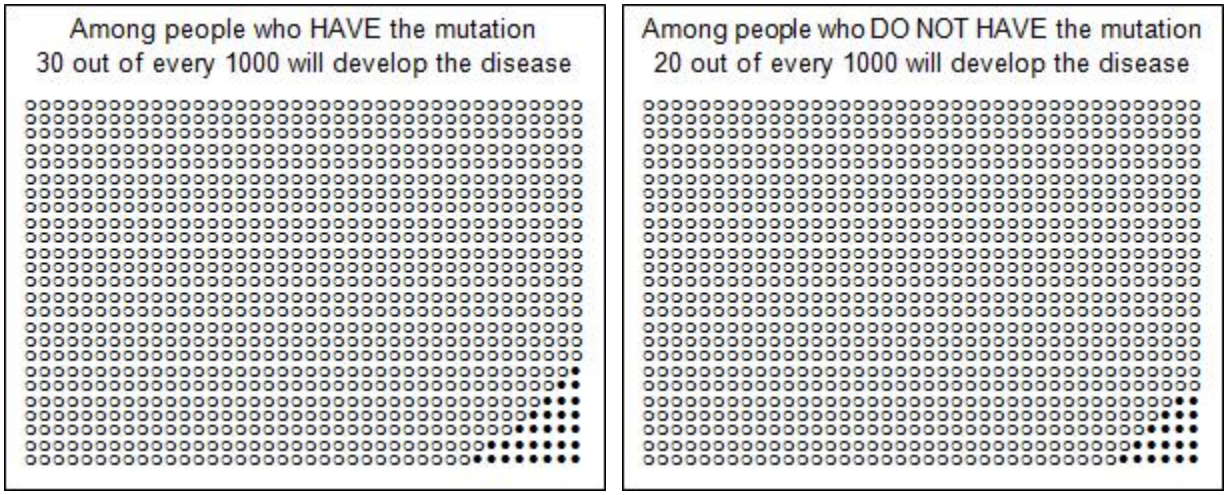
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

45**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

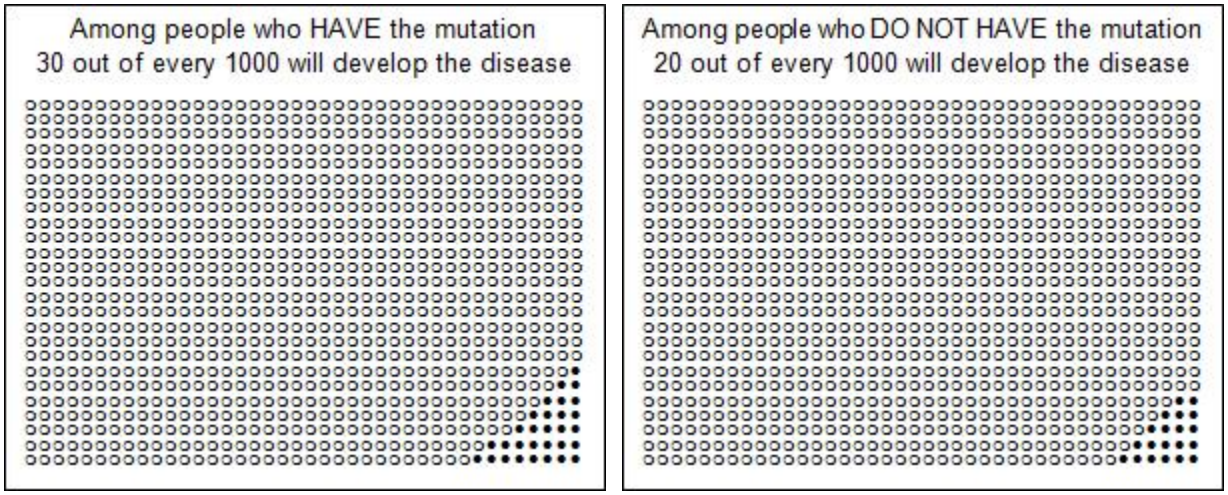
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

46**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

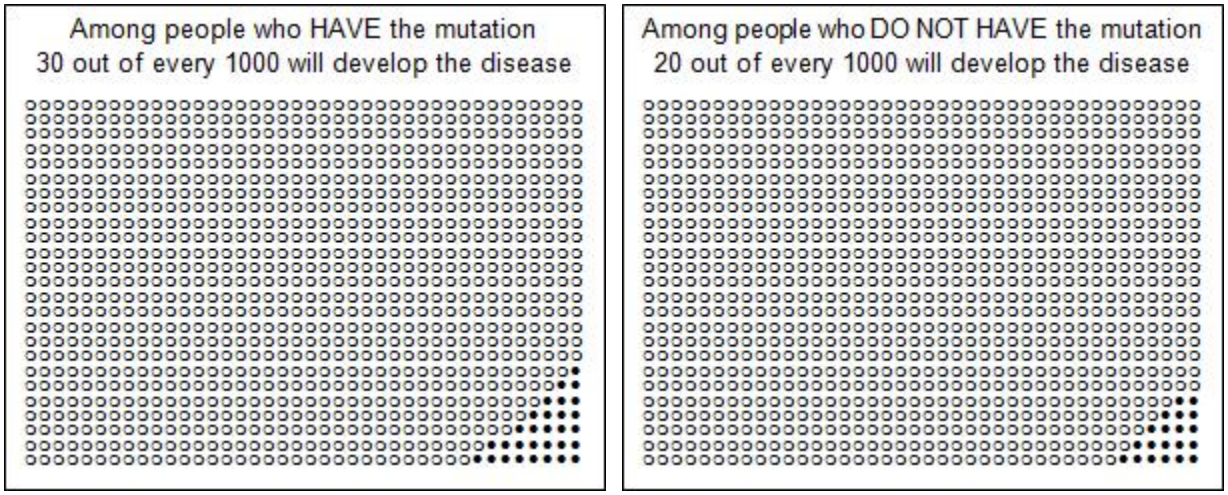
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

47**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

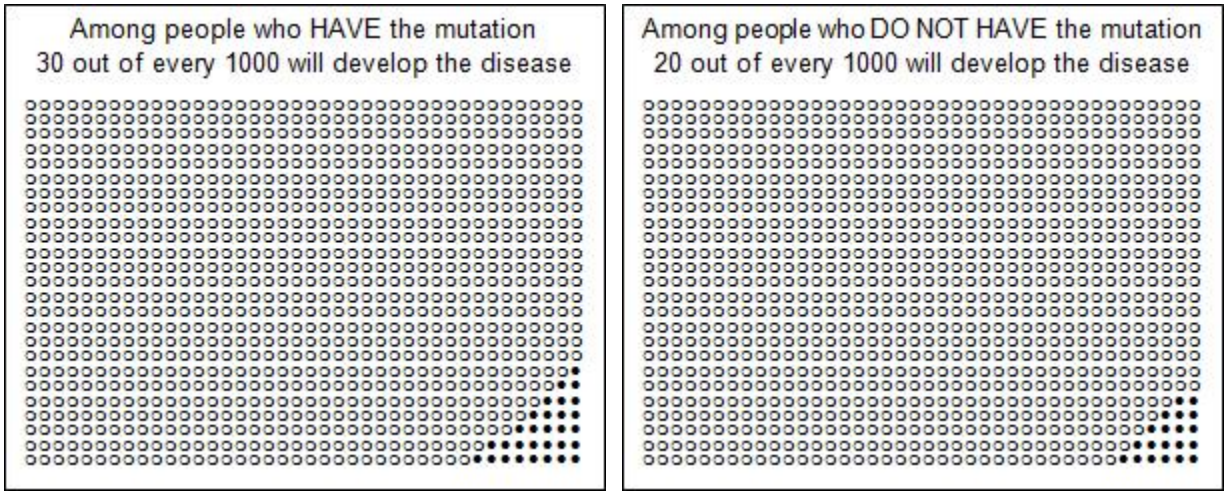
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

48**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

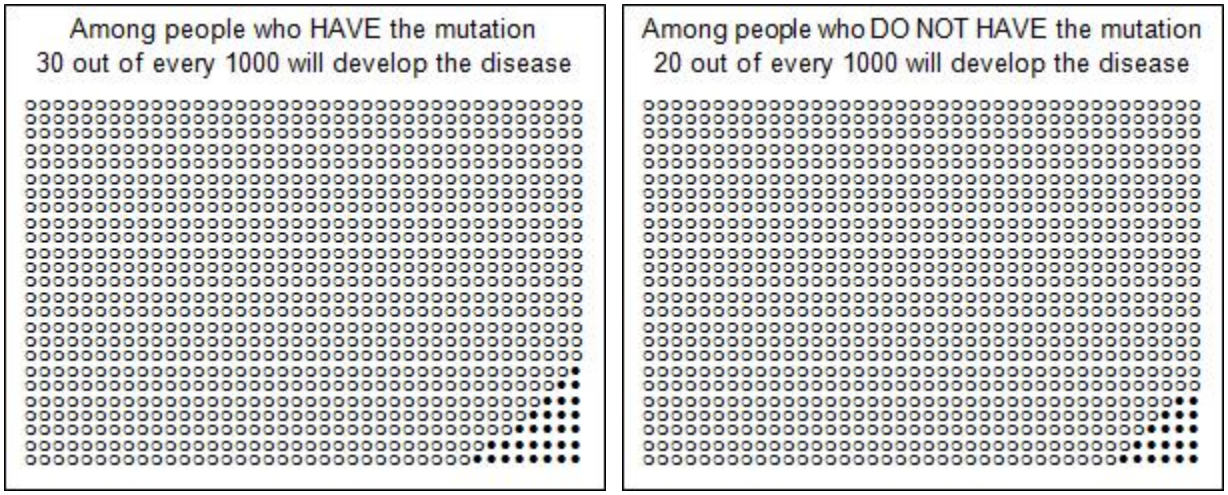
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

49**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

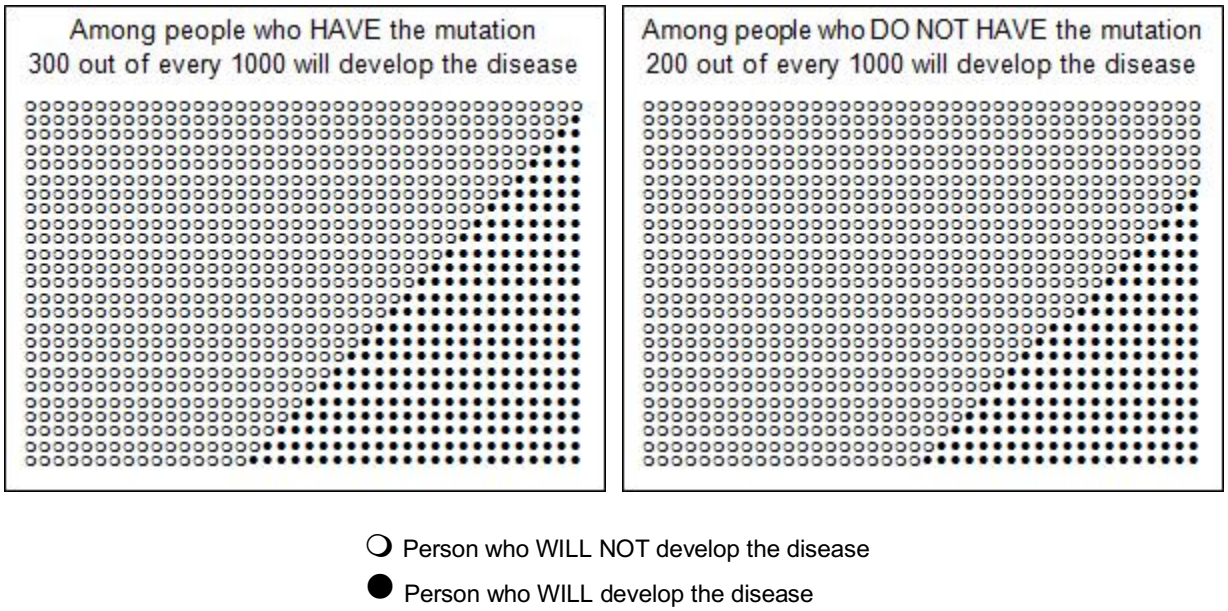
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

50**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

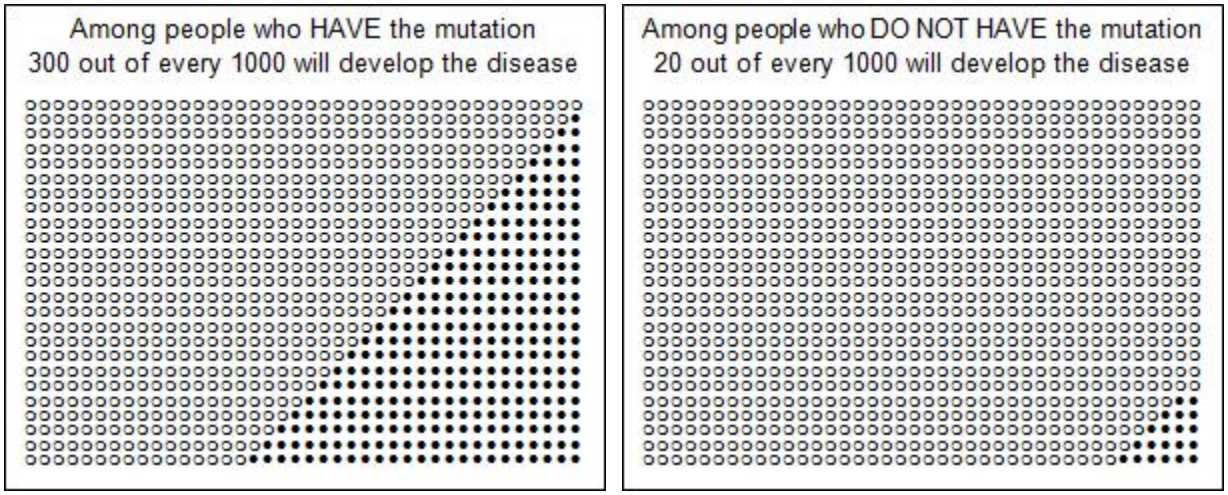
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

51**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

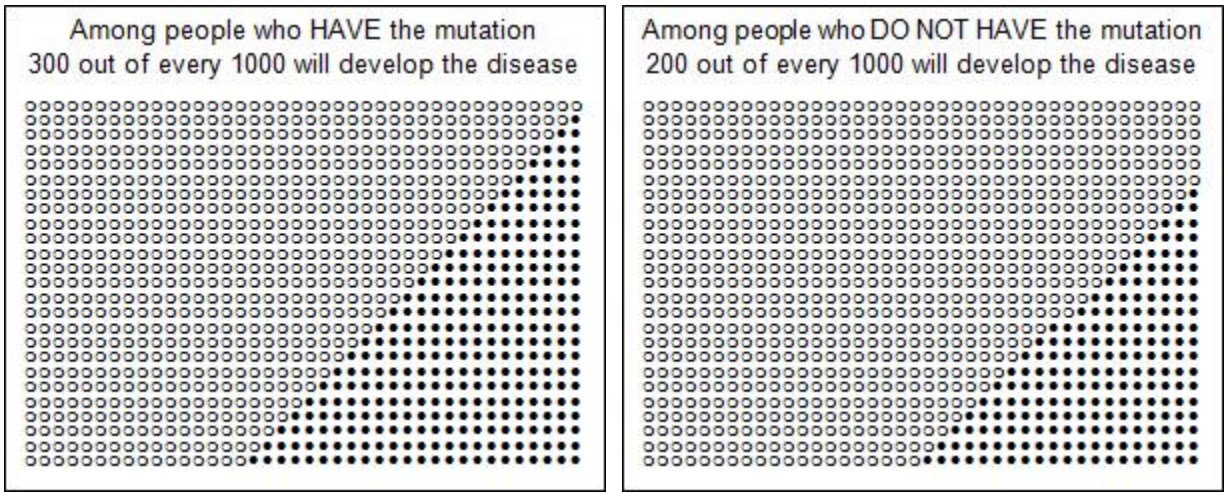
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

52**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

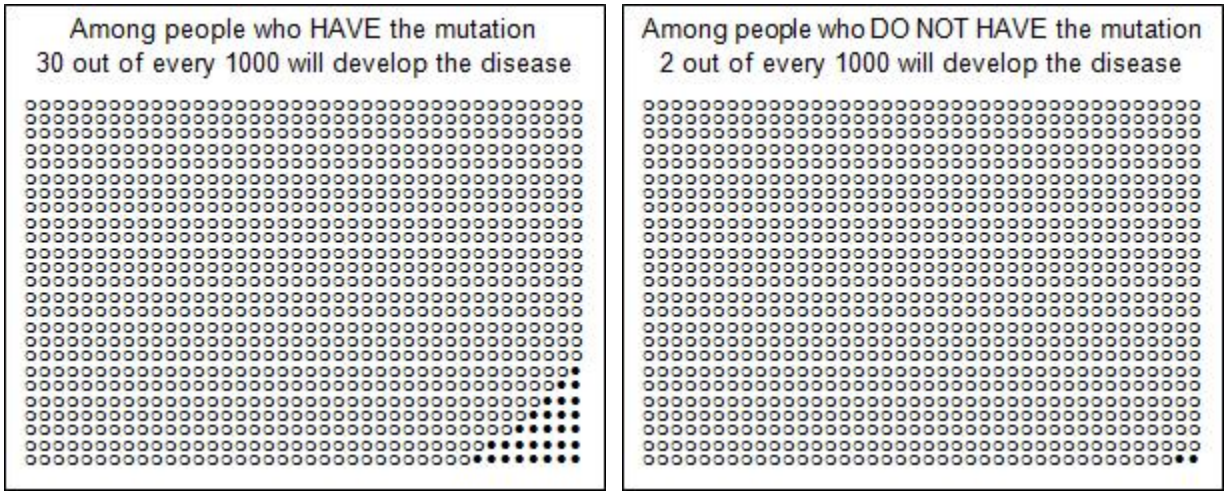
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

53**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

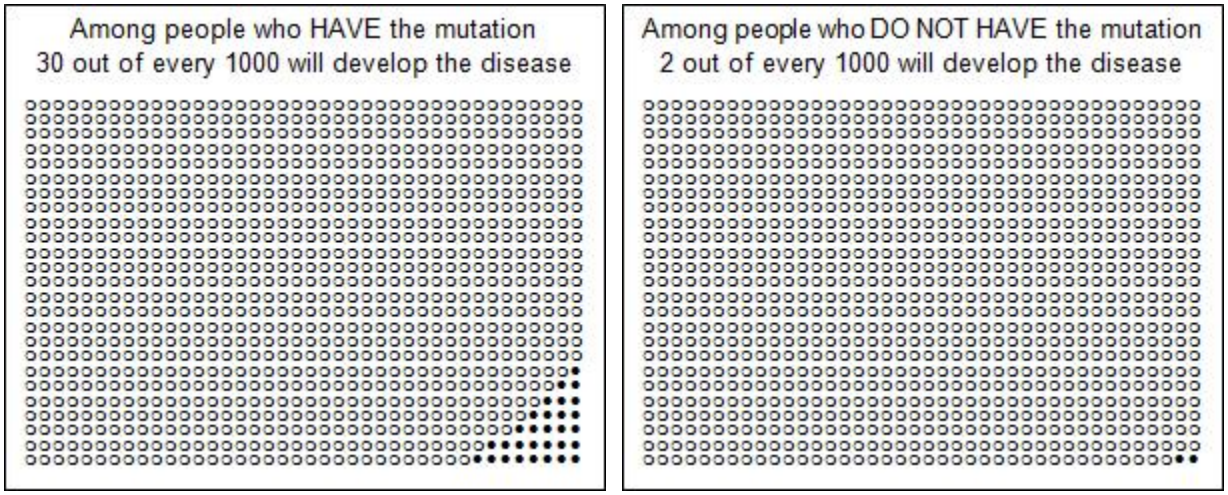
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

54**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

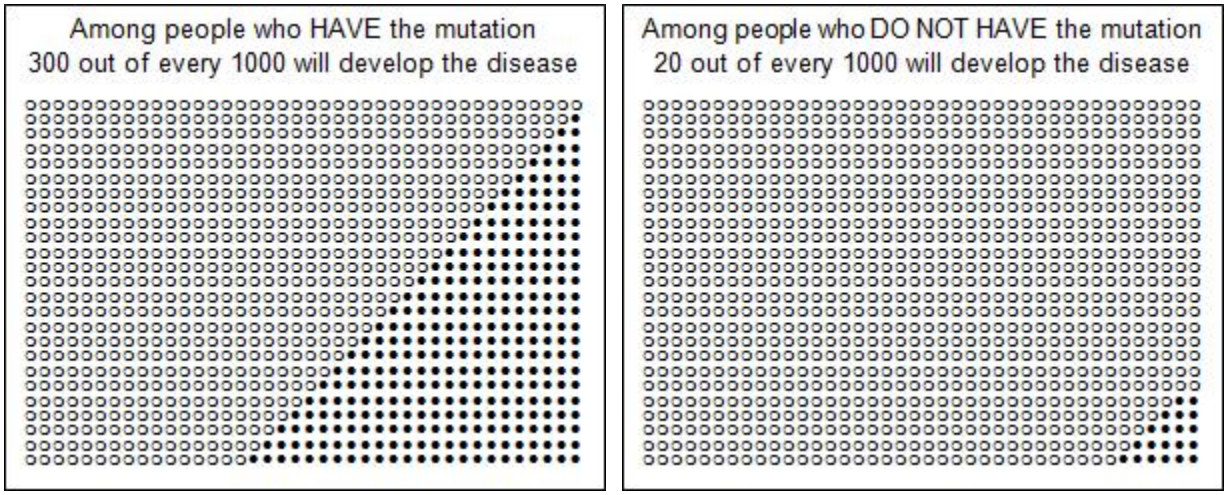
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

55**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

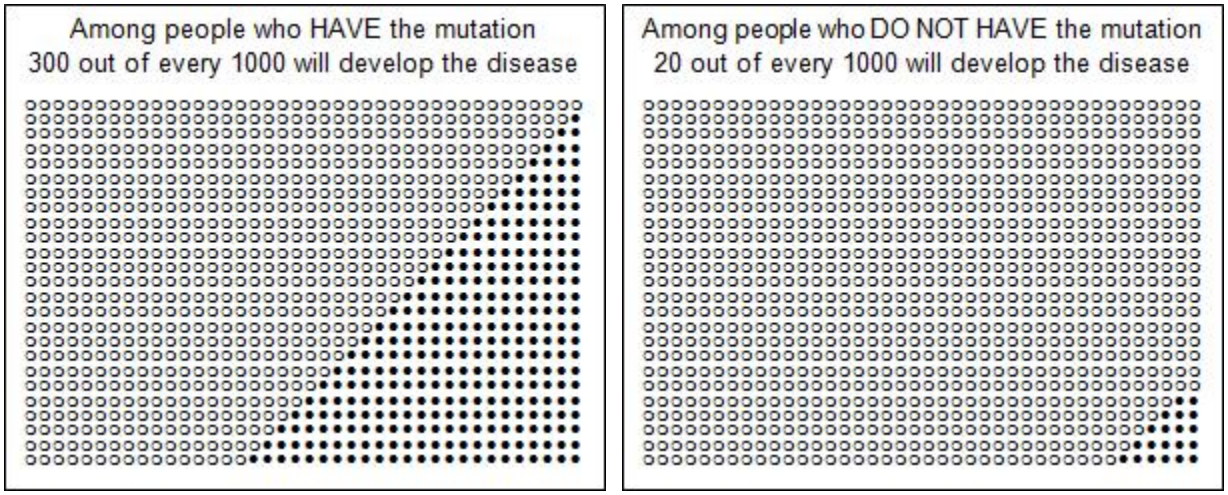
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

56**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

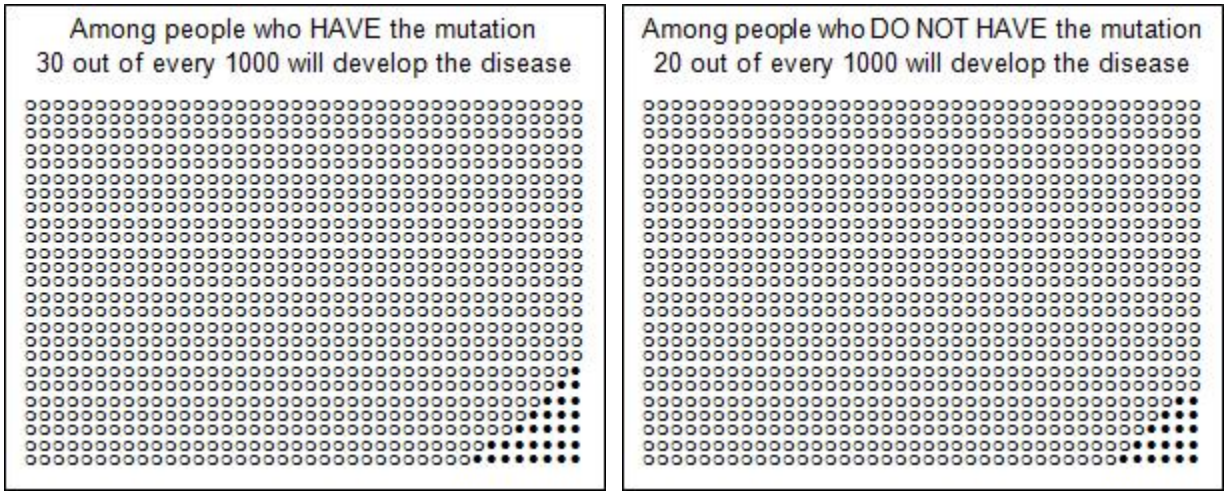
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

57**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

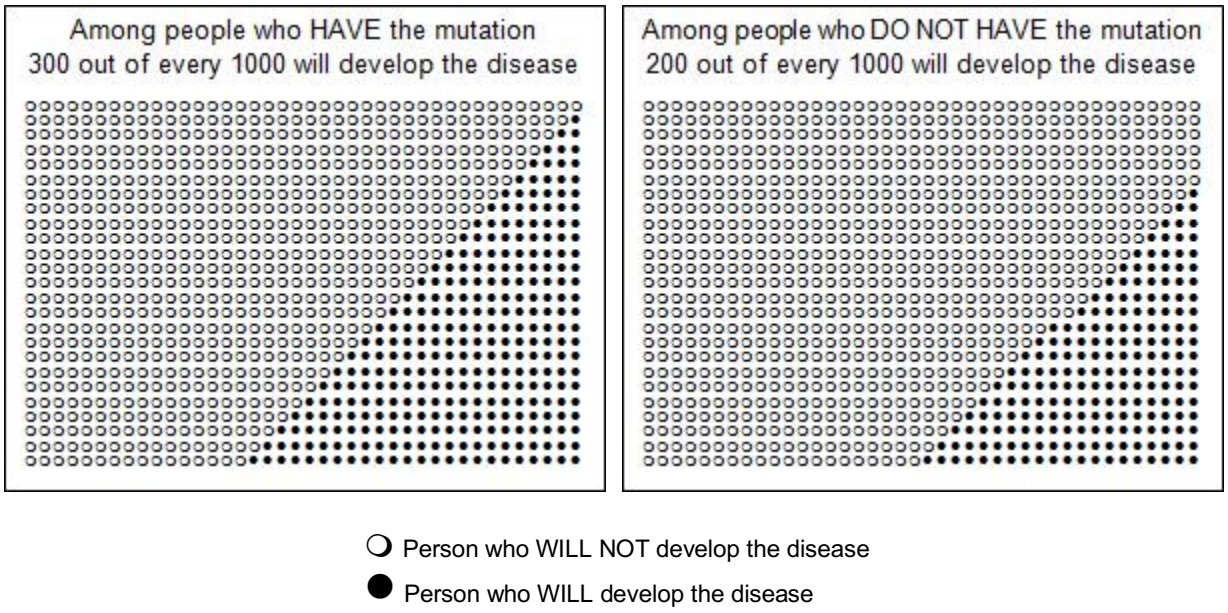
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

58**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

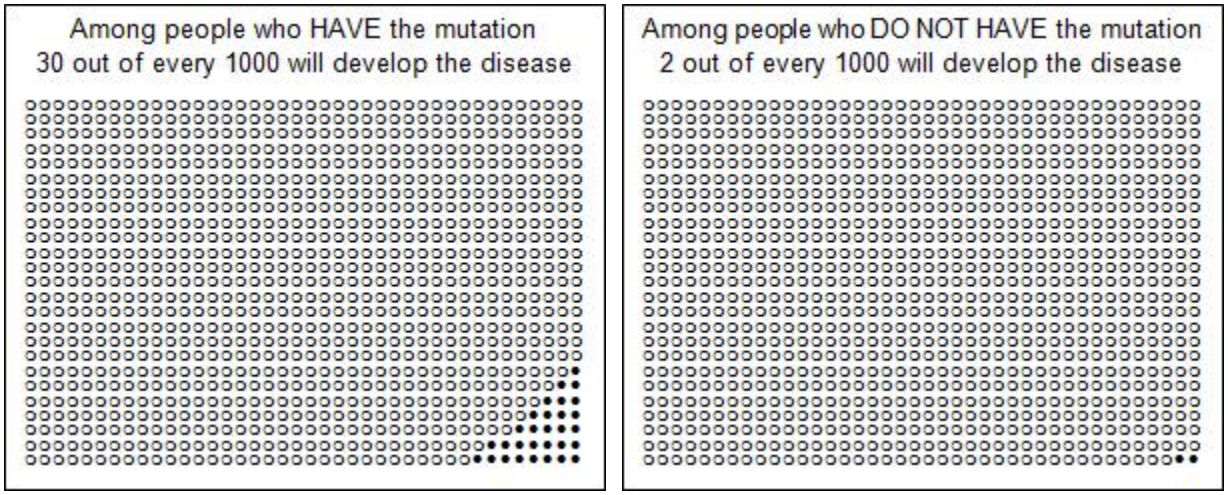
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

59. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

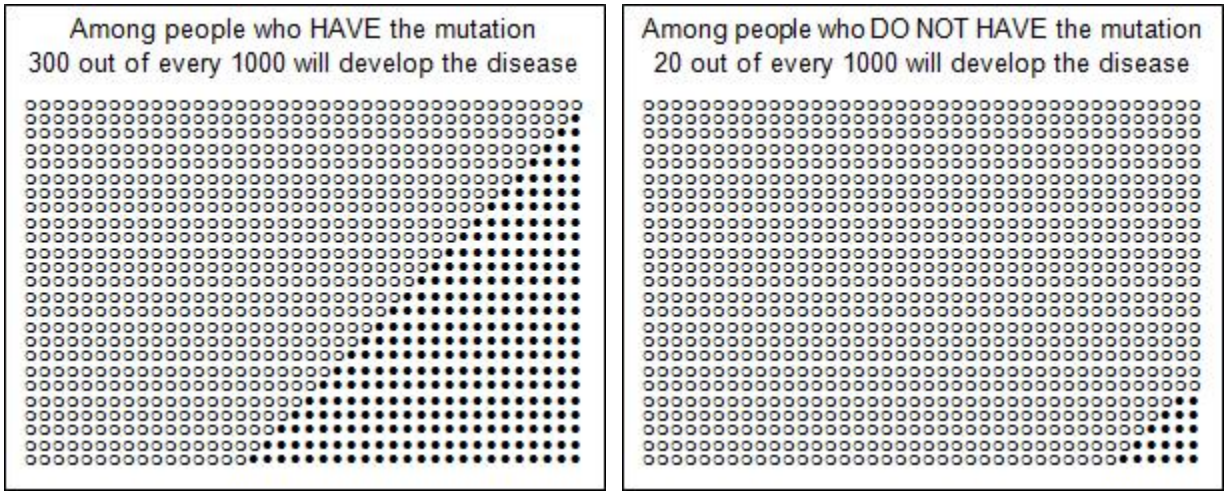
Would you want the researchers to tell you about your increased risk for this disease?
Please check one.

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

60**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

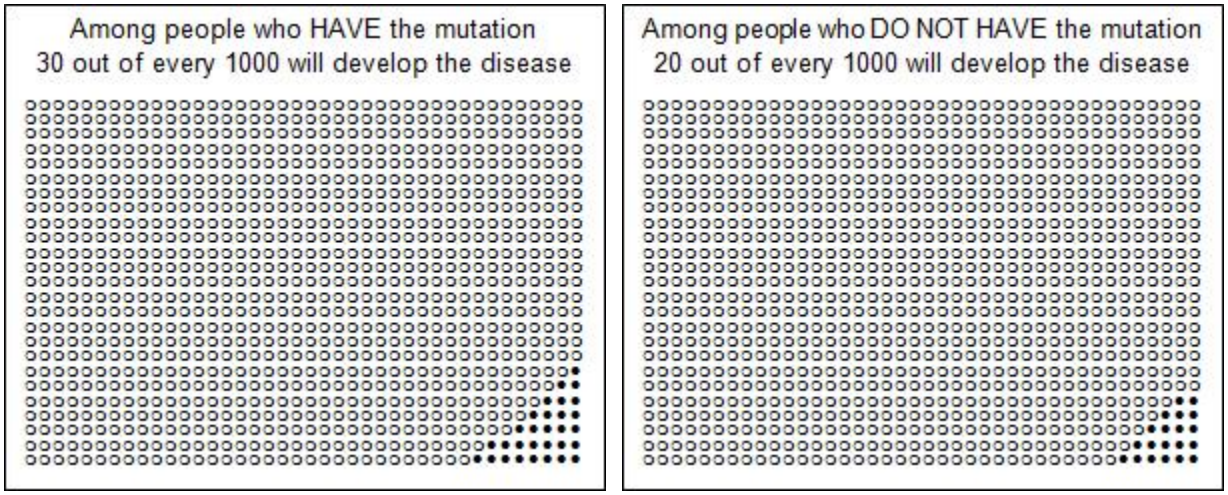
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

61**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes chronic arthritis (pain and swelling in joints).
- The development of the disease can be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

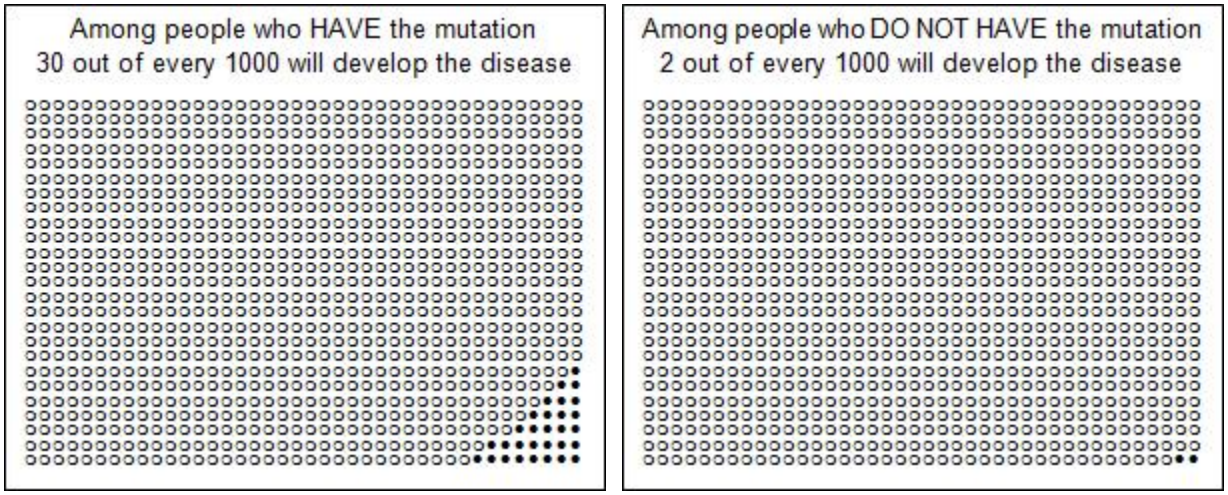
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

62**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes loss of memory and other mental abilities.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



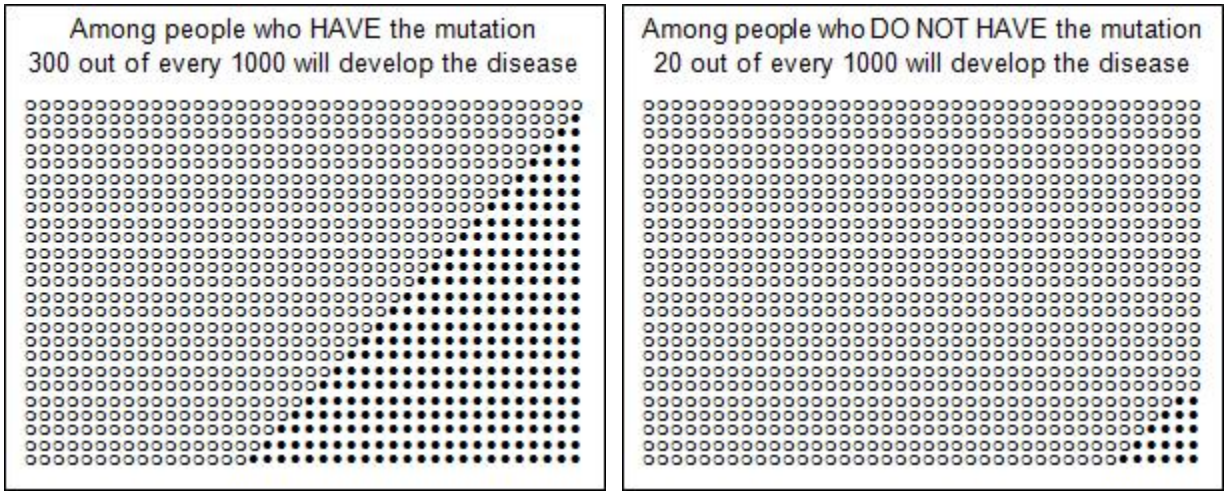
This means that the risk of the disease is 15 times as high among people who have the mutation.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

63**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes death.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 15 times as high among people who have the mutation.

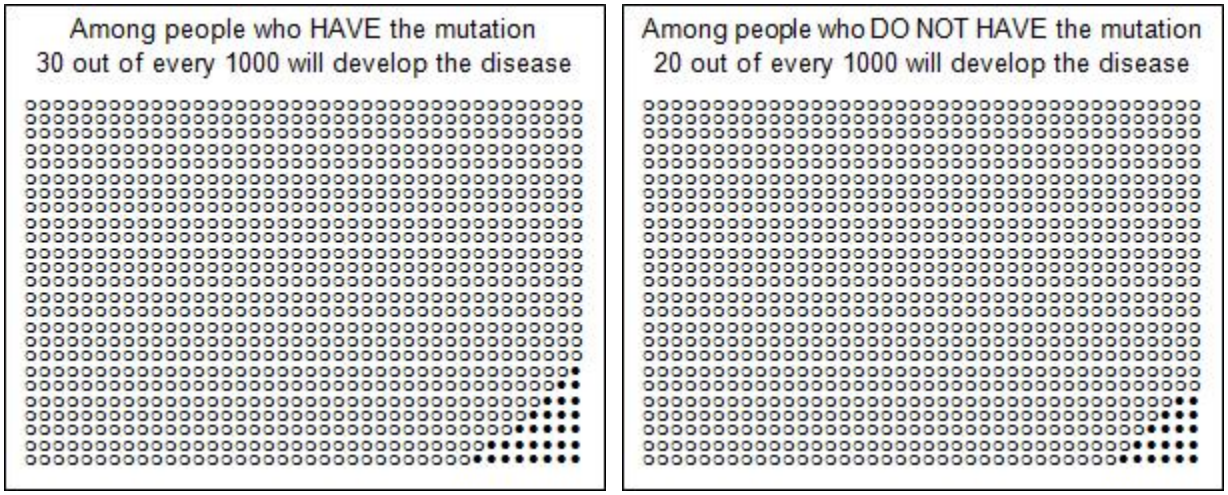
Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer

FULL SET OF 64 FACTORIAL VIGNETTES

64**. Suppose that the tests run on your genes show that you have a mutation that increases your risk for a disease. Some important facts about this disease include:**

- It causes a painless rash.
- The development of the disease cannot be prevented by medical treatment.
- The pictures below show the risk of disease for people who have the mutation and for people who do not have the mutation.



This means that the risk of the disease is 1-½ (one and a half) times as high among people who have the mutation.

Would you want the researchers to tell you about your increased risk for this disease? ***Please check one.***

- ☐ Definitely not tell me
- ☐ Probably not tell me
- ☐ Probably tell me
- ☐ Definitely tell me
- ☐ Prefer not to answer