

## **EDITORIAL**

## Genetic testing

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It is sobering that Home Genetic Testing is being called to order by the US Government Accountability Office (GAO), not by voluntary professional judgement or effective medical regulatory action.

The GAO report is available online (www.gao.gov/products/GAO-10-847T). The central issue is that the predictive value of the so-called genetic testing is generally trivial, even if it were reliable, which sadly is often not the case. Companies selling such testing that were included in the Report were companies like 22andMe, Nowgenics, Pathways Genetics and BeCode Genetics. Some of the companies say the results are simply to provide 'information'. This is probably disingenuous – the purpose is to identify individuals with a higher or lower risk of specific disorders. It is in effect bad medical screening. The report concluded that 'the test results are misleading and of little or no practical use to consumers'.

The marketing of so-called genetic testing should not have been introduced and now needs to be curtailed. Calling such testing an example of 'personalized medicine' is particularly misleading. Medicine through the ages has been 'personalized' in that doctors seek to do the best for each individual patient given the state of knowledge at the time. There is nothing special in this regard with the principle of genetic testing. With greater knowledge disease entities become more refined (e.g. different causes of epilepsy, ischaemic

and hemorrhagic stroke, oestrogen receptor-positive and oestrogen receptor-negative breast cancer). As long as this refinement is soundly based, and has useful preventive or therapeutic implications, it is worthwhile. Otherwise it is not. The term 'personalized medicine', with its implications of being new and good, is not a good one. If one needs to be adopted, 'genetic profiling' would be better.

The issues are scientific and ethical. If the science is sound and there are benefits to individuals, it is ethical to offer testing in a way that will give access to those who stand to benefit; if the science is shaky and there are no individual benefits, it is not ethical to promote or sell the test.

It is disappointing that it requires Government, and an 'Accountability' office at that, to have to step in and recommend the policing of such practice. It would have been far better if entities offering such testing had operated responsibly in the first place. But that is not the case, and regulations are needed, though with the global reach of internet marketing this will not be easy.

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