A Kodak moment? The effects of consumer genetics on individuals, medicine and society

Chairs: Madeleine Hayenhjelm and Truls Petersen, members of The Nordic Committee of bioethics

Emilie Niemiec: New offers of direct-to-consumer genetic testing and new ethical problems
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A variety of health-related genetic tests is currently advertised directly to consumers. The tests employ new approaches (whole exome and genome sequencing), may report on a wide range of conditions, and are targeted at new groups such as (prospective) parents (carrier testing, preconceptional and prenatal testing, testing for children). Furthermore, third-party web-based genetic data interpretation and sharing services are available to DTC GT consumers (who have their genomic data downloaded in the required format). Some of the platforms may offer payments for consumers for sharing their data. The currently salient ethical issues related to the offer of genetic testing and services include, among others: questionable analytic and clinical validity of the tests, adequacy of informed consent and pre-test counselling, potentially misleading advertising, the offer for children and reproductive purposes, research uses and commercialization of consumers' genomic data.

Henry Alexander Henrysson: DTC GT in a Small and Homogenous Population: The Future of Health Care or a Pandora Box of Insurmountable Societal Challenges?
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During breaks in the televised broadcasting of the Eurovision Song Contest, the Icelandic public was presented with advertisements from the Israel-based company MyHeritage which operates online. For many people, this was the first time they have been made aware of a company of this sort. Although people are very technology savvy and extremely willing to participate in various forms of scientific research, the marketing of direct-to-consumer genetic testing (DCT-GT) has not made much progress in Iceland until now. One can conjecture many reasons for this. There is, for example, quite significant and readily available genealogical information online for the Icelandic public. Another reason could be the strong presence of deCODE Genetics in Iceland in all things related to human DNA. Despite small steps roughly a decade ago into consumer genetics, the company has until now firmly focused on gathering anonymized genotypic and medical data from volunteer participants for research purposes.

DCT-GT could, however, easily become a very potent tool within a small and homogeneous population if any substance is in the promises of the most prominent companies on the market. It fits, for example, perfectly ideas how personalization of medicine can help already strained solidarity-based health-care systems. Furthermore, it seems to blend into an existing discourse on individual responsibility and empowerment in health-related matters. Lastly, one can easily imagine that once better known a part of DCT services promising information on genetic ancestry far back in

time could tickle the curiosity of a geographically isolated nation with tales of travelling individuals disproportionally influencing the local gene pool. In this talk, I will ask whether a small and homogenous population is perhaps indeed particularly vulnerable and not sufficiently prepared for the challenges of privacy and scientific validity commercialized genetic testing brings with it. Are the perceived and promised advantages worth the risk if the correct precautionary steps are not taken? The identification and development of these steps will be the next big project in bioethics in Iceland.

Santa Slokenberga: Ascertaining child's "best interests" through direct-to-consumer genetic testing: what could possibly be wrong with that?
Dr. in medical law, researcher at Centre for Research Ethics & Bioethics

Despite some early criticism for treating human genetic data as a special category of data and affording them special protection, many law and policy instruments have remained firm. They commonly contain significant reservations on the application of genetic testing on children, treating these interventions as impermissible, unless carried out for a direct (and immediate) health benefit of the respective child.

The increasing understanding of the human genome coupled with advances in technology is a fruitful soil for hopes, promises, and exaggerations. A hallmark of these advances and characteristics is direct-to-consumer genetic testing, which is commonly portrayed as "an empowerment tool" enabling the users to "take control" over one's health and even life choices. Moreover, it has been portrayed as the tool to help parents make "informed choices" regarding their children, their health, skill and talent management.

In addition to the obvious mismatch between the restrictive law and policy stand and the current practices of direct-to-consumer genetic testing companies, that raise questions of adequate protection of the rights of children, profound governance questions emerge. In this talk, I will scrutinize the practice of direct-to-consumer genetic testing from a child's perspective, and limitations of the current regulatory standards, and highlights ways forward.

Anne-Marie Axø Gerdes: The Danish Council on Ethics recommendations about Genome Testing with focus on Direct to consumer genetic testing.
MD, Chair The Danish Council of Ethics, Professor PhD, Head of clinic.

Direct to consumer (DTC) genetic testing is a new option for healthy individuals where they are offered a genetic test by a private provider via the internet. Apparently, an increasing number of individuals are interested in DTC. Advantages with this approach includes a possibility for the individual to plan and take responsibility of her own health and some possible benefits to the health system economy. However, several difficulties exist, such as the lack of control with the technical quality of the analyses/data; lack of clinical validation and genetic counselling to the individual or relatives; misuse of the national health system when individuals request clinical follow up/screening for dubious test results; requests for prenatal diagnostics for conditions with only a mild clinical impact or for late onset disorders were prevention or cure is possible. But also data sharing/ownership or even selling the data to third parties without consent from the individual seems to be part of these issues.