

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 because it promotes responsibility for your own health and increases the level of education and knowledge. This attitude is less dangerous than believing that MDs are gods and medicine some type of magic. DNA profiling and similar services simply empower people and give them means and vocabulary to talk with medical professionals as peers and to understand the limits and the risks. These tests will be more affordable if more people start using them.

Question 02 - Validity of information

ANSWER:

No, DNA profiling etc. should be freely available with a disclaimer as we do this is the case of all freely available (and actually all) medicine. The disclaimer should state clearly at what stage of the research is given technology/knowledge and offer a possibility to be part of the research and get the latest information.

Question 03 - Prevention

ANSWER:

Yes, definitely, and the best encouragement are financial incentives from the side of the insurance companies and health campaigns from the side of the state. It should be the same as going to the dentist once a year.

Question 04 - Who pays?

ANSWER:

Yes, it should be funded by public services, insurance, because it is a form of prevention, the tests should meet however certain scientifically accepted criteria.

Question 05 - Your experiences

ANSWER:

Yes, it was useful in terms of knowing what questions to ask the medical professional later and what to expect. I would also consult such systems after I returned from the official check up at some medical institutions in order to

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understand the results.

Question 06 - Your experiences

ANSWER:

Yes, it was useful in terms of knowing what questions to ask the medical professional later and what to expect. I would also consult such systems after I returned from the official check up at some medical institutions in order to understand the results.

Question 07 - Your experiences

ANSWER:

No, only if my GPs tells me to buy it and if it is possible to do this online.

Question 08 - Advertising health care products

ANSWER:

Permissible but regulated, so advertising of DNA profiling etc. does not promise what it can not deliver. In the case of drugs it should stay forbidden to advertise because it is much easier to make a mistake and it creates pressure on the GPs to prescribe the "popular" rather than efficient drug.

Question 09 - Your experiences

ANSWER:

Yes, telephone in case of a dentist that knew my condition well and I was away from my country, so I needed to know what I am risking if I wait with the treatment on my return... I think it could be a good service when someone lives in remote areas of travels or simply does not have time.

Question 10 - Who pays?

ANSWER:

Yes, shared, I still do not see why should such costs be higher?

Question 11 - Your experiences

ANSWER:

No, I would like to use such services for all possible reasons: health,

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entertainment, curiosity. At this moment I lack legal background to understand the nuisances of how my information will be used and I can not make an informed decision, so I hesitate. I think it should be more clear who controls the flows of these type of information and how are such companies penalized for misusing them...

Question 12 - Regulation

ANSWER:

Yes and no, I do not believe is restrictions but in regulation, should be very clear what is done with the data and information obtained from client, and strict post-market monitoring and surveillance should be penalized.

Question 13 - Responsibility for harm

ANSWER:

NO, interests of such individuals and groups will be safeguarded best by support groups and psychologists.

Question 14 - Quality of information

ANSWER:

Yes, it should be funded by both because it is in the interests of all.

Question 15 - Other issues

ANSWER:

If we prevent people from experiencing the peculiarities of their DNA, we are suppressing not only their responsibility and knowledge of their medical condition but more importantly we are suppressing the scientific curiosity and even the aesthetic qualities of such self reflections. DNA profiling and other technologies have a strong potential to promote the dialogue between science and the public on a very personal level and this should not be wasted among concerns that often sound rel