



# National Genome Projects: A New Trend in Biopolitics

A comparison of the Icelandic DeCode Project  
and the Eesti Geenivaramu in Estonia

Liese Pruitt

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# A Quick History of Iceland

- Settled by the Norse people in 930.
- At the end of the 10th century Norwegian Missionaries arrived in Iceland.
- Iceland remains a sort of province of Norway, but is ruled essentially independently.
- Norway entered into an allegiance with Denmark in 1380, and control of Iceland is transferred to Denmark.
- The English began trading in Ireland in the 14th century.
- In the 16th century Denmark restricts all contact between Iceland and the outside world.
- Become an separate state in 1918, but was not fully independent until 1944.

# Iceland DeCode Project



- First national genome project of this type.
- Approved by the Icelandic parliament in December of 1998 after much debate.
- Exclusive rights are given to a private biotechnology firm DeCode Genetics that technically is a United States company, but it operates entirely in Iceland.
- The resulting database will belong to the National Health Service.
- DeCode genetics has the rights to sell this information abroad for 12 years.

# Why Iceland?



- Iceland is unique in that it has a 900-year record of genealogical information.
- Universal, state-sponsored healthcare, which keeps comprehensive medical records for all citizens.
- Genetically homogenous population, which researchers hope will allow them to learn more about the origin of hereditary diseases.

# Social and International Response:

- Widespread social science and media interest: 700 newspaper articles in Iceland and 150 television programs.
- A group that is opposed to the project, Mannvernd, forms and encourages Icelandic citizens not to participate.
- There are ethical concerns about the methods of collection and the ownership of this information by a private corporation.
- There are opponents who argues that this is commodification of the population and the “selling of Icelandic DNA.”

# A Quick History of Estonia

- First mentioned by the Romans in the 1st century CE.
- Invaded by the Vikings in the mid 9th century.
- In the 11th and 12th centuries the Swedes and the Danes attempted to control and Christianize the Estonians.
- The Russians made 13 attempts to invade Estonia between 1030 and 1192.
- Conquered by the Germans in the early 13th century.
- Conquered by the Swedes in the late 16th century.
- Conquered by the Russians in the early 18th century.
- Briefly independent between 1920-1940.
- Part of the USSR from 1940-1990.
- Now independent again.

# Eesti Geenivaramu

- Officially established December 13th, 2000.
- Goal is to collect information from 1,000,000 individuals.
- Run by a non-profit private entity founded by the government with free access to the information for Estonian scientific research institutions.
- Two forms of data collection:
  - Phenotyping data gathered by doctors and healthcare workers about genealogy, lifestyle, and health status.
  - Genotyping data from two blood samples.
  - With patient permission the two sets of data are cross-referenced

# Why Estonia?



- Very heterogenic population genetically due to centuries of occupation by wide variety of other ethnic groups.
- Following the breakup with the Soviet Union there was a desire to rapidly establish their connections with and membership among the technologically advanced Western European nations.
- Before the Soviet occupation Estonia was a historical leader in molecular biology.



# Social and Economic Consequences

- It is a way to extract a real value and positive perspective on a difficult past, and perhaps diffuse some of the lingering tension and animosity.
- Has the potential to create highly technical research and industry opportunities in a country that is still largely dependent on less advanced industry.
- Other countries are considering establishing such databases including the United Kingdom, China, Norway, Latvia and Sweden.

# Iceland vs. Estonia



- Population Size:
  - 295,000 versus 1,330,000
- Population Characteristics and Resulting Goals:
  - Homogenous versus heterogeneous
  - In Iceland the focus is on understanding hereditary diseases and their origins, and tracing specific traits through lineages.
  - In Estonia there is instead a focus on creating a picture for the larger European population, using DNA as a diagnostic, and designing medications tailored to personal genetic characteristics to prevent adverse effects.

# Consent



- Iceland assumes that the individual wants to participate unless specifically stated otherwise.
- Many ethicists feel that the lack of a requirement for informed consent in the Icelandic system is very exploitative.
- Estonia, in part due to reaction to the Icelandic project, uses a opt-in system instead.

# Conclusions:

- The significant differences in the structure and purposes of the Icelandic and Estonian genome projects reflect the sharp learning curve in this new trend of institutions, and the contrasting characteristics of their populations.
- The ethical concerns of this new application of this technology are still emerging, and as other countries develop databases of their own policies will undoubtedly develop and change.

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