

**Iceland's DNA: The world's most precious genes? By Emma Jane Kirby BBC News, Reykjavik 19 June 2014 Magazine**

Iceland's record of low immigration and its genealogical records going back 1,000 years make it a paradise for geneticists. A third or more of the population has already donated a DNA sample to the Icelandic Biobank, DeCODE but a new push to increase that figure is meeting some resistance.

"I will not be emotionally blackmailed into giving my DNA it's my own private and personal information and I am not going to give it to anybody!" Icelandic writer and journalist Alda's latest blog describes the attempt of deCODE to recruit volunteers to give DNA samples. The company already has over a third of Icelanders in its database but now it wants to double its count. Earlier this summer, it sent out swab packs in the post with information informing households that couriers would be knocking on doors in the near future to collect the samples from willing participants.

"Noone is forcing anyone to give their DNA," snaps DeCODE's director, Dr Kari Stefansson. "But there is nothing wrong trying to convince people to take part in biomedical research. Without making discoveries about the nature of disease, we are not going to advance medicine". It was back in the mid90s that Kari first realised the potential of mining Iceland's gene pool. With little significant immigration since the Norsemen first settled here in the 9th Century, Iceland is among the most homogeneous nations on earth. With so little background noise to filter in the small population of just 320,000 people, it's much easier for scientists to isolate faulty genes than it is in larger multi-ethnic countries such as Britain or the US.

"We are probably the most productive entity in human genetics in the entire world," insists Kari. "For example we have recently published a mutation which provides almost complete protection against Alzheimer's disease. Most Icelanders support us in our work."

At the University of Iceland, Salvor Nordal, director of the Ethics faculty, says deCODE has prompted many a debate in her department. I ask her whether it's fair to argue that in a country where the gene pool can be mined so effectively, Icelanders have a responsibility and a duty to provide a DNA sample to avoid health risks in the future. "Of course one can argue that," she smiles. "But you also need to remember that in Iceland everyone knows everyone and when you give your DNA sample, you are not just giving information about yourself." She reminds me about Iceland's genealogy database and points out that deCODE's geneticists can use computational methods to calculate the odds of whether an individual carries a particular genetic variant without directly sequencing their DNA, if it knows the DNA of that individual's relatives. "They can fill in the missing gaps," says Salvor. "Now it becomes much more than asking questions about an individual's privacy we are talking about group privacy... and whether we can be discriminated against as a member of that group."

Unlike the UK's Biobank, which is a charitable and government funded venture, deCODE is a private enterprise. Having struggled financially, the firm is now owned by the American biotech giant, Amgen. The thought that a foreign company might profit from their private information has made many Icelanders baulk. "It makes me very nervous," journalist Alda Sigmundsdottir admits. "I'm thinking the DNA of 100,000 or so Icelanders is probably quite a valuable commodity for a multi-national corporation." Kari insists that all DNA in his possession is labelled with encrypted IDs and is fiercely protected.

To further assist in this effort, until a few years ago, deCODE even had guaranteed access to every Icelander's health records, thanks to a decision taken by the Icelandic Parliament. Then in 2003, a woman sued to keep her deceased father's medical records from going into the deCODE database, citing a right to privacy. Now the company has to approach individuals for their consent.

One man I asked about deCODE replies quietly; "I have a family member with a genetic condition who has suffered a lot". He meets my gaze. "Why should he suffer a lot if we know we have information that can help him? What is it to do with privacy?"