

Supplementary texts

Supplementary text 1

Introductory text in survey on direct-to-consumer genetic testing

What are direct-to-consumer genetic tests?

Nowadays, new DNA tests (genetic tests) are on the market. These tests assess a person's genetic profile for a variety of information. Companies or research institutes sell these tests directly to a consumer (hence the name direct-to-consumer), without involvement of a health professional. People can order these tests themselves online.

These tests are called direct-to-consumer (DTC) genetic tests.

The purposes of the testing can be very diverse. In this survey, we focus on two of them: (1) disease-related testing and (2) lifestyle-related testing.

(1) DTC genetic testing on **disease-related topics** provide information on **your personal risk of developing diseases in the future**, (such as cancers, heart failure, Alzheimer's, Type 2 diabetes, etc.). Additionally, these tests focus on identifying **carrier status** of a genetic mutation (a change in genetic information, the DNA), which means you have the mutation but you do not develop the disease yourself. This is relevant because you can pass on this mutation to your children.

(2) Direct-to-consumer genetic tests for **lifestyle-related purposes** provide information on your genetic predisposition for athletic ability. For example, based on your DNA, do you have more talent for endurance or sprinter type sports? On the other hand, these tests aim to predict how you respond to foods and beverages you consume. Those tests do not predict any diseases or health conditions.

Supplementary text 2

Principles knowledge questions

1. Healthy parents can have a child with an inherited disease (True)
2. If your close relatives have diabetes or heart disease, you are more likely to develop these conditions (True)
3. Some genetic disorders occur more often within particular ethnic groups (True)
4. Most genetic disorders are caused by only a single gene (False)
5. Once a genetic marker for a disorder is identified in a person, the disorder can usually be prevented or cured (False)
6. A disease is only genetically determined if more than one family member is affected (False)
7. Some genetic disorders occur later in adult life (True)
8. A healthy lifestyle can prevent or lessen the negative consequences of having genetic predispositions to some diseases (True)
9. The environment has little or no effect on how genes contribute to disease (False)
10. One can see a gene with the naked eye. (False)
11. A gene is a molecule that controls hereditary characteristics. (True)
12. A gene is a piece of DNA. (True)
13. A gene is a part of a chromosome. (True)
14. Different body parts include different genes. (False)

Supplementary text 3

How-to knowledge scenarios

Scenario 1

Imagine you have ordered a genetic test and received the results. The results are from a test assessing “carrier status”, which means that you receive information whether you are carrying a variant of the gene for a genetic disease, which you could pass on to your children. Read the example results of this genetic test below and answer the questions to your best knowledge.

Disease X Carrier Status Results

You are a carrier. You could pass this variant on to your children.

We detected one variant for Disease X. People with only one variant are not expected to have Disease X.

Your results may be relevant if you are thinking about starting a family.

If you and your partner are both carriers, each child may have a 25% chance of having this condition.

Scenario 2

On the next page of the results, you receive the information about what your risk to get the Disease Y is. Read the text and answer the questions below.

Summary

Disease	Lifetime risk	Current total risk
Disease Y	15/100	4.47

Lifetime risks

On average, 15/100 people of your age will be diagnosed with Disease Y during the rest of their lives. This is shown in the following figure: the orange men are people who will get the diagnosis of Disease Y during the rest of their lives.



Personal risks

Total current risk: Based on your personal information, your risk of developing Disease Y is currently increased with 347% (RR = 4.47). With an optimal lifestyle you can bring it back to an increase of 81% (RR = 1.81).

Supplementary text 4

How-to knowledge questions

Scenario 1

1. Based on the above results, what is your chance of displaying the symptoms of / (getting) the disease X? (correct answer: d)
 - a) I have a high-to medium chance
 - b) I have a medium-to-low chance
 - c) I have a zero chance
 - d) There is not enough information in the text to answer this question
 - e) I don't know
2. Based on above results, what is the chance (in %) that your children will display symptoms of Disease X if your partner is also a carrier of Disease X and does not show symptoms of a disease (correct answer: 25%)
3. Based on above results, what is the chance (in %) that your children will display symptoms of Disease X if your partner is not a carrier of the Disease X (correct answer: 0%)

Scenario 2

1. Based on the results, what is your personal lifetime risk of getting the disease? (correct answer: e)
 - a) No risk
 - b) Low risk
 - c) Medium risk
 - d) High risk
 - e) Cannot determine from given data
 - f) I don't know
2. According to this information, what percentage of the people in the population will get this disease during their lifetime? (correct answer: 15%)
3. Is your current lifetime risk higher than average person lifetime risk for getting the disease? (correct answer: a)
 - a) Yes, it is higher
 - b) No, it is lower
 - c) No, it is equal
 - d) Cannot determine from given data
 - e) I don't know