### Personal genetic testing: 23andMe and other true stories

# Would you be interested to find out what diseases you might have later on in life or who you are distantly related to? How much would you pay to find out?

A number of internet-based companies offer this service called 'personal genetic testing', and it can cost anything from £300 up to £45,000. For this they will read your DNA and look for genes for certain diseases such as diabetes, asthma and obesity. They also look for other characteristics such as your earwax stickiness, your eye colour, and your chance of becoming bald. Unlike sending DNA to a medical DNA database, these companies will send you results only about yourself.

For £400, you can send your DNA to the company '23andMe'. You would send a tube of your spit (which has cells containing your DNA) to the company in America to have it read. This takes one month to read, and afterwards your results are put onto your own private page on their website. Through their site you can also find and meet other people who share the same genes as you, and look for any distant relatives you may have.

23andMe was thought up by the wife of one of the founders of Google, and it has plans to become a genetics-based social networking website.

#### Would you be happy to share your genetic information with other people online? Do you think that sharing genetic information is a good use of social networking?



Some people have criticised these genetic testing companies for not helping their customers after sending them their results. As most people don't understand genetics very well, receiving this information about the risks of diseases could leave people confused and worried. This is changing however, as the customers now need to talk to their doctor before they order their 23andMe test.

Several companies offer similar services to 23andMe, such as 'deCODEme' and 'Navigenics'.

At the other end of the scale, 'Knome' is a more exclusive company. They charge £45,000, but for this they read more of your DNA than

the other companies, and offer a more personalised and secure service.

Before you order the test, you can meet one of the Knome representatives who will answer any questions you may have. You would then send the company some of your DNA, taken from a blood sample. It takes 3 to 4 months to read the DNA, and once the results are ready they are sent to you on your own secure memory stick. After finding out your results, you can ask Knome's scientists about any of the results, and they will also let you know if anything new about your genes is found out through the latest research.

## If you had the money, would you want to pay one of these companies to find out about your DNA?

If so, who which of these two companies would you rather use: 23andMe or Knome?

Whose DNA is it anyway?

[Vote] In your opinion, what is the most important thing to look for in a genetic testing company?

- 1. the cost,
- 2. how good the scientific advice they give is,
- 3. the security of your results, or
- 4. the quality of the results?

Personal genetic testing companies have been criticised that their results are often inaccurate. Craig Venter, a well-known scientist, decided to test this and sent identical DNA samples to two different testing companies. He found out that although both of the companies had the same DNA, the results they returned were not the same.

Many differences were found between the DNA results. One company found that Venter should have a high risk of having a painful skin disease called psoriasis, whilst the other company predicted that this risk was normal.

### Does Craig Venter's test make you more or less likely to have your DNA read?



It's not all bad news though, as some of these companies plan to use the information that they get from their customers DNA to help research new

genes and diseases. This will help the companies results become more accurate, and will allow scientists to discover new cures for diseases.

Many people have also found the results to be very useful. A healthy-living 55 year old American man decided to send his DNA off to one company for interest, and the results that came back showed that he was very likely to have cancer. His doctor then tested him and found out that he actually had a cancerous growth in his body. He has since had the cancer removed, and believes that he is very lucky to have taken the test and found out about the cancer before it became too serious.

There are even some people who think that finding out which diseases they might have later in life will let them take action to protect themselves from the diseases.

Why do you think it would be useful to know the risks of having a disease, even though the result may not be accurate?

Should a company tell a customer that they have a high risk of having a disease which doesn't yet have a cure?

What worries would you have in trusting a personal genetics testing company with your DNA?

Gene Jury 2010

**To the teacher:** for interest, the company deCODEme offers a 'demo page' of what a customers genetic test results would look like on their website. This can be seen at <u>http://demo.decodeme.com/your-results</u>