

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.

## **QUESTIONS ANSWERED:**

### **Question 01 - Health care as a consumer good**

#### **ANSWER:**

Yes, but.. The products and services on offer need to be assessed to a set of standards which may or may not involve regulation to ensure that products or services are scientifically valid. The recent move towards a 'Choice' agenda in the public health sector risks characterising patients as consumers rather than citizens is undesirable.

### **Question 02 - Validity of information**

#### **ANSWER:**

This answer relates only to DNA profiling. Yes. There is a vast difference between buying a book and having a test such as DNA profiling. As medical test DNA profiling should be subject to different set of criteria than a column in a women's magazine. The person having such a test is obtaining specialised information specific to them which they have paid for and could have major implications for not only their future health, lifestyle and peace of mind but also their family's. A magazine or book will usually feature generalised information which the reader is likely to evaluate in a different way and perhaps compare with other books or articles.

### **Question 03 - Prevention**

#### **ANSWER:**

This answer relates only to DNA profiling. There should be freedom of choice as to whether to take a DNA profiling test. There is an entitlement to genetic privacy which extends to individual in relation to themselves. If an individual decides to take such a test they should have the freedom to act upon their results as they choose – whether that is to bury their head in the sand, blow their life savings on a world cruise or adopt a vegan diet and tough exercise regime.

### **Question 04 - Who pays?**

#### **ANSWER:**

This answer to this question is bound to wider questions of the partitioning or

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overlapping of the private and public sectors which is probably beyond the scope of this consultation. Yes, one shouldn't make a distinction between the deserving and undeserving sick.

### **Question 12 - Regulation**

#### **ANSWER:**

This answer relates to DNA profiling tests only. NO, the same evaluation should apply to the public and private sector. The measures outlined in the consultation document are feasible and reasonable. Some problems arise because many of the companies who offer direct to consumer tests for DNA profiling are based overseas and therefore are not subject to the same advertising standards as UK based companies.

### **Question 13 - Responsibility for harm**

#### **ANSWER:**

This answer relates to DNA profiling only. YES. There is a profound difference between a pregnancy test and a DNA profile. The accuracy of a pregnancy test can easily be validated and is likely to be proven very quickly. A DNA profile is more complex and will in most cases be less conclusive. Companies offering these services should be responsible under the criminal law and under the law of contract and tort.

### **Question 14 - Quality of information**

#### **ANSWER:**

This answer relates only to DNA profiling. YES, the *caveat emptor* principle is less applicable when referring to medical test than when buying soap powder. The scientific claims made for a particular brand of detergent have fewer implications for one's life and limb. Further the majority of the companies offering these tests are based outside the UK and therefore beyond the jurisdiction of the Advertising Standards Authority. Researchers and practitioners in both the private and public sector should as a matter of course be striving to improve the usefulness and quality of the services they provide.

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### **Question 15 - Other issues**

#### **ANSWER:**

The questions in this consultation are convoluted and leading thus narrowing the scope for reply.