

Perception of Genetic Risk in Decision-making (PGRID) by College Students

You have been asked to participate in a research study entitled: "**Perception of Genetic Risk in Decision-making (PGRID) by College Students.**" The project is under the direction of Dr. Patricia Goodson and Heather Honoré at Texas A&M University (TAMU). This research study is being conducted through the TAMU Department of Health and Kinesiology.

Purpose of the Study

The purpose of this study is to examine the perception of genetic risk and its effect on reproductive and sexual decision-making by college students. Perception of genetic risk may be defined as an individual's knowledge, attitudes and beliefs concerning the chance that they might develop or be a carrier for a genetic disorder (i.e., have the genes, but not develop symptoms). This study explores the impact that perception of genetic risk may have on U.S. college students' decisions related to choosing sexual partners, having children or getting married.

Study Methods and Procedures

How was I selected?

This study will enroll a minimum of 475 participants for a web-based survey. You were selected to be a possible participant for this research project because you are over 18 years of age and currently enrolled at the University of Texas at San Antonio (UTSA). You are not being recruited to participate in this study because of a personal or family history of genetic disorders.

What am I being asked to do?

If you agree to participate, you will be asked to take part in a web-based survey of the "**Perception of Genetic Risk in Decision-making (PGRID) by College Students**" study. Participation is voluntary. You may refuse to participate at any time without penalty. Your decision whether or not to participate will not affect your current or future relationship with the University of Texas at San Antonio or Texas A&M University.

You have received an e-mail from Heather Honoré (via Zoomerang.com) that contains the URL for the web-based survey. The survey will contain closed-ended and open-ended questions on genetic health-related knowledge, skills, attitudes, and behaviors. If you agree to participate in the study, you will have 14 days to access the survey website and complete the survey. A minimum of 475 students will participate in this study. Each web-based survey will take approximately 20 minutes of your time.

Benefits of the Study

There are no known benefits to you for participating in this study. A potential benefit for some participants may be increased awareness of their own family history of genetic traits (i.e., special characteristics, "gifts," and diseases). There are no other known benefits to you other than those listed in this consent form.



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Risks of the Study

There are no known risks of participating in this study; however, some participants may experience feelings of discomfort or loss of confidentiality.

Some questions related to birth defects or genetic disorders may make you feel uncomfortable. In addition, survey questions may trigger strong feelings that differ from the rest of the survey participants. Awareness that your feelings differ from those of other participants may make you feel uncomfortable.

This study is confidential. The co-investigators involved in this project will have access to the survey data that you voluntarily provide for this study. All research staff involved in this project have been trained to maintain confidentiality of research information. The data obtained from analyses of these surveys will be stored securely in Dr. Patricia Goodson's office at Texas A&M University. To maintain confidentiality, the information provided to the co-investigators will be identified by a code number rather than by name. No identifiers linking you to the study will be included in any sort of report that might be published. In addition, you should not discuss any information that is shared within this survey with anyone who did not participate in the survey.

Compensation for Participation

Compensation for time and inconvenience related to participation in this survey will consist of an opportunity to participate in a random drawing for one of twenty-three gift cards. Specifically, after completing the survey, you will be able to voluntarily submit your name and mailing address for a random drawing for one of twenty-five (three \$25 gift cards and twenty-two \$5 movie gift cards) gift cards.

This research study has been reviewed by the Institutional Review Board – Human Subjects Research, Texas A&M University:

- Contact Dr. Patricia Goodson at (979) 845-1756 (pgoodson@hlkn.tamu.edu) or Heather Honoré at (979) 862-8574 (hthonore@hlkn.tamu.edu) with any questions about this study.

- In addition, if you have questions about your rights as a research subject, or if you have complaints, concerns, or questions about the research, you may contact the University of Texas at San Antonio Institutional Review Board at (210) 458-6473. (You may also contact the TAMU Institutional Review Board through Ms. Angelia M. Raines, Director of Research Compliance, Office of the Vice President for Research at (979) 458-4067, araines@vprmail.tamu.edu.)

• If you feel uncomfortable about topics discussed in the web-based survey, you may contact professionals at UTSA Counseling Services (University Center, Room 2.01.04, 210-458-4140) or UTSA Student Health Services (210-458-4142) for further assistance.

1 By choosing the "Go to Survey" link located at the end of this Information Sheet, you are confirming your understanding and voluntary compliance with the details of the study.

- Yes
 No



Survey Page 2

Perception of Genetic Risk in Decision-making (PGRID) by College Students

2 What is your current age (in years)?

3 Please indicate your gender.

- Female
 Male

4 What is your **current** marital status?

- Cohabiting (currently living with partner)
 Dating, Short-term
 Dating, Long-term
 Divorced
 Engaged
 Married
 Married, but Separated
 Single, and Not Dating
 Single, and Dating
 Widowed
-

5 How do you identify your racial or ethnic heritage?

- Asian
- American Indian (Native American) or Alaska Native
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Pacific Islander
- White or Caucasian
- Other, please specify



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

6 What is your religious preference?

- Agnosticism
- Atheism
- Buddhism
- Catholicism
- Hinduism
- Judaism
- Mormonism (Latter Day Saints)
- Muslim/Islam
- Native American
- None
- Protestantism (Baptist, Lutheran, Methodist, etc.)
- Other, please specify

7 To what extent do you consider yourself a religious or spiritual person?

- Not Religious or Spiritual At All
 - Slightly Religious or Spiritual
 - Moderately Religious or Spiritual
 - Very Religious or Spiritual
-

- 8 How often do you attend or participate in religious or spiritual services on a weekly basis?
- 0
 - 1
 - 2-4
 - 5 or more



Survey Page 4

Perception of Genetic Risk in Decision-making (PGRID) by College Students

- 9 What College are you **currently** enrolled in at the University of Texas at San Antonio?

-
- 10 What is your **current** educational status?

- Undergraduate student
- Graduate student
- Professional student (Law, Medicine, etc.)

-
- 11 Are you **currently** pursuing a degree in biology, genetics, or a related field?

- Yes
- No

-
- 12 To date, what is your highest degree **completed**?

- GED/High School Diploma
- Associate's degree
- Bachelors degree
- Masters degree
- Doctoral degree
- Professional degree (JD, MD, etc.)



**Perception of Genetic Risk in Decision-making (PGRID)
by College Students**

13 What is **your parents'** estimated annual household income? (If you are **financially independent or a graduate student**, please indicate **your** estimated annual household income.)

- less than \$10,000
- \$10,000-\$14,999
- \$15,000-\$24,999
- \$25,000-\$34,999
- \$35,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,000
- greater than \$100,000



**Perception of Genetic Risk in Decision-making (PGRID)
by College Students**

14 How often have you used the following resources to obtain genetic information (definitions, case studies, etc.)?

	1 Never	2 Not Very Often	3 Not Often	4 Often	5 Very Often
Read about genetics on the internet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about genetics in newspapers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about genetics in magazines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about genetics in a non-fiction book?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about genetics in a scientific (peer-reviewed) journal?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Talked about genetics with your relatives?

1 2 3 4 5

Talked about genetics with your friends?

1 2 3 4 5

Talked about genetics with your physician?

1 2 3 4 5

Talked about genetics with other health professionals (i.e., genetic counselors, geneticists, etc.)?

1 2 3 4 5

Heard about genetics on TV?

1 2 3 4 5

Heard about genetics on the radio?

1 2 3 4 5



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15 Have you ever taken a genetics course?

- Yes
- No
- I Don't Know

16 Have you ever taken a course that included information on genetics?
(Examples include general biology, physiology, or human sexuality courses.)

- Yes
- No
- I Don't Know

17 Have you ever charted your family tree (genealogy)?

- Yes
- No
- I Don't Know

18 Have you ever charted your family health history? (Examples might include doctor's office charts or class assignments.)

- Yes
- No
- I Don't Know



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

19 Which of the following issues would you classify as a "genetic disorder"? (please select **all** that apply)

- Down's Syndrome
- Mental Retardation
- Spina Bifida
- Cystic Fibrosis
- Cerebral Palsy
- Obesity
- Blindness
- Deafness
- Depression
- Major Deformities
- ADD/ADHD
- Physical Defects
- Sickle Cell Anemia
- Tay Sach's
- Diabetes
- Cervical Cancer
- Breast Cancer
- Prostate Cancer
- Lung Cancer
- Cancer (in general)
- Drug Addiction

- Fragile X Syndrome
- HIV/AIDS
- Asthma
- Allergies
- Multiple Sclerosis
- Muscular Dystrophy
- Amyotrophic Lateral Sclerosis (Lou Gherig's disease)
- Charcot-Marie-Tooth
- Bipolar Disorder
- Schizophrenia
- Obsessive Compulsive Disorder
- Cardiovascular (heart) Disease
- Gambling
- Neurological Problems
- Huntington's Disease/Chorea
- Autism



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

20 How much would you say that you have heard or read about genetic testing?

21 Based on what you know, do you think that genetic screening will do more good than harm, or more harm than good?



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

22 Do you have biological children?

23 Have you ever had genetic testing to determine if you carry a specific gene(s) for a specific genetic disorder(s)?

24 Today, tests are being developed that make it possible to detect serious genetic defects before a baby is born. But so far, it is impossible either to treat or to correct many of them.

If you have ever been pregnant, did you undergo prenatal testing for genetic disorders?

25 **If you or your partner were pregnant**, would you want (her) to have a test to find out if the baby has any serious genetic disorders?

SUBMIT

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Perception of Genetic Risk in Decision-making (PGRID) by College Students

How likely are you to...?

26 Date someone who does not know his/her genetic status (genotype).

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

27 Date someone who is an **asymptomatic** carrier (e.g., has the genes,

but will not develop symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

28 Date someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

29 Date someone who has a physical disability that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

30 Date someone who has a mental disorder that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

31 Date someone who has any type of genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

How likely are you to...?

32 Marry someone who does not know his/her genetic status (genotype).

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

33 Marry someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

34 Marry someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

35 Marry someone who has a physical disability that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

36 Marry someone who has a mental disorder that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

37 Marry someone who has any type of genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5



Perception of Genetic Risk in Decision-making (PGRID) by College Students

How likely are you to...?

38 Have children with someone who does not know his/her genetic status (genotype).

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

39 Have children with someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

40 Have children with someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

41 Have children with someone who has a physical disability that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
1	2	3	4	5

- 42 Have children with someone who has a mental disorder that is genetic in origin.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 43 Have children with someone who has any type of genetic disorder.

Not at all likely (Never)	Not very likely	Somewhat likely	Very likely	Extremely likely (Always)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

The following questions ask you to think about how your family members might react under specific conditions.

- 44 If I dated someone who does not know his/her genetic status (genotype), my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

- 45 If I dated someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific disorder, my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

- 46 If I dated someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific disorder, my family would...
- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

- 47 If I dated someone who has a physical disability that is genetic in origin, my family would...
- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

- 48 If I dated someone who has a mental disorder that is genetic in origin, my family would...
- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

- 49 If I date someone who has any type of genetic disorder, my family would...
- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

- 50 If I married someone who does not know his/her genetic status (genotype), my family would...

- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

51 If I married someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific disorder, my family would...

- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

52 If I married someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific disorder, my family would...

- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

53 If I married someone who has a physical disability that is genetic in origin, my family would...

- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

54 If I married someone who has a mental disorder that is genetic in origin, my family would...

- Strongly Disagree (Would disapprove outright)
 - Disagree
 - Agree
 - Strongly Agree (Would approve unconditionally)
-

55 If I married someone with any type of genetic disorder, my family would...



- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

56 If I had children with someone who does not know his/her genetic status (genotype), my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

57 If I had children with someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder, my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

58 If I had children with someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder, my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

59 If I had children with someone who has a physical disability that is genetic in origin, my family would...

- Strongly Disagree (Would disapprove outright)

- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

60 If I had children with someone who has a mental disorder that is genetic in origin, my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

61 If I had children with someone who had any type of genetic disorder, my family would...

- Strongly Disagree (Would disapprove outright)
- Disagree
- Agree
- Strongly Agree (Would approve unconditionally)

SUBMIT

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Perception of Genetic Risk in Decision-making (PGRID) by College Students

The following questions ask you to think about how your closest friends might react under specific conditions.

62 If I dated someone who does not know his/her genetic status (genotype), my closest friends would...

63 If I dated someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder, my closest friends would...

- 64 If I dated someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder, my closest friends would...

- 65 If I dated someone who has a physical disability that is genetic in origin, my closest friends would...

- 66 If I dated someone who has a mental disorder that is genetic in origin, my closest friends would...

- 67 If I dated someone who has any type of genetic disorder, my closest friends would...



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

- 68 If I married someone who does not know his/her genetic status (genotype), my closest friends would...

- 69 If I married someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder, my closest friends would...

- 70 If I married someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder, my closest friends would...

71 If I married someone who has a physical disability that is genetic in origin, my closest friends would...

72 If I married someone who has a mental disorder that is genetic in origin, my closest friends would...

73 If I married someone who has any type of genetic disorder, my closest friends would...



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

74 If I had children with someone who does not know his/her genetic status (genotype), my closest friends would...

75 If I had children with someone who is an **asymptomatic** carrier (e.g., has the genes, but will not develop symptoms) for a specific genetic disorder, my closest friends would...

76 If I had children with someone who is a **symptomatic** carrier (e.g., has the genes, and also has symptoms) for a specific genetic disorder, my closest friends would...

77 If I had children with someone who has a physical disability that is genetic in origin, my closest friends would...

78 If I had children with someone who has a mental disorder that is genetic in origin, my closest friends would...

79 If I had children with someone who has any type of genetic disorder, my closest friends would..



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate how much control you think you have in the following situations.

In this case, 0% control means that you have no control over the situation. 100% control means that you have complete control over the situation.

80 I have control over whether I date someone who is/has...

1 10% Control	2	3	4	5 50% Control	6	7	8	9	10 100% Control	0% (No (Complete Control) Control)
---------------------	---	---	---	---------------------	---	---	---	---	-----------------------	--

an asymptomatic carrier for a genetic disorder.

 1 2 3 4 5 6 7 8 9 10

a symptomatic carrier for a genetic disorder.

 1 2 3 4 5 6 7 8 9 10

a physical disorder that is genetic in origin.

 1 2 3 4 5 6 7 8 9 10

a mental disorder that is genetic in origin.

 1 2 3 4 5 6 7 8 9 10

any type of genetic disorder.

 1 2 3 4 5 6 7 8 9 10


Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate how much control you think you have in the following situations.

In this case, 0% control means that you have no control over the situation. 100% control means that you have complete control over the situation.

81 I have control over whether I marry someone who is/has...

1 10% Control	2	3	4	5 50% Control	6	7	8	9	10 100% Control (Complete Control)	0% (No Control)
---------------------	---	---	---	---------------------	---	---	---	---	---	--------------------

an asymptomatic carrier for a genetic disorder.

1 2 3 4 5 6 7 8 9 10

a symptomatic carrier for a genetic disorder.

1 2 3 4 5 6 7 8 9 10

a physical disorder that is genetic in origin.

1 2 3 4 5 6 7 8 9 10

a mental disorder that is genetic in origin.

1 2 3 4 5 6 7 8 9 10

any type of genetic disorder.

1 2 3 4 5 6 7 8 9 10



Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate how much control you think you have in the following situations.

In this case, 0% control means that you have no control over the situation. 100% control means that you have complete control over the situation.

82 I have control over whether I have children with someone who is/has...

1 2 3 4 5 6 7 8 9 10
 10% Control 50% Control 100% Control (Complete Control) 0% (No Control)

an asymptomatic carrier for a genetic disorder.

1 2 3 4 5 6 7 8 9 10

a symptomatic carrier for a genetic disorder.

1 2 3 4 5 6 7 8 9 10

a physical disorder that is genetic in origin.

1 2 3 4 5 6 7 8 9 10

a mental disorder that is genetic in origin.

1 2 3 4 5 6 7 8 9 10

any type of genetic disorder.

1 2 3 4 5 6 7 8 9 10



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83 When children are born with genetic disorders or birth defects, who is responsible (at fault)?

In this case, 0% responsibility means that you assign no responsibility (fault) in the situation. 100% responsibility means that you assign complete responsibility (fault) in the situation.

1 2 3 4 5 6 7 8 9 10
 10% Responsible 50% Responsible 100% Responsible (Complete Responsibility) 0% (No Responsibility)

Both Parents

1 2 3 4 5 6 7 8 9 10

The Mother

1 2 3 4 5 6 7 8 9 10

The Father

1 2 3 4 5 6 7 8 9 10

The Medical Doctor (Obstetrician/Gynecologist or OB/GYN)

1 2 3 4 5 6 7 8 9 10

God or a Higher Power

 1
 2
 3
 4
 5
 6
 7
 8
 9
 10

84 When children are born with genetic disorders or birth defects, **no one** is responsible. It just happens.

- Strongly Disagree
 Disagree
 Agree
 Strongly Agree



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree to which you agree or disagree with the following scenarios.

85 It is okay for individuals who do not know their genetic status to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Marry	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Have Children	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4



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Please indicate the degree to which you agree or disagree with the following scenarios.

- 86** It is okay for individuals who are **asymptomatic** carriers (e.g., has the genes, but will not develop symptoms) for genetic disorders to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree to which you agree or disagree with the following scenarios.

- 87** It is okay for individuals who are **symptomatic** carriers (e.g., has the genes, and also has symptoms) for genetic disorders to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree to which you agree or disagree with the following scenarios.

88 It is okay for individuals who have physical disorders that are genetic in origin to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree to which you agree or disagree with the following scenarios.

89 It is okay for individuals who have mental disorders that are genetic in origin to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree to which you agree or disagree with the following scenarios.

90 It is okay for individuals who have any kind of genetic disorder to...

	1 Strongly Disagree	2 Disagree	3 Agree	4 Strongly Agree
Date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have Children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

91 I believe that it is _____ for someone I am dating (or will date) to know his/her genetic status.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important

92 I believe that it is _____ for someone I will marry (or married) to know his/her genetic status.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important

93 I believe that it is _____ for someone I will have/had children with to know his/her genetic status.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

94 I believe that it is _____ if the person I am dating (or will date) is an **asymptomatic** carrier for a genetic disorder.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important

95 I believe that it is _____ if the person I will marry (or married) is an **asymptomatic** carrier for a genetic disorder.

- Not Important At All
- Not Important
- Somewhat Important

- Extremely Important

96 I believe that it is _____ if the person I will have/had children with is an **asymptomatic** carrier for a genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

97 I believe that it is _____ if the person I am dating (or will date) is a **symptomatic** carrier for a genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important

98 I believe that it is _____ if the person I will marry (or married) is a **symptomatic** carrier for a genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important

99 I believe that it is _____ if the person I will have/had children with is a **symptomatic** carrier for a genetic disorder.

- Not Important At All
 Not Important

- Somewhat Important
- Extremely Important



Survey Page 33

Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

100 I believe that it is _____ if the person I am dating (or will date) has a physical disorder that is genetic in origin.

- Not Important At All
 - Not Important
 - Somewhat Important
 - Extremely Important
-

101 I believe that it is _____ if the person I will marry (or married) has a physical disorder that is genetic in origin.

- Not Important At All
 - Not Important
 - Somewhat Important
 - Extremely Important
-

102 I believe that it is _____ if the person I will have/had children with has a physical disorder that is genetic in origin.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important



Survey Page 34

Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

103 I believe that it is _____ if the person I am dating (or will date) has a mental disorder that is genetic in origin.

- Not Important At All
 - Not Important
 - Somewhat Important
 - Extremely Important
-

104 I believe that it is _____ if the person I will marry (or married) has a mental disorder that is genetic in origin.

- Not Important At All
 - Not Important
 - Somewhat Important
 - Extremely Important
-

105 I believe that it is _____ if the person I will have/had children with has a mental disorder that is genetic in origin.

- Not Important At All
- Not Important
- Somewhat Important
- Extremely Important



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please indicate the degree of importance that you assign to the following scenarios.

106 I believe that it is _____ if the person I am dating (or will date) has any type of genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important

107 I believe that it is _____ if the person I will marry (or married) has any type of genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important

108 I believe that it is _____ if the person I will have/had children with has any type of genetic disorder.

- Not Important At All
 Not Important
 Somewhat Important
 Extremely Important



Survey Page 36

Perception of Genetic Risk in Decision-making (PGRID) by College Students

109 Please rate the **severity** (seriousness) of each of the following conditions.

1 Not Severe at All 2 3 4 5 6 7 8 9 10 Extremely Severe

Bipolar Disorder

1 2 3 4 5 6 7 8 9 10

Cervical Cancer

1 2 3 4 5 6 7 8 9 10

Depression

1 2 3 4 5 6 7 8 9 10

Down's Syndrome

1 2 3 4 5 6 7 8 9 10

Genetic Disorders (in general)

1 2 3 4 5 6 7 8 9 10

HIV/AIDS

1 2 3 4 5 6 7 8 9 10

Physical Disabilities

1 2 3 4 5 6 7 8 9 10

Schizophrenia

1 2 3 4 5 6 7 8 9 10

Sickle Cell Anemia

1 2 3 4 5 6 7 8 9 10



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

110 Please rate your **risk** (susceptibility) for developing each of the following conditions.

1	2	3	4	5	6	7	8	9	10	0% (No Risk)
10% Risk				50% Risk					100% Risk	

Bipolar Disorder

Cervical Cancer

Depression

Down's Syndrome

Genetic Disorders (in general)

HIV/AIDS

Physical Disabilities

Schizophrenia

 1 2 3 4 5 6 7 8 9 10

Sickle Cell Anemia

 1 2 3 4 5 6 7 8 9 10


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Perception of Genetic Risk in Decision-making (PGRID) by College Students

111 Which of the following items are potential barriers/obstacles to having "healthy" children?

	1	2	3	4
	Not A Barrier At All	Not a Barrier	Somewhat A Barrier	A Strong Barrier
Lack of knowledge about genetics	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Lack of knowledge about genetic technology and services (screening, testing, etc.)	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Lack of financial resources to access to genetic technology and services	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Geographic distance to nearest genetic technology and services	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Mistrust of genetic technology and services	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Incompatibility between family planning and my religious beliefs	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Lack of knowledge about my family tree (genealogy)	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Lack of knowledge about my partner/spouse's family tree (genealogy)	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4

112 Preventing genetic disorders or birth defects is not a priority for me.

- Strongly Disagree
- Disagree
- Agree

Strongly Agree



Survey Page 39

Perception of Genetic Risk in Decision-making (PGRID) by College Students

113 Which of the following items are potential **advantages** of having a child who is born without genetic disorders or defects?

	1	2	3	4
	Not A Benefit At All	Not a Benefit	Somewhat A Benefit	A Strong Benefit
Having a "healthy" child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a "normal" child (e.g., one who is like other children)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having lower financial costs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having no feelings of guilt about "passing on" a genetic disorder or defect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having no feelings of shame about "passing on" a genetic disorder or defect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a child who has a better quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a child who can live independently as an adult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

114 If one of the following relatives were diagnosed with a genetic disorder, how would you rate your risk for

developing the **same** disorder?

1 10% Risk	2	3	4	5 50% Risk	6	7	8	9	10 100% Risk (Will Develop the Disorder)	0% (No Risk)
<hr/>										
Mother										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Father										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Sibling(s)										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Aunt or Uncle										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Niece or Nephew										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Grandparent(s)										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
1st Cousin										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
More distant relatives										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>
<hr/>										
Your child(ren)										
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10	<input type="radio"/>



Survey Page 41

Perception of Genetic Risk in Decision-making (PGRID) by College Students

Please respond to the following questions based on your current understanding of genetics and genomics.

115 Genes instruct cells how to make specific _____.

- Carbohydrates
- Fats
- Proteins
- DNA

116 According to the National Institutes of Health (NIH), the term _____ refers to "the study of all of a person's genes including interactions of those genes with each other and the person's environment."

- Genetics
- Genomics
- Genetic engineering
- Genetic screening

117 Most humans have _____ chromosomes, or _____ autosomal chromosome pair(s) and _____ sex chromosome pair(s).

- 26, 12 autosomal pairs, 1 sex pair
- 36, 17 autosomal pairs, 2 sex pairs
- 46, 22 autosomal pairs, 1 sex pair
- 56, 27 autosomal pairs, 2 sex pairs

118 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...?

- 10%
- 25%
- 50%
- 100%

119 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...?

- 10%
- 25%
- 50%
- 100%



Perception of Genetic Risk in Decision-making (PGRID) by College Students

120 Which of the following traits do you find attractive in a potential dating or marital partner? (Please select **all** that apply)

- Physical attractiveness
- Strength
- Sincerity
- Faithfulness
- Passion
- Reliability
- Maturity
- Intelligence
- Sports Talent
- Musical Talent
- Artistic Talent
- Thinness
- Curvaceousness
- Introversion
- Extroversion
- Selfishness
- Insecurity
- Aggressiveness
- Independence
- Communication Skills
- Love of Children
- Kindness
- Love of Animals
- Self-Confidence
- Sense of Humor
- Good Manners
- Similar Morals and Values
- Similar Religious or Spiritual Preference
- Similar Family Structure

- Successful Career
- Financial Stability
- Good Taste in Clothes
- Good Taste in Art
- Good Taste in Music
- Popularity
- Optimism



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Perception of Genetic Risk in Decision-making (PGRID) by College Students

121 Do you think that your responses to this survey accurately reflect your knowledge, attitudes, and beliefs?

122 Is there anything that we did not ask that you feel we should have asked?



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Perception of Genetic Risk in Decision-making (PGRID) by College Students



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