

Private company wins rights to Icelandic gene database

Abi Berger, *science correspondent*

The Icelandic parliament has passed a bill that has critical implications for countries around the world. The bill, passed on December 17, makes it legal for a private company to obtain a comprehensive electronic database containing health information about the entire population of Iceland.

The bill will also allow deCODE Genetics, a privately funded company based in Reykjavik, to manage the database, enabling the company to add both genetic and genealogical information to medical details that will be taken from hospital records. The final vote was taken after months of political wrangling, and only one member of the 41 strong coalition government voted against it.

deCODE Genetics, which is largely funded by American investors, has already signed a deal with the Swiss pharmaceutical company Hoffman-La Roche, giving them exclusive access to the database in order to establish the genetic origins of 12 diseases. Much of the growing opposition to the bill stems from the monopoly it clearly gives to a single company so that no other biotechnology or pharmaceutical company will have access to the data.

A significant proportion of the Icelandic population was initially said to have been in favour of the bill, seeing it as a way of helping medical science. But this confidence was eroded by growing opposition to the bill which was orchestrated by both scientists and doctors in the country.

Two large bodies in Iceland opposed the bill: the Icelandic Medical Association (IMA) and Mannvernd (the Association of Icelanders for Ethical Science), an organisation which was set up in October 1998 with the sole aim of preventing the bill being passed.

According to one founder member of Mannvernd, Laufey Tryggvadottir, an epidemiologist at the Iceland Cancer Society, there are three reasons why this bill should not have been allowed to get through parliament.

Firstly, there is the issue of personal privacy. Although deCODE has promised to

encrypt the data so that individuals cannot be recognised, many people argue that in a country such as Iceland, where there are only 270 000 people, it will be comparatively easy to establish which data belongs to which individual, particularly in cases of rarer conditions.

Moreover, since the database is a dynamic system, with data being added to it all the time from hospital records, newly added data may be easily identifiable. According to Dr Ross Anderson, an adviser on computer security to the British Medical Association, who was brought in to assess the bill, having all the information in one place will make it easy to decode, whatever security measures are taken to try to prevent this happening.

Secondly, doctors say that if the database is made available to deCODE, the trust of confidentiality between doctor and patient will effectively be broken. Consent for data to be passed on to deCODE has not been obtained from patients up to now.



The deCODE company's website logo

Why is this database so important?

Iceland's history and medical resources make this database an extremely valuable asset to scientists, and biotechnology and pharmaceutical companies. Since the first world war, meticulous medical records have been kept on every Icelander. Also, tissue samples have been taken from a large proportion of the population and stored since the second world war. In addition, family trees have been devised and documented for the vast majority of Iceland's 270 000 population.

The genetic isolation in which Iceland has been living, with virtually no immigration for the best part of 1000 years, makes this population ideal for anyone interested in establishing the genetic basis of disease. Additionally, the population enjoys a uniformly good standard of living.



Dr Gudmundur Bjornsson, chairman of the Icelandic Medical Association

The present draft of the bill, the third, allows those who object to opt out but Icelanders will otherwise be presumed to have consented. In addition, it will not be possible to withdraw, at a later stage, data that has already been entered.

"The government is trying to bully us into accepting this bill, and we are deeply concerned that politics are being seen to

have a greater bearing than the protection of patients," says Dr Gudmundur Bjornsson, chairman of the IMA.

The third reason for rejecting the bill, according to Mannvernd, is the monopoly being given to one company to develop new drugs and to test candidate drugs on the Icelandic population. "These data are very valuable, and there's a great chance of them being used in a criminal way," says Bjornsson.

"This database brings great possibilities but only if we get it right," he says. "At the moment there are more negatives than positives. Doctors will stick to the ethical principles of looking after their patients, and this may lead us to break the law." According to Mannvernd, the ethical council of the IMA has advised doctors not to participate in the proposed collection of data.

Scientists are also up in arms because of the effective "lockout" that they see occurring to anyone not working with deCODE or Hoffman-La Roche. Scientists will no longer have equal rights to data. Because public funding for science is low in Iceland, and the database will not be made available to any other groups, the careers of scientists outside these companies are likely to be seriously affected.

"People are slowly beginning to understand the real implications of what could happen," says Tryggvadottir. "It's a sad day for Iceland." □