

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Medical profiling and online medicine: the ethics of 'personalised' medicine in a consumer age* between April 2009 and July 2009. The views expressed are solely those of the respondent(s) and not those of the Council.

Time prevents me from offering a full and considered response to this consultation, but I do want to endorse one or two particular points in the document.

There is a tendency in the private sector to talk about the information gained from tests as though it would necessarily be beneficial. Very, very little attention is paid to the possibility that information can be harmful, both directly harmful psychologically and indirectly harmful physically because of follow on tests and the side effects of unnecessary treatment. Most tests offered to the public are intended to serve a screening not a diagnostic function, but the difference between the two is not easy to explain, and easily ignored in a sales context. I was recently involved in some work for Which? Magazine (NB Please look out for a forthcoming article on health MOTs), and was asked to comment on a few "selling points". I've copied extracts from my response in below.

*"Can these tests give peace of mind?* Peace of mind can arise from misunderstanding - people don't know what they don't know. The companies do not mention all the things they don't test for at all, and they say very little about false negatives arising from the tests they do use, so it is unsurprising that people think they have had everything checked, and that a clean bill of health means exactly that. (I'm sure a lot of people were reassured by their financial advisers early last year - doesn't mean they were right to be.)

*All the tests used are safe - how can you say a simple blood test or scan can be harmful?* The point is that if somebody has symptoms AND a positive test result, then it is much more likely that the positive screen will be a true positive, i.e. the person really does have a problem. In these circumstances, having follow on tests - which may be invasive, painful, involve radiation etc - is justified. The balance of probabilities, and hence the balance of possible benefits versus possible harms, is quite different in the absence of symptoms - people with a screen positive result will still want to get a definitive answer, so they will go ahead and have the follow on tests with all their disadvantages, even though the likelihood of getting any benefit is extremely small. Any company information that essentially relates to the procedure of testing is either missing the point or a fudge: it is the use of screening test procedures in this context that is controversial, not the procedures themselves."

There are standard procedures for the evaluation of test performance, which the National Screening Committee draws upon before recommending a test for use in the NHS. Companies however prefer to imply tests are only restricted for financial reasons, rather than because using the test on the general public would do more harm than good.

One of the reasons I was approached by Which? is that for several years I have been helping the NSC write the information given to pregnant women about screening for Down's syndrome, and about fetal anomaly ultrasound scanning. Both are available in the private sector, and scanning in particular is very attractive to customers because people like "seeing their baby". Minor anomalies are common, but generate much anxiety and unnecessarily increase the rate of invasive diagnostic testing.

It seems to me that companies offering screening should be obliged also to provide diagnostic testing. Otherwise, the NHS will be overwhelmed, and people in real need will have to join a long queue, most of whom should not be there at all.

Finally, genetic tests bring all the above, but implicate other family members too. Harms as well as benefits can be amplified, and in some cultural settings, whole families can suffer needlessly. Greater regulation is definitely required.