

Personal genetic profiling services lack evidence for claims

October 12 2010

Direct-to-consumer personal genetic profiling services that claim to predict people's health risks by analysing their DNA are often inconclusive and companies that sell them should provide better information about the evidence on which the results are based, says the UK Nuffield Council on Bioethics, in a new report on the ethics of so-called personalised healthcare services.

The report says that claims that these services are leading to a new era of 'personalised healthcare' are overstated and should be treated with caution. The Council recommends that regulators of these services and advertising regulators should request evidence to back up the claims made by companies.

The services are marketed to healthy people as a way of finding out their risk of developing serious conditions such as diabetes, [heart disease](#), Parkinson's disease and some cancers. But people taking the tests are faced with complicated risk data in their results and may experience undue anxiety, or be falsely reassured, says the Council.

Professor Christopher Hood, chair of the Working Party that produced the report, said:

"Commercial genetic profiling services may seem to be providing more choice to consumers, but the test results can be unreliable and difficult to interpret and they are often offered to people with little or no genetic counselling or support".

"People should be aware that other than prompting obvious healthy [lifestyle choices](#) such as taking more exercise, eating a balanced diet and reducing [alcohol consumption](#), the tests are unlikely to inform them of any specific disease risks that can be significantly changed by their behaviour," added Professor Hood.

Currently there is no overarching system of regulation for personal genetic profiling. The tests are mainly provided by companies based in the US, and they can cost up to US \$2,000. During its inquiry, the Council wrote to providers of genetic profiling services to try to find out how many people are currently using them, but the companies were not willing to share this information.

The Council recommends that genetic profiling companies should provide more information about their services to consumers before they buy, such as their limitations, the fact that the results may require interpretation by a doctor or geneticist, and which other third parties may have access to the data arising from the test. Government-run health websites should provide information about the risks and benefits associated with personal genetic profiling services, including whether or not it could be necessary for people to inform insurance companies of the results.

Professor Nikolas Rose, one of the authors of the report, said:

"Genetic profiling services come with the promise that people will be able to take more responsibility for their health – but it is not clear what that responsibility would imply."

"You may feel a responsibility to change your lifestyle on the basis of your results, without the help of a doctor to interpret the ambiguous risk statistics. You may feel a responsibility to inform family members, insurers or potential employers of your risks, even though you may never

develop the conditions in question," added Professor Rose.

To make these recommendations, the Working Party weighed up whether the need to reduce harm was strong enough to propose interventions that compromised people's freedom to pursue their own interests.

The report also considers another so-called personalised healthcare service – direct-to-consumer CT, MRI and ultrasound body scans as a form of 'health check-up' for people without pre-existing symptoms, a service which some companies offer at a cost of more than £1,000.

CT scans carry serious physical risks from the radiation involved, especially if whole body scans are used, and carried out on repeated occasions.

The Council says that the commercial sale of whole body CT scans as a health check for people without prior symptoms of illness should be banned, as any potential benefits do not justify the potential harms caused by the radiation. It also suggests that companies offering scans as part of a health check should be regulated to ensure they are meeting standards of quality and safety.

The Council recommends that doctors should receive specific training on giving advice to patients about direct-to-consumer genetic profiling and body imaging services, and about making referral decisions on the basis of these tests.

More information: www.nuffieldbioethics.org/

Provided by Nuffield Council on Bioethics

Citation: Personal genetic profiling services lack evidence for claims (2010, October 12)
retrieved 17 April 2024 from
<https://medicalxpress.com/news/2010-10-personal-genetic-profiling-lack-evidence.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.