

Decode – the story of the Icelandic DNA database

A DNA database is a place where all of the information from the DNA lots of people is held. If DNA is thought of as a barcode, a DNA database would be the supermarket computer which stores all of the barcodes and their information: such as what product it belongs to and its price. DNA databases are very valuable because of the person information that they contain.

Iceland is a unique place to study genetics because most Icelandic people are closely related to each other. The Icelanders have a strong interest in their history, and over many years have built up very detailed medical records, including samples of their DNA, details of their medical problems and their family histories.



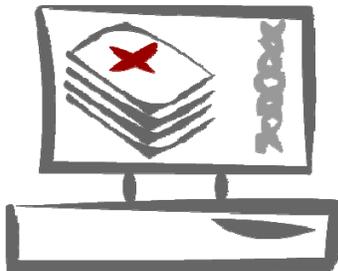
In 2000, the Icelandic Government decided to sell this information to an Icelandic company called Decode. The medical records were perfect for research, and the government thought the sale would improve the local economy.

How would you feel if you were one of the Icelanders?

This sparked anger amongst the Icelanders because nobody had asked for their permission. Worried doctors set up an organisation to stop the sale of the information. Icelanders felt that their privacy was not being protected, and they were concerned that if just one company owned all of their medical data, then that company could do whatever they wanted with it.

The company then decided to give the Icelanders a choice to 'opt-out' before the sale: they could decide not to include their records.

Do you think this 'opt-out' system is fair? Do you think the Icelandic government should have done more to protect the peoples' privacy?



British medical research databases such as 'Bio-Bank' and 'Generation Scotland' may also plan to sell their DNA data to interested people such as scientists or companies. Unlike in Iceland, people here volunteer to put their DNA on the database (they 'opt-in') and unlike the Decode example, the data are available to many companies, preventing control of the data by only one company.

The data from the Icelandic database has however, been used to discover many new and interesting disease genes, such as a gene that increases the risk of stroke and another which increases the risk of endometriosis (a disease which causes pain for women). Scientists can now try to find a cure for these diseases, thanks to the information revealed from the Icelandic DNA database.

What is your opinion of the use of DNA databases for medical research? What are the pros and cons of putting your DNA onto such a database? Would you offer your DNA to a medical research database, and under what conditions?

Do you think it is right for a company holding a DNA database to sell the information held on it? If so, to whom and under what conditions?

Which system to share DNA information do you think is fairer: the Icelandic or the British one?