

**CHAPTER 19****HANDOUT****Scientific Interest in  
Founder Communities****BLM 19.2.4**

**Read the following news story and then answer the questions.**

The total population of Iceland is less than 300,000 people, and genealogy (family history) is a national interest. Most Icelanders can trace their families back around 1200 years.

In December of 1998, after much heated debate, the parliament of Iceland passed a bill that mandated the creation of a centralized database of all the Icelandic peoples' genealogical, genetic, and personal medical information. The original bill did not include genetic information; this provision was added when the bill was amended during parliamentary review. The Icelandic parliament then granted an exclusive contract to deCODE genetics, a biomedical company, giving deCODE access to Iceland's national health records.

About a year before the bill was passed, deCODE signed an agreement with Hoffman-LaRoche, a Swiss pharmaceutical corporation, on the understanding that deCODE would get the contract from the government of Iceland. deCODE requested the contract because it was searching for genes associated with over 30 diseases (for example, heart disease, emphysema, and Alzheimer's); 12 of these searches would be financed by Hoffman-LaRoche.

To research these diseases, deCODE initially worked with the voluntarily donated DNA of small groups of Icelanders. Later, the company launched a media campaign to attract DNA donors on a larger scale. deCODE has been able to combine genetic information with the genealogical and health records of each Icelandic citizen in order to create a comprehensive database. On January 1, 2000, deCODE announced that it had almost completed "The Book of Icelanders," an extensive family history database of all Icelandic citizens, past and present, and was planning to publish it on the Internet. According to deCODE, an individual's information is encrypted. Most experts who reviewed the project's privacy measures consider the information in the database to be personally identifiable.

Icelanders can refuse to continue to participate in the database but cannot petition to have any information already in the database removed. Furthermore, the law does not require that Icelanders be told what kind of research will be done with their personal data.

Source: Oksana Hlodan, 2000 <http://www.actionbioscience.org/genomic/hlodan.html>

1. With respect to the "founder effect," explain why the Icelandic population would be ideal for this type of study.

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2. Why would scientists want to study a population rather than an individual?
3. Do you think there might be opposition to the project? If you lived in Iceland, would you want your family data to be part of the project? Why or Why not?