

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, I think this is a positive development. It will help to de-mystify a particular range of medical products and services. It will also help to make clear to individuals that they are the ones who decide to have it or not and whether it seems worth the price.

Question 02 - Validity of information

ANSWER:

DNA profiling should be freely available. Body imaging should in principle also be freely available; weighing the potential risks inherent to the procedure as such, however, should be a responsibility for the service provider / involved health care professional. E.g., the risks inherent to radiation exposure (e.g. cumulative low-dose irradiation, exposure of the eyes in high resolution CT, etc.) should be carefully judged by the health care professional/service provider, the same applies to the use of contrastmedium and invasive procedures. The immediate risks related to imaging procedures cannot be directly compared to the - assumed - risks of DNA profiling, as the latter are of a fundamentally different nature.

Question 03 - Prevention

ANSWER:

No, people should not be expected to be pro-active here. It should still remain the responsibility of the 'state-approved' health care system to provide the best possible level of care that a distributive model allows for - in terms of availability, accessibility, and affordability. Equity is a key notion here.

Question 04 - Who pays?

ANSWER:

Health care services should at a minimum take notice of the information/results that an individual presents and provide information about its particular clinical relevance or lack of it.

Question 05 - Your experiences

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ANSWER:

If it would be available in my country I would consider making use of it. Most important criterion would be that I myself would be the keeper of the record and holding the key to allowing access.

Question 06 - Your experiences

ANSWER:

Any information on the web may under circumstances lead to diagnostic use. This can range from scientific PubMed literature search to patient blogs.

Question 07 - Your experiences

ANSWER:

Till now I never did. It could be useful in case of pharmaceutical products that are not available in my own country.

Question 08 - Advertising health care products

ANSWER:

I think that prescription drugs should not be directly advertised to consumers. Pharmacotherapy decisions are complex and the consequences may be profound. Even for physicians it is hard to judge the evidence for effectiveness and relate it to safety (in general and for a particular patient) and it is well-known how hard it is for professionals to deal with the pressure from pharmaceutical industry with often aggressive marketing of products. Lay persons will usually not be able to decide about prescription (= non-trivial) pharmacotherapy. DNA profiling and body imaging are a very different type of services, as there will no direct and irreversible physical harm result from it. (except in the case of radiation damage, invasive procedures as mentioned before).

Question 09 - Your experiences

ANSWER:

For some purposes I would use it, as it will be as good as face-to-face

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consultation, it saves time and effort and it offers the opportunity of consulting top-experts even if far away. It seems very useful for an (second) opinion on images, all kinds of test- and lab results, incl. genomics data.

Question 10 - Who pays?

ANSWER:

Yes, of course it should! That is the logical extension of the classical duties of physicians in modern times. Due care is always context-dependent. If telemedicine is possible, it should be available whenever needed. Extra costs should be included in overall negotiations for primary care reimbursement. Note: this is very different from elective consultation of experts abroad on the initiative of individuals.

Question 11 - Your experiences

ANSWER:

I have bought a PET-CT scan abroad. The information was very useful for the therapy decisions (surgery) that had to be made very urgently. The doctors at my 'own' hospital were very happy to have the information, however, it would have not been possible for them to offer these diagnostics for reasons of resource allocation. It would not have been covered by my insurance. The services of the radiologists abroad were excellent. The biggest drawback was the huge provision fee that had to be paid to the intermediary offering the arrangement of the procedure (100% of the net price of the diagnostics).

Question 12 - Regulation

ANSWER:

I think that it is good if there remain two tiers. However, this should be made very clear to patients/customers. One can buy products and services on the market - there will always be inherent risks and drawbacks, as with any product. One can seek medical help (information, diagnosis, treatment) in the established health care system - that 'product' should have a very special 'state approved quality' tag on it. It is not hard to see that that has particular benefits, but at the same time one needs to accept the limitations of (a) the equal distribution of public goods, and (2) the professional, political and normative (incl. possibly moral) restrictions that go along with it. Post-marketing monitoring and surveillance are very important in either case.

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Question 13 - Responsibility for harm

ANSWER:

No, providers should not be responsible for the follow-up by users. To my knowledge, there is no clear evidence so far of 'disasters' resulting from this particular type of information. BTW, such concerns were also raised as DIY pregnancy tests became available. Till then, it was tacitly assumed that only medical professionals (doctors, in some countries pharmacists) could 'take care' of disclosing to women their being pregnant or not. No increase or decrease in 'disasters' has been reported since the market introduction of home-kits. There are many vulnerable women for whom the test result has dramatic impact.

Question 14 - Quality of information

ANSWER:

In principle, the client should be aware / made aware of the limits of the usefulness of the product. In many cases, DNA profiling and body imaging may be of little or no use from a clinical point of view. However, for many people that is not a reason not to purchase it. It is not unlikely that companies - commercial providers of diagnostic services - will develop quality criteria that apply to their circles. Just as hotels, airlines, real estate agents, and exterminators have defined quality labels and may organize in quality chains etc..

Question 15 - Other issues

ANSWER:

With all these topics (DNA profiling, body imaging, tele-medicine etc.) the global / cross-border aspect is of particular relevance. How to deal with that? People can and will (and should be able to do so, in my opinion) buy products and services at the global market place. What does it mean for 'local quality'? In my opinion, this would deserve a positive approach, as it is a challenge and it can offer national health care systems and its professionals a new profile of high-quality services that come with state oversight and guarantees. But it also comes with a price - people should decide for themselves if they are willing to pay for that.