

Considering the Ethics of Genetic Testing— Group Discussion Scenarios

Scenario A

Imagine that you want to have a personal genetic test, but your sibling is strongly against finding out his or her own genetic information. Would you have the test done, and what would you do with the information you discover?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- What effects do you think your genetic test results might have on your sibling?
 - Why do you think your sibling might not want to know his or her genetic information?
 - What could you and your sibling talk about to help you understand each other's positions?
 - You have the right to learn about your genetic information without the consent of the rest of your family, but why might you decide not to exercise that right?
 - How do you think having a personal genetic test done against your sibling's wishes might affect your relationship?
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Scenario B

Imagine that when you were a baby, your parents found out that you carried genes that made it likely that you would develop a heart problem, and so they never let you participate in strenuous activities while you were growing up. Would you make the same choice for your own child?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- How do you think knowing particular genetic information might affect a child's self-perception?
- How do you think genetic information might affect how others treat the child?
- Is genetic information different from other kinds of health information? Why or why not?
- Do you think parents should be able to find out their child's genetic information, or does the information belong to the child?
- What if new advances revealed that in spite of your genetic profile, you did not have a particularly high risk of developing the disease, and there had been no need to keep you from physical activities? How might feel?

Scenario C

Imagine that you have a sick child who could benefit from a tissue or cell transplant. You have the opportunity to genetically test embryos to try to ensure that your second child would be a perfect donor match. Would you undergo in vitro fertilization (IVF) and test the embryos so that you could select only those that would produce a second child who could help save your older child's life?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- Would you tell your second child about how he or she was created? If so, what would you say?
 - How do you think your second child might react to the news that he or she was engineered to help save your older child?
 - Do you think your second child should have a right to decide if he or she wants to donate cells or tissues to your older child?
 - What if the transplant doesn't cure your older child? How do you think different family members might react?
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Scenario D

Imagine that in the future, preimplantation genetic diagnosis has advanced so that you can test traits such as intelligence and physical ability in addition to diseases. Would you want to select embryos based on genetic test results?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- How do you think a family history of genetic disorders might influence your decision?
- Do you think parents should be allowed to select embryos based on genes associated with nondisease traits such as sex (male or female) or, if it ever becomes possible, intelligence or physical ability?
- How do you think society would be affected if preimplantation genetic diagnosis became commonplace? How might it affect the way parents think about their children?
- What values in a family or culture could influence parents' decisions about which genetic traits to test for?
- What can selecting for or against a particular trait say about the kind of people we as a society value?

Scenario E

You are a senator and must vote on whether genetic testing should be available only through a doctor or genetic counselor or whether people should be able to purchase a test directly from a company. What would you vote for?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- Why do you think someone might want direct access to his or her genetic information without the involvement of a doctor?
 - How do you think genetic testing can improve health care?
 - How reliable are the test results, and how much information can they actually give people about their health? Should genetic tests be regulated to meet accuracy and reliability standards?
 - Do you think most people would be able to interpret such test results without the guidance of a doctor or genetic counselor? What are some of the risks of misinterpreting genetic information?
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Scenario F

Imagine that direct-to-consumer personal genetic testing is widely available at low cost to everyone. You are currently dating someone and considering spending the rest of your life with this person. Would you ask him or her to take a genetic test?

Discuss with your group the concerns and consequences of the different actions you could take. What are the benefits and risks of different choices? What are the possible ethical, legal, and social implications? Prepare a summary of your analysis to present to the class.

Some things to consider:

- What could you learn from a genetic test? What can't you learn from a genetic test?
- What factors do you think are important to consider when choosing a lifelong partner?
- Do you think people should choose partners based on their genetics? Why or why not?
- How do you think society might be different if personal genetic testing were commonplace?