

CHAPTER 19**ANSWER KEY****Scientific Interest in
Founder Communities****BLM 19.2.4A**

1. Answers should include information that relates to some of the following:
 - Iceland's population is relatively small.
 - The population of Iceland was established by a relatively small, homogenous population and remained isolated for centuries. The lack of genetic diversity in this population makes it easier to study the incidence of inherited diseases.

You may also note:

 - Because genealogy is an integral part of the culture—80 percent of all Icelandic people who have ever lived can be traced on family trees—a list of people with a common disease can be run through the genealogical database to look for clues to genetic and environmental causes.
 - Within Canada, such a study would be much more difficult to conduct because Canada's population is not homogeneous, although there has been some interest in studying the relatively more isolated population of Newfoundland.
2. Answers should note the key principle in the study of population genetics: that it is not the individual, but the population that changes over time. Populations are not defined exclusively by geographical isolation but also by such factors as cultural heritage and family lineage. Thus, population genetics can reveal mutations unique to specific groups.

You may also note that the geographic and cultural isolation of Iceland makes it easier to identify genetic predispositions to certain diseases, and perhaps help reveal which diseases have a genetic component and which ones do not.
3. Arguments in favour may cite
 - Service to humanity in curing disease.
 - Free medications for specific conditions have been promised to Icelanders, if deCODE and its business partners acknowledge that the medications were developed as a result of the database.
 - Jobs in the biotechnology field may become available in Iceland; critics note that the Internet publication of the data means that it can be accessed and worked on anywhere in the world.

Arguments against may cite

- The possible rise of medical or genetic stereotyping, leading in extreme cases to theories of genetic predisposition to certain insurable medical conditions, theories of racial superiority or inferiority, the exclusion of social and environmental causes of human illness, and eugenic pressures, i.e., to improve the hereditary qualities of a group or individual.
- Violation of privacy, including access to health information that may be abused.
- The data monopoly of one company (including commercial rights to the data) means that other parties that could make the same or better use of the data will not be able to use it.
- The marketing of the information means that human genetic information is a commercial commodity that can effectively be "owned" by an enterprise or individual and subject to the same restrictions that apply to other commercial commodities.

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