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Nordic Committee on  
Bioethics

# Genetic Self testing

**G**enetic self tests, i.e. tests provided directly to the consumers on the open market, are becoming more and more common. Most of the tests are not diagnostic in nature, but merely suggest a more or less increased risk for various diseases. The conference showed that such tests indeed raise many difficult questions.

**S**everal speakers pointed out that at the moment many tests that are provided by the companies directly to consumers are neither very useful nor informative. They have a rather low predictive value and at the conference comparisons to astrology were made several times.

**S**cientifically, however, there are great potentials in genetic testing. Scientists have identified several genes for frequent, severe diseases and risks of serious conditions that can significantly influence an individual's life. These results will be used for diagnosis and for developing novel treatments.

**D**ue to technological advances the tests provided directly for the consumers may have higher predictive values in the near future. Some therefore argue that there is a need for new legislation and regulations in this field; not necessarily as prohibitions but rather as consumer service and protection, e.g. as guidelines and demands on the companies that provide the tests, concerning information, guaranteed quality and genetic counselling. International organisations, such as Council of Europe, recommend as a general rule that genetic tests be performed only under medical supervision, accompanied with appropriate pre- and post-test genetic counselling. In general genetic self testing is not regulated in Europe.



*The Nordic Committee on Bioethics (NCBio) was founded in 1989 to promote Nordic cooperation and exchange of information between scientists, parliamentarians, opinion leaders and public officials in the area of bioethics. NCBio organise yearly public conferences and symposia. The Committee publishes reports and other publications to promote Nordic and international debate on bioethical issues.*

*Presentations from the conference can be seen at the homepage for the Nordic Committee on Bioethics <http://www.ncbio.org/> and manuscripts from the speakers will be published in a future report from the committee.*

**M**ost participants at the conference did not recommend a full ban. Several participants argued that the most important issues were to provide better information about the limited value of these tests, and about the fact that these tests can lead to information that the individual neither wants nor is prepared for. The general recommendation is that qualified, genetic counselling is necessary – both before and after the tests have been made.

**T**he speakers at the conference included:

- From Denmark two human geneticists from the University of Aarhus (Lars Bolund and Anders Børglum) who described the state of the art of molecular analysis of the human genome.
- Ingileif Jónsdóttir, from the Icelandic company deCODE genetics talked about the genetic services offered to the public.
- Robin Engelhardt, science journalist, from the magazine Ingeniøren in Denmark talked about his own personal experiences with gene tests.

- From Finland Helena Kääriäinen, professor of medical genetics at the University of Turku, talked about Clinical Genetic Viewpoints on Genetic Analysis.

- Also from Finland, Sirpa Soini, a legal adviser from the Institute for Health and Welfare, gave an overview of National and International Regulations.

- From Norway Terje Kilin from the Norwegian Consumer Council talked about consumer perspectives.

- Astridur Stefánsdóttir from the University of Iceland talked about ethical aspects of genetic analysis.

- From University of Linköping in Sweden professor Anders Nordgren discussed philosophical aspects.

- And finally from London Dr. Frances Flinter representing The Human Genetics Commission in UK gave viewpoints on Profiling Over-the-Counter Genetic Tests.

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