

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:**

No. Choice is not currently informed by full and accurate descriptions of risks and benefits. Online storage of medical records is probably an exception, however.

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

###### **ANSWER:**

Yes. Limitations of the information provided (in the USA, and in the UK by a Which report out this month) have been demonstrated. Access should be limited to those tests for which there is supportive scientific evidence (of course, there is the tension with publicly-provided screening services [e.g. breast], which have been adopted by the NHS, but whose effectiveness is still debated). Ideally this would be a randomised controlled trial of screening, or at least a randomised controlled trial demonstrating the effectiveness of an intervention for an asymptomatic abnormality detected by screening.

##### **Question 03 - Prevention**

###### **ANSWER:**

No. Responsibility should be for primary prevention, and participation in screening programmes for which there is robust supportive scientific evidence.

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

###### **ANSWER:**

No, for screening services that are not supported by high quality evidence. The screening companies themselves should take responsibility for the treatment of abnormalities identified by non-evidence-based activities. If this increased the tariff, it could only be a good thing: fewer people would attend for unproven screening services.

##### **Question 05 - Your experiences**

###### **ANSWER:**

No. My use would be determined by the data security of the provider, and the ease of my accessing accurate information about my health from my existing medical records.

##### **Question 06 - Your experiences**

###### **ANSWER:**

No. I would only consider using these services for non-urgent problems. In my experience of NHS24, if I had anything serious, the advice would be likely to be to see my GP (or attend A&E) anyway!

##### **Question 07 - Your experiences**

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**ANSWER:**

No. I would only consider purchasing them if the provision of the drug was quality-assured, and the treatment was not available on the NHS.

**Question 08 - Advertising health care products**

**ANSWER:**

No. I think doctors should be the gatekeepers for access to pharmaceuticals (other than those authorised for over-the-counter use), DNA profiling, and body imaging.

**Question 09 - Your experiences**

**ANSWER:**

Yes. I have used it as a doctor in prescribing thrombolysis for patients with acute stroke. Evidence is being gathered for its effectiveness in this situation; for those in remote and rural communities with acute medical emergencies (such as stroke), the benefits of telemedicine seem beyond doubt.

**Question 10 - Who pays?**

**ANSWER:**

Yes. The costs should be borne by the patient if consulting a doctor from home (as opposed to consulting a specialist at a tertiary centre, having been admitted to a district general hospital). After all, they would have to pay for travel and parking to reach the GP or hospital.

**Question 11 - Your experiences**

**ANSWER:**

No. I would want to know the risks and benefits of attending for such screening, whatever the results turned out to be. In other words, evidence for the screening activity itself.

**Question 12 - Regulation**

**ANSWER:**

No. Regulation should be imposed: services without an evidence base should have kitemarked information leaflets (explaining all pros and cons), and bans on advertising.

**Question 13 - Responsibility for harm**

**ANSWER:**

Yes. The responsibility here lies with the providers of predictive tests of unproven (or negligible) value; which is quite distinct from pregnancy testing.

**Question 14 - Quality of information**

**ANSWER:**

Yes. This is purely the responsibility of the providers themselves, but it should be regulated, and information should be kitemarked. There is plenty of evidence of poor quality

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information - published studies from the USA (Illes et al) and an August 2009 Which report in the UK.

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

#### **ANSWER:**

I have a paper in press which provides the most accurate information (from a meta-analysis and systematic review) of the chance of detecting an incidental finding on brain MR imaging; the risk is 1 in 37, and there is no RCT evidence indicating what to do with any of these incidental abnormalities! The reference is: Morris Z, Whiteley WN, Longstreth Jr WT, Weber F, Lee Y-C, Tsushima Y, Alphas H, Ladd SC, Warlow C, Wardlaw JM, Al-Shahi Salman R. Incidental findings on brain magnetic resonance imaging: systematic review and meta-analysis. BMJ 2009 [in press]