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Genetic Numeracy in College Students: A quantitative analysis

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## Dedication

What though the radiance which was once so bright Be now for ever taken from my sight, Though nothing can bring back the hour Of splendour in the grass, of glory in the flower; We will grieve not, rather find Strength in what remains behind;
---Wordsworth

For Rhys, Erin and Chase
Thank you for your inspiration and love

## Introduction

## The Genomic Era

We are moving forward into a new era. An era in which a mere prick of a finger will allow a health care provider to be able to see the pattern of interwoven amino acids that created the tapestry of one's existence. The hope of this era is that humanity can use this information to prevent and treat disease, to protect future generations from harm, and reduce suffering in the world. As with most important things, though, it is not as straightforward as it may sound. Scientists in the lab have to understand the interplay within genes, between genes and the environment, amongst genes and the exome. They have to determine the influence these various aspects of DNA on matters of health: what genes link to which disease, what possible treatments arise are there, how can individuals play their part. Clinicians have to learn this information and bring into the health care setting. The final step is for a patient to internalize and act upon the information he or she has received. While this archetype is evident in all health care interventions, genetics presents unique obstacles, since the science and its presentation to the public is highly probabilistic, and evidence shows us that dealing with probabilities is hard for large sections of the population (Tversky and Kahneman, 1974; Choi et al, 2011; Zikmund-Fisher et al, 2010; Campitelli and Labollita, 2010; Thaler et al, 1997). Understanding the causes of these difficulties can help prevent this final piece of translation to the patient from unraveling the entire framework of using genetic information to improve health.

## Health Literacy

The degree to which a patient understands health information concerns many in the field of science and medicine. Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004, pg. iv ). The Institute of Medicine (IOM) estimates that nearly $50 \%$ of U.S. adults have low health literacy. Low levels of literacy have been shown to negatively impact the use of preventative care (IOM, 2004), lead to higher rates of hospitalization (Baker et al, 1998; Schillinger et al, 2002), and results in higher mortality rates (Baker et al, 2007). These negative health outcomes lead to higher health care costs. Studies show increases per patient of nearly $\$ 1000$ per hospital stay due to lower literacy (Howard, 2004) and total costs of low literacy in patients have been estimated to be as high as $\$ 238$
billion dollars (Friedland, 1998; Friedland, 2002; Vernon et al, 2007). Increasing health literacy in all its forms will expand the quality of life of U.S. citizens by improving health and reducing costs.

## Health Numeracy

One important aspect of literacy to genetics is the concept of numeracy. Numeracy, at is core, is the ability to work fluently with numbers. Originally coined by an educator, Geofrrey Crowther in 1959 (Crowther Report, 1959) to give voice to the problems schoolchildren have with mathematical and analytical problems, it includes the ability to understand graphs, numbers, and other quantitative information (Bernhardt, Brownfield, and Parker, 2005). Baker (2006) further refines the concept of health numeracy to encompass both the numerical skills necessary to solve the problems presented and the "conceptual knowledge of health and health care" (ibid, pg 878) required to place those skills in context. This definition of numeracy encompasses the idea that patients should have the skills to identify and differentiate between risks. Because medical decision making often involves a choice between treatments, proper assessment of the benefits and risks of the different options is of the utmost importance to the overall health of the patient. (Burkell, 2004). Numeracy levels affect the basic computational skills necessary to process the information, as well as having implications for the interpretation and acceptance of genetic information (Lipkus, 2009). Low numeracy has also been linked to bias in judgment and decision making that can have negative impacts on medical decision making (Reyna et al, 2009).

What role does knowledge play in the assessment of numeracy? Unlike literacy, where it is possible to separate the ability to read from the contextual knowledge necessary to understand what you have read, numeracy contains within itself the need for context, content and cognition (Ginsburg et al, 2006). Even the most simple of tests of numeracy, asking a person how many times out of 100 they would expect a flipped coin to come up heads, requires knowledge of coins and physics. Knowledge and numeracy go hand in hand.

As a result a patient's understanding of genetic information is directly related to their numeracy level as well as their understanding of basic genetic concepts. Conveying the results of a genetic test, the risk of inheriting a genetic disorder, or the likelihood of developing a disease that has some genetic origin require that the patient has a high level of fluency with numerical analysis (Lea et al, 2011), as well as a basic understanding of DNA and the laws of inheritance.

## Genetic Numeracy

Determining the genetic numeracy levels of populations is necessary for determining if, and where, interventions to improve genetic numeracy are needed. To date, very few quantitative studies of genetic numeracy have been performed (Lea et al, 2011). Previous qualitative work has determined that people's perceptions of their own genetic risks of disease are affected by their knowledge of disease in family members (Walter, 2004). Other research has shown that different subsets of the population have varying skills in regards to numeracy (Smith, 2003). Questions remain, however, as to the impact these perceptions and differing levels of numeracy have on behavior. This thesis furthers this line of research by presenting a quantitative study of genetic numeracy. It will assess quantitative levels of numeracy; identify differences in subgroups, if present; and determine if these differing levels impact behavior.

## Research Question

As previously stated, the existing literature presents very few quantitative studies of genetic numeracy. Quantitative analysis provides researchers with an opportunity to verify and validate models that have been designed using qualitative methods (Bryman, 1994). Quantitative analysis is also better suited for studying large populations in order to determine the presence of predictive characteristics. The main goal of this thesis is to create a foundation for the future assessment of genetic numeracy by identifying the strengths and flaws in an original objective measurement tool.

This thesis shall design an ordinal scale of genetic numeracy to explore within a specific population the level of numeracy, determine what demographic factors might influence a person's numeracy, and determine if different levels of numeracy can predict different behaviors. This will be accomplished through secondary data analysis of an existing survey data set.

This project affords a unique opportunity to evaluate quantitatively the genetic numeracy of a population through an analysis of the perceived risk to themselves when a relative is diagnosed with a genetic disorder and knowledge questions pertaining to different types of inheritance. This measure of genetic numeracy is used in the creation of a numeracy scale that presents an overall picture of the numeracy of an individual. This scale is then analyzed to see if there are differences based on age, gender, marital status, ethnicity, religion, major, socio-economic status, and self-reported knowledge of genetics. Additionally it provides a chance to evaluate the association between numeracy and interpersonal
behaviors that are based on questions regarding intentions for dating, marrying, or having children with a person who had been diagnosed with a genetic disorder.

## Methods

## Dataset

This study is based on secondary analysis on data from the Perception of Genetic Risk in Sexual and Reproductive Decision Making (PGRID) by College Students dataset (Honoré, 2008). The original data were collected using a 138 -item web-based survey instrument. This survey was administered over a twoweek time period in 2008 to college students, aged 18 years and over, enrolled at two Southwestern Universities in the 2007-2008 school year. All students that had not opted out of including their email in the campus directory ( $\mathrm{N}=68.125$ ) were eligible to receive survey invitation. Participant incentive for the original survey was the opportunity to enter a random drawing for gift cards valued at $\$ 5-\$ 25$. Upon completion of the survey, all personal identifiers were removed, and therefore this study does not represent human subjects research. The original dataset consists of 2,576 respondents, representing a response rate of $3.7 \%$ of the total eligible population. This analysis excludes those respondents who had missing answers on any of the demographic survey items. The final N for this study is 2,568 .

## Specific Aims:

## Specific Aim 1

Specific Aim 1: Identify the level of genetic numeracy in a college-age population based on survey results

There is no generally accepted standard for assessing genetic numeracy. The survey from which this data are taken includes a question about the perception of risk to oneself if a relative (i.e. mother, father, siblings, etc) was diagnosed with a genetic disorder. The answers to these questions are compiled to create a scale that is used to gauge how accurate the respondents actually are. Additionally, the knowledge component of genetic numeracy is analyzed through the answers to two specific questions about genetic knowledge. The numeracy scale is described next followed by a description of the two knowledge questions.

## Genetic Numeracy Measurements

## Numeracy Scale

The following question was posed to the respondents: "If one of the following relatives were diagnosed with a genetic disorder, how would you rate your risk for developing the same disorder?" The relatives indicated were: mother, father, sibling, aunt or uncle, nieces or nephews, grandparent, and your (hypothetical) children. The possible answers ranged between $0 \%$ and $100 \%$, by $10 \%$ increments. For purposes of this analysis, overall numeracy has been divided into three categories: High, Medium and Low.

## Coefficient of Relationship: Measuring Genetic Inheritance

The risk posed to a respondent by the diagnosis of a genetic disorder in a relative will differ depending on the genetic distance between the respondent and the family member. This distance is measured by the coefficient of relationship or kinship coefficient (Wright, 1921).

## Coefficient of Relationship $=1 / 2($ Mother, Father, Child $)$

A Coefficient of Relationship of $1 / 2$ implies that we share half our genetic material with the person in question. For these relationships High level of numeracy was assigned to answers ranging from 20\%-50\% inclusive. Medium numeracy was assigned if the respondent listed $10 \%$ or $60 \%$ as their answer. Low numeracy was assigned for answers ranging from $70 \%-100 \%$ inclusive, and $0 \%$.

## Coefficient of Relationship $=1 / 4$ (Aunt, Uncle, Nephew, Niece, Grandparents)

A Coefficient of Relationship of $1 / 4$ implies that we share one-quarter our genetic material with the person in question. For these relationships High level of numeracy were assigned to answers ranging from 10\%$30 \%$ inclusive. In this coefficient of relationship, the true risk relationship should be $25 \%$, so we used that number as a base, again allowing for the fact that this number was not present in the survey. Medium numeracy was assigned if the respondent listed $40 \%-60 \%$ as their answer. Low numeracy was assigned for answers ranging from 70\%-100\% inclusive, and 0\%.

One concern with the creation of the scale is that the original survey did not allow the option to choose $25 \%$ (or any $5 \%$ increment). Given that recessive disorders will be inherited from mother or father at a rate of $25 \%$, this is a significant limitation on the ability to precisely determine the numeracy of the respondents. In order to compensate for this, the scale allows for the possibility that the respondent rounded up or down, and therefore $20 \%$ and $30 \%$ are both considered to be a good understanding of genetic inheritance. Including a range of numbers was important because a person might correctly identify the risk relationship with their mother or father of a recessive disorder as being $25 \%$, but then be unable to select that number, since it was not an available choice. $50 \%$ would be the correct answer for the risk relationship to this coefficient of relationship for a dominant disorder. Therefore, we allowed for the possibility the respondent might choose any of the risks between $20 \%-50 \%$ for their mother and father and this would be considered a High level of numeracy. The scale is optimistic, rather than pessimistic, about the numeracy of the population being studied. In further studies, more precise question will be used, in order to eliminate this concern.

| Numeracy | Mother | Father | Siblings | Children | Aunt or Uncle | Niece or Nephew | Grandparents |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Answer |  |  |  |  |  |  |  |
| $0 \%$ | L | L | L | L | L | L | L |
| $10 \%$ | M | M | M | M | H | H | H |
| $20 \%$ | H | H | H | H | H | H | H |
| $30 \%$ | H | H | H | H | H | H | H |
| $40 \%$ | H | H | H | H | M | M | M |
| $50 \%$ | H | H | H | H | M | M | M |
| $60 \%$ | M | M | M | M | M | M | M |
| $70 \%$ | L | L | L | L | L | L | L |
| $80 \%$ | L | L | L | L | L | L | L |
| $90 \%$ | L | L | L | L | L | L | L |
| $100 \%$ | L | L | L | L | L | L | L |

Table 1 - Scale measuring level of genetic numeracy

## Genetic Knowledge

The first knowledge question asks the respondents "Sickle cell anemia is an autosomal recessive genetic disorder. If a man who is a carrier (e.g., has one copy of the gene, but not the disorder) for sickle cell anemia has children with a woman who is also a carrier, their risk for having a child who has sickle cell anemia is...?" with the choices being $0 \%, 25 \%, 50 \%$ and $100 \%$. The correct answer in this case is $25 \%$. The second question asks respondents "Huntington's disease is an autosomal dominant genetic disorder. If a woman who has Huntington's (e.g., has a copy of the defective gene, and the disorder) has children with a man who does not carry any of the genes for Huntington's, their risk for having a child who has Huntington's is...?" with the choices being $0 \%, 25 \%, 50 \%$ and $100 \%$. The correct answer in this case is 50\%.

## Hypotheses: Specific Aim 1

Hypothesis 1: Respondents will understand best the risk relationship to their biological parents, with decreasing degrees of understanding in regards to the risk relationship with more distant relatives.

Hypothesis 1 is analyzed using two-sample tests of proportions. This analysis of Specific Aim 1, Hypothesis 1 is presented in Section 1a of the results.

Hypothesis 2a: When comparing two different relationships: mother/father, mother/siblings, etc., respondents will have the same number of correct answers for each pair.

Hypothesis 2b: That the number of correct answers, compared to the correct answers in regards to the risk relationship with the mother, will decrease in this order: father, siblings, child, grandparents, aunt/uncle, niece/nephew.

The more distant the relative, the less likely a person should be to understand that a genetic disorder in that relative creates an increased risk for themselves.

McNemar's tests for the various paired relationships for these hypotheses are presented in Section 1b of Results.

Finally the two knowledge questions are compared independently, and then together, to the numeracy scale for the various relationships.

Hypothesis 3a: The number of people who answer correctly on both knowledge questions will be the same.

Hypothesis 3b: The number of people who answer correctly on the knowledge question about an autosomal recessive disorder will be the same as the number of people who have High numeracy regarding the risk relationship to their mother (father, siblings, etc.).

Hypothesis 3c: The number of people who answer correctly on the knowledge question about an autosomal dominant disorder will be the same as the number of people who have High numeracy regarding the risk relationship to their mother (father, siblings, etc.).

The relationship between knowledge and numeracy is presented in Section 1c of the results.

The first two hypotheses in this aim use the numeracy scale and the detailed responses about relative risk to assess a picture of the overall understanding of risk inheritance. The third hypothesis in this aim looks at the answers given to two knowledge questions and relates this to the numeracy scale.

## Specific Aim 2

## Specific Aim 2: Determine what, if any, demographic characteristics predict lower genetic numeracy

After determining what, if any, portions of the study population possess lower genetic numeracy, analysis will determine what characteristics might predict these lower levels of genetic numeracy. It is the hope that in doing so this information can be used to help implement programs to improve genetic literacy in all populations.

This is accomplished using logistic regression analysis. The following demographic characteristics are the independent variables: Age, Gender, Income, Marital Status ${ }^{1}$, Race/Ethnicity, Religion ${ }^{2}$, Extent

[^0]Religious ${ }^{3}$, Weekly Service Attended ${ }^{4}$, Education Level, Biological Science Degree ${ }^{5}$, Highest Degree, Taken a Genetics Course, Taken a Course with Genetic Info ${ }^{6}$, Charted a Family Tree, Charted Family Health History, Taken a Genetic Test ${ }^{7}$.

A priori, being enrolled in a biological science degree, having taken a genetics course, and having taken a genetic test should protect against lower numeracy.

The generalized logit in the model is as follows:

$$
\begin{aligned}
& L N=\beta_{0}+\beta_{1} A G E+\beta_{2} G E N D E R+\beta_{3} \text { INCOME }+\beta_{4} \text { MARITALSTATUS }+\beta_{5} \text { RACE } \\
& +\beta_{6} \text { RELIGION }+\beta_{7} \text { EXTENTREL }+\beta_{8} \text { WEEKSER } \\
& +\beta_{9} \text { EDUCATIONLEVEL }+\beta_{10} \text { BIOSCIDEGREE }+\beta_{11} \text { GENCOURSE } \\
& +\beta_{12} \text { GENINFO }+\beta_{13} \text { CHARTTREE }+\beta_{14} \text { CHARTHEALTH }+\beta_{15} \text { GENTEST }
\end{aligned}
$$

AGE and INCOME are continuous variables. EDUCATIONLEVEL, EXTENTREL, and WEEKSER are ordinal variables. GENDER, BIOSCIDEGREE, GENCOURSE, GENINFO, CHARTTREE, CHARTHEALTH, and GENTEST are dichotomous variables. MARITAL STATUS, RACE, and RELIGION are categorical variables. Dummy variables were used in the regression. The categories for the dummy variables can be seen in Table 2, Table 3 and Table 4 in the Results section.

A separate logistic regression was run for each risk relationship.

## Specific Aim 3

The literature suggests that differing levels of genetic literacy will result in different behaviors (McBride, 2010; Brewer, 2009; Driessnack, 2009). This study addresses a similar question about whether lower levels of genetic numeracy will result in stating different intentions to date, marry, or have children with a potential partner diagnosed with a genetic disorder. Respondents were asked to rate, on a five-point Likert scale, this likelihood of a hypothetical person in six different possible genetic statuses ${ }^{8}$.

[^1]Specific Aim 3: Determine what, if any, relationship lower genetic numeracy has towards intentions relating to dating, marrying and having children with a hypothetical person who has been diagnosed with a genetic disorder.

Specific Aim 3, Hypothesis 3a: Overall numeracy level will have no effect on the likelihood of dating a person with any of these genetic statuses.

Specific Aim 3, Hypothesis 3b: Overall numeracy level will have an effect on the likelihood of marrying a person with any of these genetic statuses. Those with lower numeracy will be more likely to marry a person with each of these genetic statuses.

Specific Aim 3, Hypothesis 3c: Overall numeracy level will have an effect on the likelihood of dating a person with any of these genetic statuses. Those with lower numeracy will be more likely to have children with a person with each of these genetic statuses.

A composite numeracy score is created that combines the numeracy levels of each of the risk relationships into a single score. This composite numeracy scale is compared to each of the six possible genetic statuses in the three different partnering scenarios using Spearman correlation.

The results of this analysis are reported in Section 3 of the results.

## Results

## Summary Statistics - Demographic Variables

| Gender |  |  |
| :--- | :--- | :--- |
|  | Male | $35 \%$ |
|  | Female | $65 \%$ |
| Average Age |  | 23.3 |
| Ethnicity |  |  |
|  | White | $66 \%$ |
|  | Black/African | $3 \%$ |


|  | American |  |
| :---: | :---: | :---: |
|  | Hispanic | 19\% |
|  | Other | 11\% |
| Marital Status |  |  |
|  | Single, Not Dating | 31\% |
|  | Single, Dating | 16\% |
|  | Dating, Long Term | 25\% |
|  | Dating, Short Term | 4\% |
|  | Married | 13\% |
|  | Other ${ }^{9}$ | 11\% |
| Income (parents) |  |  |
|  | < \$10,000 | 7\% |
|  | \$10,000-\$14,999 | 6\% |
|  | \$15,000-\$24,999 | 10\% |
|  | \$25,000 - \$34,999 | 9\% |
|  | \$35,000 - \$49,999 | 12\% |
|  | \$50,000-\$74,999 | 15\% |
|  | \$75,000-\$99,999 | 14\% |
|  | > \$100,000 | 28\% |

Table 2 - Summary Statistics - Demographics

| Religion |  |  |
| :--- | :--- | :--- |
|  | Catholic | $25 \%$ |
|  | Hindu | $2 \%$ |
|  | Buddhist | $1 \%$ |
|  | Agnostic | $5 \%$ |
|  | Atheist | $3 \%$ |
|  | Protestant | $8 \%$ |
|  | Judaism | $.6 \%$ |
|  | LDS | $1 \%$ |
|  | Muslim | $.4 \%$ |
|  | None | $9 \%$ |

[^2]|  | Other $^{10}$ | $53 \%$ |
| :--- | :--- | :--- |
| Extent Religious <br> or Spiritual | Not at all | $11 \%$ |
|  | Slightly | $26 \%$ |
|  | Moderately | $40 \%$ |
|  | Very | $23 \%$ |
|  | 0 |  |
| Weekly <br> attendance at <br> religious services | 1 | $46 \%$ |
|  | $2-4$ | $36 \%$ |
|  | $5+$ | $16 \%$ |
|  | $2 \%$ |  |

Table 3 - Summary Statistics - Religion

| Educational <br> Status |  |  |
| :--- | :--- | :--- |
|  | Undergraduate | $79 \%$ |
|  | Graduate | $20 \%$ |
|  | Other | $1 \%$ |
| Enrolled in a <br> Biological <br> Science Degree |  |  |
|  | Yes | $19 \%$ |
|  | No | $81 \%$ |
| Highest Degree to <br> Date | GED/High School <br> Diploma | $68 \%$ |
|  | Associates | $9 \%$ |
|  | Bachelor's | $15 \%$ |
|  |  |  |

[^3]|  | Master's | $6 \%$ |
| :--- | :--- | :--- |
|  | Doctoral | $.2 \%$ |
|  | Professional | $.3 \%$ |
| Taken a Genetics <br> Course |  |  |
|  | Yes | $18 \%$ |
|  | No | $82 \%$ |
| Taken a course <br> with Genetic Info |  |  |
|  | Yes | $83 \%$ |
|  | Yo | $17 \%$ |
| Charted your <br> family tree | No | $49 \%$ |
|  | Yes | $51 \%$ |
|  | Yes | $6 \%$ |
| Charted your <br> family health <br> history | No | $94 \%$ |
|  | $39 \%$ |  |
|  | No |  |
| Taken a Genetic <br> Test |  |  |
|  |  |  |
|  |  |  |

Table 4 - Summary Statistics - Education/Genetic Exposure

## Section 1a: Numeracy scale results

This thesis will focus on analysis of responses for coefficient of relationship of $1 / 2$. Results of coefficient of relationship of $1 / 4$ are included in Appendix A.

Coefficient = 1/2 : Mother, Father, Siblings, Child

It was thought, a priori, that the level of numeracy with regards to the maternal relationship would be the highest. However, there were essentially no differences in the assigned numeracy scale percentages of High numeracy for mother, father or siblings.

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 909 | $35.4 \%$ |
| Medium | 185 | $7.2 \%$ |
| High | 1474 | $57.4 \%$ |

Table 5 - Numeracy Level - Mother


Figure 1 - Graph of Numeracy - Mother

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 837 | $32.6 \%$ |
| Medium | 203 | $7.9 \%$ |


| High | 1528 | $59.9 \%$ |
| :---: | :---: | :---: |

Table 6 - Numeracy Level - Father


Figure 2 - Graph of Numeracy Level - Father

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 755 | $29.4 \%$ |
| Medium | 274 | $10.7 \%$ |
| High | 1539 | $59.9 \%$ |

Table 7 - Numeracy Level - Siblings


Figure 3 - Graph of Numeracy Level - Siblings

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 816 | $31.78 \%$ |
| Medium | 463 | $18.03 \%$ |
| High | 1389 | $50.19 \%$ |

Table 8 - Numeracy Level - Children


Figure 4 - Graph of Numeracy Level - Children

The detailed responses of these four risk relationships do show differences in response patterns. For the risk relationship to their mother and father, the majority of the respondents chose $50 \%$. A box plot (Figure 5 ) shows us this visually.


Figure 5-Comparison of Risk Relationship Responses - Mother and Father

It does appear, though that when the respondent does not choose $50 \%$ for the risk relationship to their mother or father that there is some tendency to overestimate risk from genetic inheritance. Very few people chose a risk amount that was less than $50 \%$ for the risk relationship to their mother or father. A much larger percentage (two-sample $\mathrm{z}=-22.8407, \mathrm{p}=1.0$ ) of people estimated the risk relationship to their mother as $60 \%-90 \%(\mathrm{~N}=868)$ than those that chose $10 \%-40 \%(\mathrm{~N}=204)$.

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 67 | $2.6 \%$ |
| $10 \%$ | 24 | $.9 \%$ |
| $20 \%$ | 23 | $.9 \%$ |
| $30 \%$ | 79 | $3 \%$ |
| $40 \%$ | 78 | $3 \%$ |
| $50 \%$ | 1295 | $50.4 \%$ |
| $60 \%$ | 161 | $6.3 \%$ |
| $70 \%$ | 330 | $12.9 \%$ |
| $80 \%$ | 225 | $8.8 \%$ |


| $90 \%$ | 152 | $5.9 \%$ |
| :---: | :---: | :---: |
| $100 \%$ | 135 | $5.3 \%$ |

Table 9 - Risk Relationship Detailed Responses - Mother


Figure 6 - Graph of Risk Relationship Details - Mother

Similarly, an analysis of differences in responses to the risk relationship to the father shows again a much larger percentage (two-sample $\mathrm{z}=-20.8215, \mathrm{p}=1.0$ ) of people estimated the risk relationship to their father as $60 \%-90 \%(\mathrm{~N}=818)$ than those that chose $10 \%-40 \%(\mathrm{~N}=220)$.

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 73 | 2.84 |
| $10 \%$ | 25 | 0.97 |
| $20 \%$ | 31 | 1.21 |
| $30 \%$ | 80 | 3.11 |
| $40 \%$ | 84 | 3.27 |
| $50 \%$ | 1,334 | 51.93 |


| $60 \%$ | 178 | 6.93 |
| :---: | :---: | :---: |
| $70 \%$ | 315 | 12.26 |
| $80 \%$ | 204 | 7.94 |
| $90 \%$ | 121 | 4.71 |
| $100 \%$ | 124 | 4.83 |

Table 10 - Risk Relationship Detailed Responses - Father


Figure 7 - Graph of Risk Relationship Detailed Responses - Father

Looking into the details of the risk relationship to a sibling shows us a different picture. Here, unlike our results comparing mother to father, we cannot say that the number of people who overestimate risk is significantly different than those that estimate risk below $50 \%$ (two-sample $\mathrm{z}=3.82, \mathrm{p}=.99$ ). The number of people who thought that their risk relationship to their siblings was $10 \%-40 \%$ is 862 , compared to 734 who thought that the risk relationship was $60 \%-90 \%$.

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 139 | 5.41 |
| $10 \%$ | 83 | 3.23 |
| $20 \%$ | 164 | 6.38 |
| $30 \%$ | 418 | 16.27 |
| $40 \%$ | 197 | 7.67 |
| $50 \%$ | 761 | 29.62 |
| $60 \%$ | 191 | 7.43 |
| $70 \%$ | 298 | 11.60 |
| $80 \%$ | 157 | 6.11 |
| $90 \%$ | 88 | 3.43 |
| $100 \%$ | 73 | 2.9 |

Table 11 - Risk Relationship Detailed Responses - Siblings

In this case of siblings, though, while the theoretical risk relationship is the same as mother or father, and while the respondents had approximately equal numbers of High numeracy as to mother and father, respondents had a much wider range of responses.


Figure 8 - Graph of Risk Relationship Detailed Responses - Siblings


Figure 9 - Comparison of Risk Relationships Reponses - Mother, Father and Siblings

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 357 | 13.9 |
| $10 \%$ | 317 | 12.34 |
| $20 \%$ | 186 | 7.24 |
| $30 \%$ | 214 | 8.33 |
| $40 \%$ | 175 | 6.81 |
| $50 \%$ | 714 | 27.8 |
| $60 \%$ | 146 | 5.69 |
| $70 \%$ | 183 | 7.13 |
| $80 \%$ | 127 | 4.95 |
| $90 \%$ | 76 | 2.96 |
| $100 \%$ | 73 | 2.84 |

Table 12 - Risk Relationship Detailed Responses - Children

In regards to their risk relationship to their child, again, we can reject that hypothesis that as many people believe that their risk is less than $50 \%(\mathrm{~N}=892)$ as those who believe that it is over $50 \%(\mathrm{~N}=532)$ (two-
sample $\mathrm{z}=11.22, \mathrm{p}=1.0$ ). In fact, many more people think that their risk relationship to their children is under $50 \%$. There is not the same tendency here to overestimate risk.


Figure 10 - Graph of Risk Relationship Detailed Responses - Children


Figure 11 - Comparison of Risk Relationship Responses - Mother, Father, Siblings and Children

A final comparison of all four risk relationships shows that the answers for sibling and child have a much wider range, and represent a lowered perception of risk, than for mother and father. This is especially true for the child relationship.

## Section 1b: Comparisons of Levels of numeracy

$\mathrm{N}=2586$

| Relationship | High Numeracy | Percent of Sample |
| :---: | :---: | :---: |
| Mother | 1474 | $57 \%$ |
| Father | 1528 | $59 \%$ |
| Siblings | 1539 | $60 \%$ |
| Child | 1289 | $50 \%$ |

Table 13 - Levels of High Numeracy - coefficient of relationship of $1 / 2$

In contrast to hypothesis 2 b , the relationship with the highest level of numeracy for coefficient of $1 / 2$ was that of siblings, then father, mother, and child (See Appendix A for coefficient of relationship of $1 / 4$ ) However, the different between these pairs is very small, as they all rest around $50 \%{ }^{11}$.

McNemar's test is used to determine the relationship between how well respondents understood each pair's risk relationship. In all cases, except one, the hypothesis that people understood their risk relationship equally among pairs cannot be rejected. In the case of father/siblings, there were a significantly larger percentage of the people who had correct answers for both of these risk relationships than had incorrect answers.

| Relationship Pair | Both Correct | Both Incorrect | McNemar's <br> statistic | P |
| :---: | :---: | :---: | :---: | :---: |
| Mother/Father | 1423 | 988 | 18.46 | 0.0000 |
| Mother/Siblings | 1193 | 747 | 6.72 | 0.0107 |
| Mother/Children | 911 | 716 | 36.73 | 0.0000 |
| Father/Siblings | 1238 | 739 | .20 | 0.6509 |
| Father/Children | 938 | 689 | 60.70 | 0.0000 |
| Siblings/Children | 942 | 682 | 66.21 | 0.0000 |

Table 14 - McNemar's Test - pairwise risk relationships

## Section 1c: Knowledge questions

Turning now to the questions regarding genetic knowledge, the first hypothesis in this arena is that people will equally understand both autosomal recessive and autosomal dominant disorders.

| Question | Correct responses | Percentage |
| :---: | :---: | :---: |
| Autosomal Recessive (Sickle <br> Cell) | 1152 | $44.86 \%$ |
| Autosomal Dominant <br> (Huntington's) | 1363 | $53.08 \%$ |

Table 15 - Knowledge questions - recessive versus dominant

[^4]A McNemar's test $\left(\right.$ chi $\left.^{2}=37.07, \mathrm{p}=0.00\right)$ indicates that it is highly unlikely that the number of people who had a correct answer to the risk of an autosomal recessive disorder is equal to the number of people who had the correct answer to the risk of an autosomal dominant disorder. Over $53 \%$ of the population answered the latter correctly.

The final hypothesis relates the number of correct answers on the knowledge tests to a High level of numeracy. As above, 1152 respondents answered correctly on the knowledge question about an autosomal recessive disorder.

| Risk Relationship | High Numeracy | Both | McNemar's Stat | P |
| :---: | :---: | :---: | :---: | :---: |
| Mother | 1474 | 723 | 87.87 | 0.000 |
| Father | 1528 | 739 | 117.62 | 0.000 |
| Siblings | 1539 | 716 | 118.96 | 0.000 |
| Children | 1289 | 612 | 15.42 | 0.001 |
|  |  |  |  |  |

Based on this, the hypothesis that people who had correct answers on the knowledge scale also had the level High on the Numeracy scale can be rejected.

## Section 2: Logistic Regression analysis

Logistic regression analysis in used to identify predictors of low numeracy in the study population. Each risk relationship was evaluated. The results are presented by risk relationship. Significant predictors are highlighted in italics.

|  | OR | $95 \%$ | CI |
| :--- | :---: | :---: | :---: |
| Age | 1.010663 | 0.992912 | 1.030116 |
| Gender | 1.00587 | 0.844769 | 1.20231 |


| Income | 0.980005 | 0.94221 | 1.019315 |
| :---: | :---: | :---: | :---: |
| Marital Status |  |  |  |
| Cohabit | 1.007668 | 0.659113 | 1.540546 |
| Short Term Dating | 0.990119 | 0.634086 | 1.546061 |
| Long Term Dating | 1.013144 | 0.781374 | 1.313661 |
| Divorced | 0.75345 | 0.359645 | 1.578464 |
| Engaged | 1.082262 | 0.699246 | 1.675075 |
| Married | 0.761658 | 0.535203 | 1.083932 |
| Separated | 2.477974 | 0.427145 | 14.37535 |
| Single Not Dating | 1.037026 | 0.806297 | 1.33378 |
| Race/Ethnicity |  |  |  |
| White | 0.775186 | 0.572652 | 1.04935 |
| BAA | 0.721587 | 0.413595 | 1.25893 |
| Hispanic/Latin | 0.831344 | 0.590318 | 1.170779 |
| Religion |  |  |  |
| Extent Religious | 0.862758 | 0.757568 | 0.982554 |
| Services Attended per week | 1.12657 | 0.980185 | 1.294817 |
| Agnosticism | 0.891649 | 0.411344 | 1.932778 |
| Atheism | 0.588804 | 0.2613 | 1.32679 |
| Buddhism | 1.511694 | 0.542864 | 4.20956 |
| Catholic | 1.635817 | 0.818028 | 3.271155 |
| Hindu | 1.561671 | 0.619361 | 3.937634 |
| Judaism | 0.621604 | 0.169449 | 2.280282 |
| LDS | 1.80613 | 0.651994 | 5.003276 |
| Muslim | 1.421185 | 0.333379 | 6.058475 |
| NoneRel | 1.279261 | 0.613812 | 2.666138 |
| Prot | 1.034052 | 0.762358 | 1.402575 |
| OtherRel | 1.615316 | 0.81768 | 3.191033 |
| Education variables |  |  |  |
| Education Level | 0.810755 | 0.594899 | 0.988802 |
| Biological Science Degree | 0.733807 | 0.562473 | 0.879103 |
| Highest Degree | 1.029981 | 0.76848 | 1.081424 |
| Taken a Genetics Course | 0.766966 | 0.949547 | 1.352513 |
| Taken a Course | 0.703186 | 0.643086 | 1.275884 |


| with Genetics <br> Information |  |  |  |
| ---: | :--- | :--- | :--- |
| Charted Family <br> Tree | 0.911621 | 0.594899 | 0.988802 |
| Charted Family <br> Health History | 1.133258 | 0.562473 | 0.879103 |
| Taken a <br> Genetic Test | 0.905816 | 0.76848 | 1.081424 |

Table 17 - Logistic Regression Analysis - Mother

|  | Coef. | $95 \%$ | CI |
| :--- | :---: | :---: | :---: |
| Age | 1.005343 | 0.986895 | 1.024137 |
| Gender | 0.915894 | 0.766975 | 1.093727 |
| Income | 0.998055 | 0.959246 | 1.038433 |
| Marital Status |  |  |  |
| Cohabit | 1.306839 | 0.85511 | 1.997201 |
| Short Term <br> Dating | 1.029588 | 0.656649 | 1.614333 |
| Long Term <br> Dating | 1.04474 | 0.80363 | 1.35819 |
| Divorced | 1.038931 | 0.497995 | 2.167447 |
| Engaged | 0.969004 | 0.621104 | 1.511773 |
| Married | 0.849492 | 0.595373 | 1.212075 |
| Separated | 2.96468 | 0.51352 | 17.11583 |
| Single Not | 1.050075 | 0.814392 | 1.353965 |
| Dating |  |  |  |
| Race/Ethnicity |  |  |  |
| White | 0.858932 | 0.632431 | 1.166555 |
| BAA | 0.708329 | 0.400123 | 1.253942 |
| Hispanic/Latin | 0.99899 | 0.707515 | 1.410544 |
| Religion |  |  |  |
| Extent <br> Religious | 0.885247 | 0.776557 | 1.00915 |
| Services | 1.166397 | 1.013755 | 1.342022 |
| Attended per |  |  |  |
| week |  |  |  |


| Agnosticism | 0.853499 | 0.393422 | 1.851604 |
| :---: | :---: | :---: | :---: |
| Atheism | 0.495887 | 0.21783 | 1.128877 |
| Buddhism | 1.629605 | 0.58526 | 4.537494 |
| Catholic | 1.411725 | 0.70615 | 2.8223 |
| Hindu | 1.504526 | 0.594888 | 3.805082 |
| Judaism | 0.77268 | 0.224183 | 2.663154 |
| LDS | 1.191966 | 0.426786 | 3.32903 |
| Muslim | 1.416259 | 0.332181 | 6.038241 |
| NoneRel | 1.104783 | 0.529456 | 2.305279 |
| Prot | 1.117207 | 0.822773 | 1.517008 |
| OtherRel | 1.323838 | 0.670318 | 2.614499 |
| Education variables |  |  |  |
| Education <br> Level | 0.87293 | 1.268519 | 0.600706 |
| Biological Science Degree | 0.668572 | 0.857015 | 0.521565 |
| Highest Degree | 1.021347 | 1.213486 | 0.85963 |
| Taken a Genetics Course | 0.743814 | 0.963351 | 0.574306 |
| Taken a Course with Genetics Information | 0.759847 | 0.950166 | 0.607649 |
| Charted Family Tree | 0.879803 | 1.045154 | 0.740611 |
| Charted Family Health History | 1.17709 | 1.406881 | 0.984832 |
| Taken a Genetic Test | 0.873093 | 1.235501 | 0.616989 |

Table 18 - Logistic Regression Analysis - Father

|  | OR | $95 \%$ | CI |
| :--- | :---: | :---: | :---: |


| Age | 0.998585 | 0.980128 | 1.017389 |
| :---: | :---: | :---: | :---: |
| Gender | 0.927037 | 0.777055 | 1.105967 |
| Income | 0.990717 | 0.952393 | 1.030584 |
| Marital Status |  |  |  |
| Cohabit | 1.348034 | 0.884268 | 2.05503 |
| Short Term Dating | 0.845675 | 0.53457 | 1.337833 |
| Long Term Dating | 1.156512 | 0.890642 | 1.501749 |
| Divorced | 1.199576 | 0.573444 | 2.50937 |
| Engaged | 1.262425 | 0.816595 | 1.951663 |
| Married | 0.903151 | 0.6329 | 1.288798 |
| Separated | 1.664455 | 0.317571 | 8.723749 |
| Single Not Dating | 1.20107 | 0.93243 | 1.547108 |
| Race/Ethnicity |  |  |  |
| White | 0.799469 | 0.591001 | 1.08147 |
| BAA | 0.826899 | 0.474895 | 1.439816 |
| Hispanic/Latin | 0.885986 | 0.62971 | 1.24656 |
| Religion |  |  |  |
| Extent Religious | 0.930601 | 0.817251 | 1.059672 |
| Services <br> Attended per week | 1.053857 | 0.91679 | 1.211418 |
| Agnosticism | 1.4455 | 0.674635 | 3.097186 |
| Atheism | 1.037791 | 0.470991 | 2.286687 |
| Buddhism | 1.35188 | 0.483949 | 3.776386 |
| Catholic | 1.675304 | 0.843303 | 3.328157 |
| Hindu | 1.53323 | 0.612738 | 3.836538 |
| Judaism | 0.310956 | 0.062277 | 1.552639 |
| LDS | 1.125151 | 0.395508 | 3.200855 |
| Muslim | 1.171326 | 0.269981 | 5.081848 |

$\left.\begin{array}{|r|l|l|l|}\hline \text { NoneRel } & 1.140124 & 0.549281 & 2.366515 \\ \hline \text { Prot } & 0.89346 & 0.656079 & 1.216729 \\ \hline \text { OtherRel } & 1.675732 & 0.854239 & 3.287227 \\ \hline \begin{array}{r}\text { Education } \\ \text { variables }\end{array} & & & \\ \hline \begin{array}{r}\text { Education } \\ \text { Level }\end{array} & 0.894701 & 0.619539 & 1.292073 \\ \hline \begin{array}{r}\text { Biological } \\ \text { Science Degree }\end{array} & 0.93845 & 0.737433 & 1.194262 \\ \hline \text { Highest Degree } & 1.033873 & 0.872328 & 1.225334 \\ \hline \text { Taken a } & 0.862937 & -0.14741 & 0.128956 \\ \text { Genetics }\end{array}\right)$

Table 19 - Logistic Regression Analysis - Sibling

|  | OR | CI | OR |
| :--- | :---: | :---: | :---: |
| Age | 1.022535 | 1.003748 | 1.041674 |
| Gender | 0.732342 | 0.615539 | 0.871311 |
| Income | 0.978157 | 0.940935 | 1.016851 |
| Marital Status |  |  |  |
| Cohabit | 0.861508 | 0.568053 | 1.306563 |
| Short Term <br> Dating | 1.107179 | 0.715066 | 1.714309 |
| Long Term | 0.932376 | 0.722287 | 1.203573 |


| Dating |  |  |  |
| :---: | :---: | :---: | :---: |
| Divorced | 0.785187 | 0.376678 | 1.636727 |
| Engaged | 0.729306 | 0.473178 | 1.124075 |
| Married | 0.785543 | 0.556365 | 1.109124 |
| Separated | 1.216844 | 0.21133 | 7.006607 |
| Single Not Dating | 0.878092 | 0.685362 | 1.12502 |
| Race/Ethnicity |  |  |  |
| White | 1.084677 | 0.804497 | 1.462435 |
| BAA | 1.094181 | 0.633041 | 1.891238 |
| Hispanic/Latin | 1.238028 | 0.88224 | 1.737297 |
| Religion |  |  |  |
| Extent <br> Religious | 0.899512 | 0.791601 | 1.022133 |
| Services Attended per week | 1.128474 | 0.983479 | 1.294846 |
| Agnosticism | 1.502967 | 0.677394 | 3.334706 |
| Atheism | 1.62257 | 0.716278 | 3.675573 |
| Buddhism | 3.106539 | 1.073701 | 8.988148 |
| Catholic | 2.054741 | 0.991654 | 4.257493 |
| Hindu | 3.238216 | 1.253025 | 8.368588 |
| Judaism | 1.949997 | 0.598561 | 6.35272 |
| LDS | 2.312408 | 0.8141 | 6.568273 |
| Muslim | 3.495095 | 0.786132 | 15.53899 |
| NoneRel | 2.231687 | 0.069639 | 19.71839 |
| Prot | 1.013371 | 1.03879 | 4.794447 |
| OtherRel | 2.448889 | 0.751463 | 1.366562 |
| Education variables |  |  |  |
| Education Level | 0.725954 | 0.505142 | 1.043291 |
| Biological | 0.877649 | 0.693614 | 1.110515 |


| Science Degree |  |  |  |
| ---: | :--- | :--- | :--- |
| Highest Degree | 1.038272 | 0.878375 | 1.227277 |
| Taken a <br> Genetics <br> Course | 1.093932 | 0.335403 | 1.093932 |
| Taken a Course <br> with Genetics <br> Information | 0.868039 | 0.855691 | 1.398503 |
| Charted Family <br> Tree | 1.046872 | 0.694444 | 1.085027 |
| Charted Family <br> Health History | 1.057772 | 0.884774 | 1.238668 |
| Taken a <br> Genetic Test | 1.395595 | 0.888738 | 1.258956 |
| Table 20 - Logistic Regression Analysis - Children |  |  |  |

In each of the risk relationships, most of the demographic variables have little predictive value for determining what leads to low numeracy levels ${ }^{12}$. There are some interesting exceptions, although due to the large number of comparisons, these results should be seen as indications of possible relationships only.

For almost every risk relationship, whether the respondent indicated that he or she had taken a class with some genetic information (examples included general biology, physiology or human sexuality) was significantly protective against of Low numeracy. The only risk relationships for which this is not the case is with one's own children. Having taken a specific genetics course, which a much smaller set of the respondents have done, is significant for mother and father but not any other relationships.

Pursuing a biological sciences degree is significant being protective of Low numeracy for mother and father, but is not significant in any other relationship.

Gender is found to have significant predictive power only with regards to one's own children, where being male predicts Low numeracy for this risk relationship.

[^5]Having taken a genetic test in the past was predictive of Low numeracy with respect to one's own children, but surprisingly, this was found to protect against Low numeracy with regards to grandparents

The demographics surrounding religion present some of the most interesting results in this section of the study. Self-identifying as more religious offers a protection against Low numeracy in the risk relationships with one's mother. However, attending more church services per week predicts higher rates of Low numeracy with respect to one's father or children. Specific religious identifications, such as Buddhism, Catholicism or Hinduism, represent more likelihood of Low numeracy with some risk relationships. ${ }^{13}$

## Section 3: Spearman Correlations

|  | Composite Numeracy Score |
| :--- | ---: |
| Date Unknown | -0.0084 |
| Date Asymptomatic | 0.0123 |
| Date Symptomatic | 0.0123 |
| Date Physical | 0.0067 |
| Date Mental | -0.0036 |
| Date Any | -0.0039 |
| Marry Unknown | -0.0009 |
| Marry Asymptomatic | 0.0063 |
| Marry Symptomatic | -0.0027 |
| Marry Physical | -0.013 |
| Marry Mental | -0.0121 |
| Marry Any | -0.0126 |
| Children Unknown | 0.0222 |
| Children Asymptomatic | 0.0363 |
| Children Symptomatic | 0.0109 |
| Children Physical | -0.0118 |
| Children Mental | -0.0086 |

[^6]| Children Any | 0.002 |
| :--- | ---: |

Table 21 - Spearman Correlations - Intentions

The Spearman correlations imply that there is little relationship between the numeracy level of the individual, and the intentions to date, marry or have children with hypothetical people with genetic disorders ${ }^{14}$.

## Section 4: Post-Hoc Analysis

After completing the analyses based on the original hypothesis, additional analyses were completed in order to provide context and clarification for the discussion. Those results are presented here.

| Degree of Relative | $\mathbf{0 \%}$ | Percent of <br> Respondents | $\mathbf{1 0 0 \%}$ | Percent of <br> Respondents |
| :---: | :---: | :---: | :---: | :---: |
| Mother | 67 | $2.61 \%$ | 135 | $5.26 \%$ |
| Father | 73 | $2.84 \%$ | 124 | $4.83 \%$ |
| Siblings | 139 | $5.41 \%$ | 73 | $2.84 \%$ |
| Aunt or Uncle | 124 | $4.83 \%$ | 23 | $0.90 \%$ |
| Nieces or Nephews | 256 | $9.97 \%$ | 22 | $0.86 \%$ |
| Grandparents | 74 | $2.88 \%$ | 49 | $1.91 \%$ |
| Own Children | 357 | $13.9 \%$ | 73 | $2.84 \%$ |

Table 22 - Percentage of respondents stating $0 \%$ or $100 \%$ risk relationship

|  | Date - Any <br> Genetic Disorder | Marry - Any <br> Genetic Disorder | Have Kids - Any <br> Genetic Disorder |
| :---: | :---: | :---: | :---: |
| Not at all Likely | 142 | 263 | 475 |
| Not Very Likely | 612 | 795 | 934 |
| Somewhat Likely | 1236 | 1068 | 855 |
| Very Likely | 463 | 337 | 230 |
| Extremely Likely | 116 | 106 | 75 |

Table 23 - Trends in intentions

[^7]
## Discussion

## Strengths and Limitations

This study is one of the few quantitative studies of genetic numeracy. It has a large sample size, and contains a wide variety of variables that are used to determine what, if any, predictive value they contain with respect to correctly identifying risk relationships.

There are limitations to this work, however. The analysis assumes that when people are considering their answers for genetic risk from different relationships, that those relationships are full genetic relationships. The data cannot account for answers that were given based on non-genetic or partial-genetic relationships (i.e. adoption, step-parents, half-siblings, etc.). If respondents were considering their own families, and they happened to be adopted, they might answer that they had no genetic risk to their relatives, and thereby underestimate risk. It is unclear the magnitude of this effect, however, given that most respondents overestimated their risk relationship with their relatives. In future research, more specific details about the relationships in question will be included in the question, to better ascertain the thinking of the respondents.

Additionally, the quantitative portion was not capable of allowing the respondents to fully choose the risks they associated with each risk relationship. Further work will include sliding scales that allow a respondent to choose a specific risk from $0 \%-100 \%$, by single units, rather than tens.

The study is not wholly representative of the population, given that the original study population was limited to college students, and it did not fully control for a background in science. The sample was predominately young, white, female, and single (Table 2). Further work should include a wider sample of ages, life situations and ethnicities.

## Implications

The numeracy scale created for this analysis highlights some of the difficulties of quantitative analysis of genetic numeracy. Collapsing the responses to the risk relationship portion of the survey improves the ability to obtain numerical analysis of the results, but removes the subtleties of the answers, which can decrease true understanding of the cognitive processes that create the beliefs of the respondents. Refinements to both the questions that underlie the scale, and the scale itself will be of great benefit to future quantitative analysis.

The detailed responses of the risk relationships of mother and father may explain the core of the beliefs that people have about genetics. The majority of the correct responses were for risks of $50 \%$ (Table 9 and Table 10). This seems to imply that people believe that risk relationships with their parents follow inheritance patterns of autosomal dominant genes. Only a small percentage of the respondents chose risks between $20 \%$ and $40 \%$, (Table 9 and Table 10) which would be indicative of indicative of expressing an understanding of recessive disorders as well as dominant. This is further supported by the results of the genetic knowledge questions (Table 16) which showed that significantly higher percentage of the study population understood risks relating to a dominant disorder than a recessive one. However, due to the limitations imposed by the original question, the exact cause cannot be defined. It is possible that respondents were correctly identifying that while they must share a specific allele in common with one of their parents at every possible locus, that for siblings, the possibility exists to share none, even though the total genetic material in common, on average, is the same as with parents. Further research, both quantitative and qualitative, could dissect the actual beliefs and cognitive processes that respondents undergo when thinking about genetic inheritance. More investigation is also necessary to determine the impact these differences have on the perception of risk of genetic disease.

Overestimating risk was another common theme in this area of investigation. The second most common risk relationship chosen for both mother and father was $70 \%$. (Table 9 and Table 10) For siblings it was third (Table 11). Given that these degrees of risk are mathematically unsupported this implies that these people have poor understanding of genetic risk at it relates to their own family. It could also mean that they are considering factors other than simply the genetics, and including learned behavior, or perhaps some vague concept of the epigenome, and increasing the baseline risk accordingly, but the more likely answer is a lack of genetic numeracy.

With respect to one's own children, it is safe to say that these respondents are very unsure of what implications having a child with a genetic disease means for themselves. Nearly $14 \%$ of the respondents said this would imply that they had no risk at all of that disease (Table 12). A nearly equal number chose
$10 \%$. While it is certainly possible that the population could have understood the concept of de novo mutation, and be perfectly correct that children could have diseases that we ourselves did not, it is less clear what the motivation for choosing $10 \%$ is. About half as many respondents choose $50 \%$ for the risk relationship to their children as chose $50 \%$ for mother and father (Table 9, Table 10, and Table 12). This implies that they do not believe that parents and children, while possessing the same coefficient of relationship and therefore the same amount of genetic material, have reciprocal risk relationships.

It is interesting to note that there is some degree of the study population that believes that their risk of a genetic disorder is $0 \%$ when their relatives are diagnosed with said disorder (Table 22). Even more surprisingly, these people are not always the same people from risk relationship to risk relationship, although there is a large degree of overlap (i.e., one person answered $0 \%$ for their relationship to their mother, but a higher percentage for their father). Only 48 of the respondents (1.87\%) answered zero to the genetic risk for each of the risk relationships. It is possible that some of the answers that seem incongruous can be attributed to the mechanical design of the test or test fatigue ${ }^{15}$, but this seeminglyvast misunderstanding of the genetic relationships warrants further investigation.

In each of the risk relationships, most of the demographic variables have little predictive value for determining what leads to low numeracy levels ${ }^{16}$. There are some interesting exceptions (Table 17,Table 18,Table 19,Table 20).

Education is a key predictor of understanding of genetic risk. Having classes that include genetic information, even if it is not the subject of the class, can help improve people's baseline knowledge of the science of genetics, which can improve their numeracy. It does not seem necessary for people to take specific genetics courses for this improvement to occur.

These results and previous work (Honoré, 2008) show that the predictor variables in this model are not sufficient to explain the fact that people do show different intentions when presented with different hypothetical situations. This leads to possible avenues of further research, including employing qualitative methods, to determine what factors might be more relevant, and looking at actual choices rather than hypothetical situations.

[^8]The relationship between religion and numeracy presents some of the most interesting opportunities for further research. What is it about identifying as practicing Hindu or Buddhist that implies that there is much less understanding of familial genetic relationships? Is it the religion at all, or is this result actually a proxy for cultural differences?

The final section of analysis led to more questions than answers. From Table 23 we can see that the trend to be increasingly unwilling to marry, and then have children with, a person with a genetic disorder, is present in the study population. If one's numeracy isn't related to one's intentions, then what does drive a person to decide to not to marry or have kids with someone with a genetic disorder?

## Public Health Genetics Practice

One implication of the fact that a majority of the respondents chose $50 \%$ as their risk relationship with both their mother and father is that this population is not considering the possibility of autosomal recessive disorders when they identify their genetic risk. Given that the many more diseases are autosomal recessive, or follow even more complex patterns based on gene-environment interactions, (King et al, 2006) this shows an overestimate of the risk from a parent's diagnosis of a genetic disorder. The true estimates of risk, for most standard genetic disorders, will be either $25 \%$ or $50 \%$, assuming full penetrance. As we move forward in the genomic era these more complicated risk patterns will be identified. This work shows that care should be taken when presenting genetic information to a patient or the general public as to not make assumptions about the genetic knowledge of the population. Even people who have some college education have misunderstandings about the implications of the genetic information being presented to them. Therefore, this work supports creating educational interventions that improve understanding of the mathematics of inheritance and the recognition of all the factors that can affect disease.

This analysis also indicates that there are religious or cultural differences that affect a person’s perception of genetic risk inheritance. Cultural background can lead to an overestimation of genetic risk. With the current emphasis on community based intervention practices (Montoya et al, 2011; Franciskovic et al, 2008; Bruce et al, 2002), respecting the these differences in risk perception is important for public health genomics clinicians.

The Secretary's Advisory Committee on Genetics, Health, and Society (2010) advises that ensuring the clinical utility of genetic and genomic testing is of the utmost priority as these technologies are further incorporated into health care practice. Clinical utility depends on the ability of the test to alter health outcomes (Grosse and Khoury, 2006). Genetic numeracy directly affects the ability of a patient to absorb and act upon genetic information that he or she has received. This paper suggest that improving patient/provider communication relating to the patient's perception of risk is an important step in ensuring that the information received can impact patient behavior.

Genetic numeracy will only become more important as we continue our explorations deeper into the genome, the exome, the microbiome and the interactions between them, ourselves and our environment. Much work remains to be done to ensure that the population has the tools to interpret and act upon the information they receive about this complex tapestry that is the foundation of life.

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## Appendix A

## Additional Analysis

## Coefficient of relationship $=1 / 4:$ Aunt/Uncle, Niece/Nephew, Grandparents

For coefficients of relationships of 114 , the hypothesis was that aunt/uncle would be the best understood niece/nephew second, and grandparents last. However, it was niece/nephew that actually had the largest percentage of High numeracy answers. Grandparents did represent the least well understood risk relationship, with only $31.6 \%$ of the population showing High numeracy, the lowest percentage of any risk relationship.

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 279 | $10.9 \%$ |
| Medium | 881 | $34.3 \%$ |
| High | 1408 | $54.8 \%$ |



Figure 12 - : Graph of Numeracy Level Aunt/ Uncle

| Level of Numeracy | Respondents | Percentage |
| :---: | :---: | :---: |
| Low | 361 | $14.1 \%$ |
| Medium | 621 | $24.2 \%$ |
| High | 1586 | $61.8 \%$ |



Figure 13 - Graph of Numeracy Level Niece/ Nephew

| Level of Numeracy | Respondents | Percentage |  |
| :---: | :---: | :---: | :---: |
| Low | 547 | $21.3 \%$ |  |
| Medium | 1210 | $47.1 \%$ |  |
| High | 811 | $31.6 \%$ |  |
|  |  |  |  |

Risk relationship to Grandparents


Figure 14-Graph of Numeracy Level - Grandparents

Looking the detailed responses for each relationship, the main difference between aunt/uncle and niece/nephew appears to result from a larger percentage of overestimation of risk. There is a significantly higher percentage of the study respondents who believe that their risk relationship to their aunt/uncle is $50 \%$ than those that believe this for their niece/nephew (two-sample $z=4.23, p=1.0$ ).

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 124 | 4.83 |
| $10 \%$ | 220 | 8.57 |
| $20 \%$ | 489 | 19.04 |
| $30 \%$ | 699 | 27.22 |
| $40 \%$ | 350 | 13.63 |
| $50 \%$ | 360 | 14.02 |
| $60 \%$ | 171 | 6.66 |
| $70 \%$ | 83 | 3.23 |
| $80 \%$ | 38 | 1.48 |
| $90 \%$ | 11 | 0.43 |


| $100 \%$ | 23 | 0.90 |
| :---: | :---: | :---: |

Table 27 - Risk Relationship Detailed Responses - Aunt/ Uncle


Figure 15 - Graph of Risk Relationship Detailed Responses - Aunt/Uncle

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 256 | 9.97 |
| $10 \%$ | 467 | 18.19 |
| $20 \%$ | 597 | 23.25 |
| $30 \%$ | 522 | 20.33 |
| $40 \%$ | 274 | 10.67 |
| $50 \%$ | 261 | 10.16 |
| $60 \%$ | 86 | 3.35 |
| $70 \%$ | 48 | 1.87 |
| $80 \%$ | 24 | 0.93 |
| $90 \%$ | 11 | 0.43 |
| $100 \%$ | 22 | 0.86 |

Table 28 - Risk Relationship Detailed Responses - Niece/ Nephew


Figure 16 - Graph of Risk Relationship Detailed Responses - Niece/ Nephew

| Risk | Respondents | Percentage |
| :---: | :---: | :---: |
| $0 \%$ | 74 | 2.88 |
| $10 \%$ | 104 | 4.05 |
| $20 \%$ | 263 | 10.24 |
| $30 \%$ | 444 | 17.29 |
| $40 \%$ | 405 | 15.77 |
| $50 \%$ | 574 | 22.35 |
| $60 \%$ | 231 | 9.00 |
| $70 \%$ | 229 | 8.92 |
| $80 \%$ | 141 | 5.49 |
| $90 \%$ | 54 | 2.10 |
| $100 \%$ | 49 | 1.91 |

Table 29 - Risk Relationship Detailed Responses - Grandparents


Figure 17 - Graph of Risk Relationship Detailed Responses - Grandparents

For grandparents, it would seem that people are overestimating their risk relationship. Significantly more people believe that their risk relationship is between $50 \%$ and $90 \%$ than believe that it is $10 \%-30 \%$ (twosample $\mathrm{z}=-11.919, \mathrm{p}=1.0$ ).

The overestimations of both aunt/uncle and grandparent risk relationships can be seen on a box plot.


Figure 18 - Comparison of Risk Relationship Responses - Aunt/ Uncle, Niece/Nephew, and Grandparents

| Aunt /Uncle | 1408 | 682 | 54.80 | 0.000 |
| :---: | :---: | :---: | :---: | :---: |
| Niece/Nephew | 1586 | 761 | 154.6 | 0.000 |
| Grandparents | 811 | 440 | 107.37 | 0.000 |

Table 30 - Relationship between level of numeracy and knowledge
Here, we see that Aunt/Uncle and Niece/Nephew were similar to coefficient of $1 / 2$ results. Grandparents, however, seem to be less well understood.

| Relationship Pair | Both Correct | Both Incorrect | McNemar's <br> statistic | P |
| :---: | :---: | :---: | :---: | :---: |
| Mother/Aunt or Uncle | 1147 | 832 | 7.38 | 0.0074 |
| Mother/Niece or <br> Nephew | 1148 | 655 | 16.38 | 0.0001 |
| Mother/Grandparents | 716 | 998 | 514.12 | 0.0000 |
| Father/Aunt or Uncle | 1187 | 819 | 25.62 | 0.0000 |
| Father/Niece or | 1188 | 642 | 4.56 | 0.0328 |


| Nephew |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: |
| Father/Grandparents | 731 | 960 | 586.19 | 0.0000 |
| Siblings/Aunt or <br> Uncle | 1138 | 759 | 25.58 | 0.0000 |
| Siblings/Niece or <br> Nephew | 1213 | 656 | 3.16 | 0.0755 |
| Siblings/Grandparents | 651 | 869 | 505.71 | 0.0000 |
| Aunt or Uncle/Niece <br> or Nephew | 1280 | 854 | 73.00 | 0.0000 |
| Aunt or <br> Uncle/Grandparents | 738 | 1087 | 479.69 | 0.0000 |
| Aunt or <br> Uncle/Children | 806 | 677 | 13.05 | 0.0003 |
| Niece or <br> Nephew/Grandparents | 699 | 870 | 601.23 | 0.0000 |
| Niece or <br> Nephew/Children | 926 | 619 | 86.23 | 0.0000 |
| Grandparents/Children | 468 | 936 | 196.29 | 0.0000 |

Table 31 - pairwise comparisons - coefficient of 1/4

|  | OR | $95 \%$ | CI |
| :--- | :---: | :---: | :---: |
| Age | 1.007706 | 0.989323 | 1.02643 |
| Gender | 0.997638 | 0.83685 | 1.189319 |
| Income | 0.95823 | 0.921359 | 0.996576 |
| Marital Status |  |  |  |
| Cohabit | 0.90082 | 0.588232 | 1.379517 |
| Short Term <br> Dating | 1.050399 | 0.675041 | 1.634476 |
| Long Term <br> Dating | 1.045266 | 0.806631 | 1.354498 |
| Divorced | 1.059223 | 0.507967 | 2.208711 |
| Engaged | 1.11807 | 0.723705 | 1.727333 |
| Married | 0.862333 | 0.60756 | 1.223941 |


| Separated | 6.968354 | 0.778561 | 62.36889 |
| :---: | :---: | :---: | :---: |
| Single Not Dating | 1.150925 | 0.895549 | 1.479125 |
| Race/Ethnicity |  | 0.588232 | 1.379517 |
| White | 0.769184 | 0.675041 | 1.634476 |
| BAA | 1.214518 | 0.806631 | 1.354498 |
| HisLat | 1.014659 | 0.507967 | 2.208711 |
| Religion |  |  |  |
| Extent <br> Religious | 0.967257 | 0.849818 | 1.100925 |
| Services Attended per week | 1.125663 | 0.979721 | 1.293346 |
| Agnosticism | 0.93573 | 0.433406 | 2.020258 |
| Atheism | 0.556815 | 0.247397 | 1.25322 |
| Buddhism | 1.521056 | 0.547982 | 4.222057 |
| Catholic | 1.251131 | 0.62623 | 2.499605 |
| Hindu | 3.087347 | 1.187833 | 8.024457 |
| Judaism | 1.795216 | 0.561917 | 5.735368 |
| LDS | 0.875238 | 0.313772 | 2.441398 |
| Muslim | 1.021522 | 0.239877 | 4.350172 |
| NoneRel | 1.052724 | 0.505455 | 2.192533 |
| Prot | 1.229138 | 0.908112 | 1.66365 |
| OtherRel | 1.254287 | 0.635311 | 2.476326 |
| Education variables |  |  |  |
| Education Level | 0.864445 | 0.599486 | 1.246508 |
| Biological Science Degree | 0.874894 | 0.688505 | 1.111741 |
| Highest Degree | 1.018261 | 0.859491 | 1.206361 |
| Taken a Genetics | 0.788215 | 0.612749 | 1.013926 |


| Course |  |  |  |
| ---: | :--- | :--- | :--- |
| Taken a Course <br> with Genetics <br> Information | 0.700645 | 0.559636 | 0.877185 |
| Charted Family <br> Tree | 0.873374 | 0.736709 | 1.035391 |
| Charted Family <br> Health History | 0.981198 | 0.82258 | 1.170402 |
| Taken a <br> Genetic Test | 1.111728 | 0.792646 | 1.559257 |

Table 32 - Logistic Regression Analysis - Aunt/Uncle

|  | OR | $95 \%$ | CI |
| :--- | :---: | :---: | :---: |
| Age | 1.015164 | 0.996419 | 1.034262 |
| Gender | 0.984691 | 0.822854 | 1.178358 |
| Income | 0.959642 | 0.922046 | 0.998771 |
| Marital Status |  |  |  |
| Cohabit | 0.887599 | 0.573711 | 1.37322 |
| Short Term <br> Dating | 0.888754 | 0.561903 | 1.405728 |
| Long Term <br> Dating | 0.971627 | 0.745863 | 1.265728 |
| Divorced | 1.115717 | 0.533778 | 2.332103 |
| Engaged | 1.159197 | 0.746972 | 1.798913 |
| Married | 0.726147 | 0.506718 | 1.040599 |
| Separated | 3.020531 | 0.519306 | 17.56884 |
| Single Not | 1.028872 | 0.796985 | 1.328228 |
| Dating |  |  |  |
| Race/Ethnicity |  |  |  |
| White | 0.69988 | 0.516204 | 0.948912 |
| BAA | 1.198968 | 0.692777 | 2.075018 |
| HisLat | 0.89551 | 0.635487 | 1.261926 |
| Religion |  |  |  |


| Extent <br> Religious | 0.980223 | 0.85912 | 1.118398 |
| ---: | :---: | :---: | :---: |
| Services <br> Attended per <br> week | 1.070456 | 0.929641 | 1.2326 |
| Agnosticism | 1.243572 | 0.304988 | 1.614432 |
| Atheism | 0.7017 | 0.335218 | 2.807698 |
| Buddhism | 0.97015 | 0.921544 | 3.707825 |
| Catholic | 1.848492 | 1.070212 | 6.825388 |
| Hindu | 2.702704 | 0.459487 | 5.012762 |
| Judaism | 1.517663 | 0.352429 | 3.010183 |
| LDS | 1.029988 | 0.451028 | 8.193567 |
| Muslim | 1.922375 | 0.304988 | 1.614432 |
| NoneRel | 1.375265 | 0.656232 | 2.88214 |
| Prot | 1.068311 | 0.784108 | 1.455523 |
| OtherRel | 1.676419 | 0.846009 | 3.321927 |
| Education |  |  |  |
| variables |  |  |  |
| Education | 0.821787 | 0.565212 | 1.194832 |
| Level |  |  |  |


| Taken a <br> Genetic Test | 1.168575 | 0.828749 | 1.647748 |
| :--- | :--- | :--- | :--- |

Table 33 - Logistic Regression Analysis - Niece/Nephew

|  | OR | 95\% | CI |
| :---: | :---: | :---: | :---: |
| Age | 1.001601 | 0.982228 | 1.021356 |
| Gender | 1.170508 | 0.970574 | 1.411627 |
| Income | 0.956947 | 0.916931 | 0.99871 |
| Marital Status |  |  |  |
| Cohabit | 0.685877 | 0.440693 | 1.06747 |
| Short Term Dating | 0.86824 | 0.539328 | 1.397742 |
| Long Term Dating | 0.858111 | 0.647277 | 1.137619 |
| Divorced | 0.908883 | 0.397581 | 2.077736 |
| Engaged | 1.158582 | 0.710363 | 1.889613 |
| Married | 0.81235 | 0.559104 | 1.180304 |
| Separated | 0.93761 | 0.16357 | 5.374532 |
| Single Not Dating | 0.832866 | 0.633495 | 1.094981 |
| Race/Ethnicity |  |  |  |
| White | 0.943759 | 0.685422 | 1.299464 |
| BAA | 1.647659 | 0.867774 | 3.128441 |
| HisLat | 1.291903 | 0.892473 | 1.8701 |
| Religion |  |  |  |
| Extent <br> Religious | 0.975694 | 0.849508 | 1.120624 |
| Services Attended per week | 1.067201 | 0.918294 | 1.240253 |
| Agnosticism | 0.435683 | -1.62201 | -0.03967 |
| Atheism | 0.350222 | 0.197501 | 0.961106 |
| Buddhism | 1.441489 | 0.155057 | 0.791034 |


| Catholic | 0.763696 | 0.451764 | 4.599506 |
| :---: | :---: | :---: | :---: |
| Hindu | 3.17819 | 0.371486 | 1.569999 |
| Judaism | 0.684984 | 1.041305 | 9.700226 |
| LDS | 0.340961 | 0.202805 | 2.31357 |
| Muslim | 0.45342 | 0.120495 | 0.964807 |
| NoneRel | 0.801582 | 0.373098 | 1.722159 |
| Prot | 1.343785 | 0.95786 | 1.885202 |
| OtherRel | 0.772979 | 0.381336 | 1.566848 |
| Education variables |  |  |  |
| Education <br> Level | 0.665043 | 0.454034 | 0.974115 |
| Biological <br> Science Degree | 0.674076 | 0.52617 | 0.863559 |
| Highest Degree | 0.986603 | 0.824404 | 1.180714 |
| Taken a <br> Genetics <br> Course | 0.79529 | 0.61404 | 1.030041 |
| Taken a Course with Genetics Information | 0.801257 | 0.621745 | 1.032597 |
| Charted Family Tree | 0.852732 | 0.709927 | 1.024263 |
| Charted Family Health History | 1.198862 | 0.991106 | 1.450167 |
| Taken a <br> Genetic Test | 0.578563 | 0.409634 | 0.817156 |

Table 34 - Logistic Regression Analysis - Grandparents

Having taken a genetic test in the past was predictive of Low numeracy with respect to one's own children, but surprisingly, this was found to protect against Low numeracy with regards to grandparents

Race was found to be a significant predictor only in regards to aunt/uncle. In this case, White/Caucasian leads to a lower likelihood of having Low numeracy. But given that the other races were not found to be significant in regards to this, or any other risk relationship, interpreting this number as anything other than an artifact of the statistics should be done with caution.

Lower Education levels predicted Low numeracy only in reference to the grandparent risk relationship. Income is significant only where the coefficient of relationship is $1 / 4$ : aunt/uncle, niece/nephew and grandparents. In these cases, lower incomes predict Low numeracy, although the odds ratios in these cases indicate only small changes ( 0.96 in all three cases).

People seem to have a much clearer picture of the risk relationship with more distant relatives. In the case of aunt/uncle the two most often chosen risk percentages were $20 \%$ and $30 \%$ (Table 16). Since these border the correct risk relationship of $25 \%$, this suggests that respondents understood that they have much less genetic connection with smaller coefficient of relationships. This was also true of niece/nephew (Table 28).


[^0]:    ${ }^{1}$ Marital Status was quite extensive, and included dating short-term, dating long-term, engaged, cohabitating, single dating, and single not-dating in addition to the more standard married, divorced, separated and widowed.
    ${ }^{2}$ The question about religion asked respondents to choose one of 13 different religious possibilities, including atheist, agnostic and no religious preference.

[^1]:    ${ }^{3}$ Extent religious/Spiritual asked the respondents to identify on a 4 point scale how religious or spiritual they identified themselves.
    ${ }^{4}$ Weekly service attendance had 4 choices: $0,1,2-4$ and 5+.
    ${ }^{5}$ Whether or not the respondent was enrolled in a biological science degree
    ${ }^{6}$ Whether the course was a genetic course, or a course with genetic info was self-identified.
    ${ }^{7}$ Whether the respondent have ever had a genetic test performed upon themselves (not a prenatal test)
    ${ }^{8}$ Unknown genotype, asymptomatic carrier of genetic disorder, symptomatic carrier of genetic disorder, physical disability of genetic origin, mental disorder of genetic origin, or any genetic disorder

[^2]:    ${ }^{9}$ Includes Engaged, Cohabitating, Widowed, Divorced, and Separated

[^3]:    ${ }^{10}$ Includes Non-denominational Christian, Native American, Wiccan and Other

[^4]:    ${ }^{11}$ The one exception to this is grandparents, where only $31 \%$ of the sample had High numeracy. See Appendix A.

[^5]:    ${ }^{12}$ Specifically, Age, Marital Status, Highest Degree, Charting a Family Tree, and Charting a Family Health History are never found to be significant.

[^6]:    ${ }^{13}$ Children in the case of Buddhism, Catholicism, and Hinduism. Hinduism also predicts Low numeracy with respect to Aunt or Uncle, Niece or Nephew and Grandparents.

[^7]:    ${ }^{14}$ In fact, no demographic variable was shown to highly correlate with intentions relating to relationships with people diagnosed with genetic disorders in this analysis.

[^8]:    ${ }^{15}$ The survey used forced completion to require the answering of every question in this section so test fatigue could be an issue.
    ${ }^{16}$ Specifically, Age, Marital Status, Highest Degree, Charting a Family Tree, and Charting a Family Health History are never found to be significant.

