

Genetic Self Testing



A Consumer Perspective

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The Consumer Council of Norway



- THE CONSUMER COUNCIL OF NORWAY is an independent organisation representing the interests of consumers. Our objectives are to increase consumer influence in society, to contribute to consumer-friendly developments and to promote measures that strengthen the position of consumers.
- The Consumer Council is free to develop independent consumer policies, and is independent of commercial interests and other organisations.
- The Consumer Council shall help put consumer issues on the agenda and promote consumer interests.

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Gens - new technology – new consumer challenges



- **The technological revolutions brought about by the Internet, digitalisation and medical developments will bring significant new challenges for consumers, business and consumer protections.**
- **According to EU this will challenge traditional modes of regulations, self-regulations and enforcement.**
 - »..traditional consumer rights will be less and less adapted to the digital age.»

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Is at-home testing new technology?



»The industry had been around for years but it wasn't until earlier this decade it really took off. Now at-home testing has become a part of life for many Americans, who use store-bought kits to diagnose or monitor medical conditions ranging from diabetes to pregnancy.»

New York Times, August 30, 1987

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Genetic testing



- Used to diagnose disease – also serious ones
- Used to predict risk for future disease
- Used to inform reproductive decision-making
- Used to manage patient care
- Making new challenges where the information about a patient/person is more critical and more valuable
 - Persons who take these tests
 - Families of those who take those tests...
 - Society
 -Insurance company

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Direct-to-Consumer (DTC) Genetic Testing – what to say?



- »There is a lot of hype and a lot of angst about how personal genome testing will play out in health care..»
- »What is missing are hard facts about this industry and its consumers, and what the public`s motivations for, and experience with, these tests have been»
- »Consumer interest clearly will drive the future market for DTC genetic testing..., but we don`t know what consumer expectations are, or whether they are met by genetic tests currently available DTC

Gail Janvitt, Genetics & Public
Policy Center, Johns Hopkins
University, October 2008

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Problems for the consumers



»Some companies say genetic testing can do all this and more. They claim that at-home genetic testing can screen for diseases and provide a basis for choosing a particular diet, dietary supplement, lifestyle change or medication. They sell their tests in supermarkets and drugstore, and they advertise their service in print, on television, and online»

Federal Trade Commission, July 2006

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Risks by doing at-home tests



- The consumer may not conduct the test correctly
- The person collecting the sample and sending it to the laboratory may lack the technical training to ensure that the specimen arrives at the clinical laboratory in the same condition as when it was collected.
- The consumer may not be able to interpret test results in a clinical context (relevant family medical history)
- And, the probability of a false negative answer is higher with home testing, and hence the consumer may not engage in various follow-up actions that would have been recommended following a positive test results

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What is the situation?



- Do people understand what a test tell them?
 - Probabilities and risks
- Do we know whether the test is telling the truth? And who said so?
- And, maybe most important; do the patients who have decided to take a test really know what they are asking for? And are they prepared for the answers?
- And if not, who is taking care of the consumer/patients interests in a situation where there are a lot of hyping about what a gen test can tell?

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Main principle when it comes to health care



Improving health and health care depends upon accurate, timely, understandable, and relevant information in the hands of consumers, patients and health professionals, where and when they need it.

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Solutions?



- Federal Trade Commission (FTC):
»A healthy dose of skepticism may be the best prescription»
- Human Genetics Society of Australasia (HGSA):
»It is naive to think that banning DTC genetic test or prohibiting advertisements for them in Australia will inhibit access to such tests for a determined consumer, particularly given the global marketplace and access to such products via the internet.»

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Consumer International's consumer rights



- **The right to satisfaction of basic needs**
- **The right to safety**
- **The right to be informed**
- **The right to choose**
- **The right to be heard**
- **The right to redress**
- **The right to consumer education**
- **The right to a healthy environment**

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What to be done?



- The focus on traditional consumer rights is still valid
 - Right to safety
 - Right to information
 - Right to consumer education
 - Right to choose
- These issues have to be raised on a European level, making rules or standards
- But also national guidance – The National Health Surveillance have to make information useful for the patients/consumers
- And already mentioned: Rules that regulate what the insurance-companies can ask for..

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