

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.

Question 1 Health care as a consumer good

If an increasing number of medical products and services are becoming available as consumer goods – that is to say, as commodities which customers may choose to purchase provided they can meet the costs (see Annexes 4 and 5) – is this development, on balance, desirable? **Yes**

If yes...

In what ways do you think the positive consequences outweigh the negative ones?

In a world where the NHS is finally supposed to be "patient-centred", it is unlikely that there could be a philosophical reason for refusing access to such new commodities. The financial arguments against making more and more products and services available on the NHS will be debated elsewhere. However, if commercial providers are willing to offer such goods, and patients are willing to buy them, I do not see any argument, apart from some paternalistic ideas, against availability. Any arguments about not understanding the results would be down to the product providers and their customers to resolve. Some 'health warnings' may be necessary, but it is not for others to prevent that relationship developing. If the goods or services are 'snake oil' then the press will no doubt do its work in exposing such quackery.

If no...

In what ways do you think the negative consequences outweigh the positive ones?

Question 2 Validity of information

While much health related information is freely available to individuals, this varies greatly in quality and accuracy. Many of the lifestyle and health books and magazines that are currently available may contain medical information that is misleading or even incorrect from a scientific point of view. Do you think that information provided by DNA profiling and body imaging services raises different questions and should be subject to different regulations? **No**

If yes...

What are the grounds for restricting access to DNA profiling and body imaging services that may also have limitations in terms of scientific validity and clinical value?

If no...

Why do you feel that DNA profiling and body imaging should be freely available to those who wish to receive it? Would you favour regulation of the information appearing in lifestyle and health books and magazines? And if so, what sorts of information in particular require regulation?

DNA Profiling and body scanning are similar to other services in many ways. The basic medical understanding of the 'masses' is low and quacks have always sought to exploit this. Even today, most fashion conscious women probably believe that there are two kinds of fat – ordinary fat and cellulite. Mathematical understanding is similarly low – so few people seem to understand percentages and probabilities. Either understanding will increase or people will be confused by the expressions used. It would be difficult to regulate this kind of information. Let the buyer beware has always been appropriate.

Question 3 Prevention

Many governments argue that every individual has some responsibility to look after their own health, in their own interest and that of society at large, for instance in matters of lifestyle and diet. Do you think such individual responsibility should extend to the use of DNA profiling and body imaging services such that people in some circumstances should be expected, encouraged or obliged to have such tests? **No**

If yes...

What are those circumstances, and what should be the nature of such encouragement (for example: information, persuasion, financial incentives)?

If no...

Do you think there are other, more appropriate ways in which people can take personal responsibility for their health, and if so, which? In cases where early diagnosis of disease and subsequent preventive action can reduce later costs of treatment, but people choose not to find out whether they need to take preventive action, is it acceptable that the higher costs for later treatment are paid for by taxpayers or those contributing to health insurance schemes?

Individuals have responsibility for looking after themselves and this includes healthy living. The phraseology of the question was strange. Individual responsibility does extend to these techniques if the person wants to use them. However, I cannot imagine a scenario where a doctor would recommend a patient use either technique at the patient's cost, any more than A&E would expect a patient to have an X-ray at a third party's premises at the patient's cost. Certainly the ideas of obligation or coercion would be inappropriate. In a circumstance where a doctor disagrees with a patient's self-diagnosis

and refuses to refer the patient for a second opinion at the doctor's (or NHS) expense, it is possible that the doctor might suggest buying such a service at the patient's cost, but this would not be construed as encouragement – simply a way of offloading the cost back on to the patient.

Question 4 Who pays?

Many DNA profiling and body imaging services (see Annexes 4 and 5) are paid for privately by the individual. However, positive findings may lead the individual to seek publicly funded services for follow-up diagnosis and treatment. Should public services be expected to fund such follow-up? **Not necessarily.**

If yes...

Under what circumstances should such funding be provided (for example: in all cases, only if the tests meet certain criteria, only for certain conditions)?

If no...

Should publicly funded health care services impose fees for such follow-up diagnosis and treatment (for instance by charging patients or by levies on private providers of body imaging and DNA profiling services)?

A GP session would be available to cover concerns raised by such tests or scans, in much the same way as a GP would help to allay fears over genetic diseases found in family members. If the GP considers such fears worth investigation, then the NHS would provide the resources in the usual way; if not, then the private health care option is always available at the patient's cost.

Electronic health records

The internet is used by more and more people. Although not all population groups use the internet equally or for the same purpose (see Annex 1), it is used widely and increasingly for access to diagnostic information, for purchasing or providing drugs and other health care services, and for storing individuals' health records (see Annex 2 for more information).

There are two main types of electronic health records. Private providers such as Google Health¹ and Microsoft HealthVault Records² are offering these services with the claim that they will enable people to manage their own health information. Public health care systems are also seeking to develop

¹ See: <https://www.google.com/health/>.

² See: <http://www.healthvault.com/Personal/index.html>.

electronic patient records – in the National Health Service (NHS) this has been argued for in the name of medical efficiency, but also because it will give patients “more control of their own healthcare”,³ as the House of Commons Health Committee has suggested (see Annex 2 for more information about providers of electronic health records).

Question 5 Your experiences

Have you used online health recording systems such as Google Health? **No**

If yes...

What led you to do so and how would you evaluate your experience?
Which aspects did you like especially, which ones did you dislike?

If no...

What factors would influence your decision whether or not to use such services in the future?

I see little point in having incomplete healthcare records. Recording the data would have to involve GPs and hospitals. However, I strongly believe that such data should be under the patient's control.

³ House of Commons Health Select Committee (2007) *The Electronic Patient Record – Sixth Report of Session 2006-2007* (London: The Stationery Office) p.3.

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Question 6 Your experiences

Have you used online sources for diagnostic purposes, for instance those provided by government agencies, patient groups, commercial companies or charities? **Yes**

If yes...

Which services have you used, what led you to do so, and how would you evaluate your experience? Did you find the service useful in providing the information you were looking for, leading to better care or empowering you when talking to health care professionals? Or did it have some negative effects?

I have only used the Internet once for such self-diagnosis. This involved searching out information on whooping cough. Unfortunately, because the medical establishment does not seem to recognise whooping cough in adults and immunised teenagers, the result was frustration with health professionals. Fortunately, the symptoms were not that serious and we just suffered for a few months. The clear 'whoop' was amply demonstrate to friends and family but never arose when a doctor was around. If we had realised earlier that blood tests might have helped diagnosis, we would have pushed for these. However, this is perhaps an unusual case and not entirely useful in this discussion.

If no...

Under what circumstances if any would you consider using such services in the future?

Question 7 Your experiences

Have you purchased prescription drugs over the internet? **No**

If yes...

What led you to do so and how would you evaluate your experience (for example, in terms of convenience, facing risks of obtaining the wrong or poor quality drugs, lack of medical supervision etc)?

If no...

Under what circumstances if any would you consider doing so for yourself or a relative or friend?

I would have to be very clearly convinced that such websites were truly legal, honest and decent. The wealth of counterfeit drugs available on-line is truly frightening and the reports of poisonous

products are very disturbing. Trust is of paramount importance on-line. Why take the chance, when it could kill you?

Question 8 Advertising health care products

Do you think it should be permissible to advertise prescription drugs direct to consumers? **No**

If yes...

Should there be no restrictions whatsoever? Do you think that it should equally be acceptable to advertise DNA profiling or body imaging services direct to consumers (which is currently not prohibited in the UK, see Annex 7)?

If no...

What are your main concerns? Are you confident that access to drugs via GPs is a better alternative, ensuring that you will always receive the drug that is best suited to your specific condition? Do you think that advertising DNA profiling or body imaging services should equally be restricted or prohibited?

If prescription drugs are only supposed to be prescribed by a medical professional, I see no point (for the sake of health) circumventing that precaution. The idea that I do not agree with this prescription, therefore I shall get what I want in my way, seems a very childish approach. I can understand that, where a drug is not available on the NHS or in a particular locality (postcode prescribing), it can be very frustrating, but I would argue for using debate and complaint rather than the back door, with all the risks that that implies.

I have seen advertising for body scanning, though not DNA profiling. I do not see a problem with such advertising, providing the risks of the techniques (especially of CT scanning) are explained. Similarly, the caveats should be explained with the results, though this may best be left to the GP. Though the number of increased visits to doctors may be of some concern, I would consider it only limited and part of doing business in this age.

Question 9 Your experiences

Have you used information technology to access individual health care expertise at a distance? **No**

If yes...

Which services did you use, what led you to do so, and how would you evaluate your experience? Would you recommend it to others?

If no...

If you were faced with the choice of using such technology or undergoing the costs and/or inconvenience of travel over a substantial distance to access or provide those services on a face-to-face basis, what factors would affect your choice?

Telemedicine has distinct advantages in remote areas and especially in third world contexts. I could only really envisage being involved in those kinds of situations, though my own holidays are restricted to the European mainland where this is not an issue.

Question 10 Who pays?

Should remote access to GP services be provided through telemedicine for those in remote and rural locations? **Yes – if this lowers costs.**

If yes...

Provided this results in higher costs: should it be the patient or the public health care provider who pays for the extra cost of providing services this way, or should costs be shared in some way?

I would expect this to be very limited in the context of the NHS.

If no...

What are your reasons? Do you think some degree of unequal access to public health care is simply justified (for example, if individuals choose to live and work or retire in remote rural areas)? Or do you think that there are means other than telemedicine that are better suited to achieving more equitable access to health care?

Question 11 Your experiences

Have you used the services of a body imaging or DNA profiling company (see Annexes 4 and 5 for examples)? **No**

If yes...

What led you to do so and how would you rate the services of the company? How useful was the information you received? Please indicate which provider and which service package you used.

If no...

If you were thinking about using such services, what information would you want to receive in advance and what kind of information would you find most useful to receive after the profiling?

Some basic information about the methods used and possible results would be useful, along with clear costs.

Question 12 Regulation

Do you think it is satisfactory for DNA profiling and body imaging services to have to pass stringent evaluations before they are provided in the NHS, but for them to be readily available on a commercial basis without having to go through such evaluations? **Yes**

If yes...

Why do you believe more stringent evaluations are required in the public sector than in the private sector? If commercial DNA self-profiling products were to be developed in the future, enabling people to profile themselves (or others) whenever they want, do you think any legal, regulatory or other restrictions should be imposed beyond those applying to existing self-profiling products, such as pregnancy testing kits?

Provided the tests are known to be safe, the criteria for the public sector usage are more about cost.

If no...

Do you think the NHS requirements should be less strict, or that more regulation should be imposed on private providers? What measures would you consider most suitable? For example: disclosure requirements such as labelling rules; voluntary codes of conduct or 'kitemarking' arrangements; legal requirements to restrict market entry; restrictions or bans on advertising; tougher penalties for breaches of established rules; or stricter post-market monitoring and surveillance.

Question 13 Responsibility for harm

The results of DNA profiling and body imaging may lead people to seek appropriate treatment. But it may also lead to harmful actions, such as inappropriate self-medication, or people may become more fatalistic, believing that there is no point in altering their lifestyles. In the most extreme cases some people could become suicidal as a result of the predictive information they receive. Should providers ever be held responsible at law for such harms? **No**

If yes...

In what circumstances? Should providers of other services such as pregnancy tests also be held responsible for what distressed or misinformed individuals might possibly do with the information they obtained?

If no...

How, if at all, do you think the interest of vulnerable groups should be safeguarded?

Health warnings would be one way to police this. Giving patients some kind of intelligence test beforehand is not likely to work.

Holding companies responsible for how people feel about the results is a waste of time. Perhaps providing counselling for each test could work, but the Government ruled it out in abortion clinics, where it could easily be shown to be useful.

Question 14 Quality of information

Some have criticised current commercially-available body imaging and DNA profiling services for giving information that is of limited quality and usefulness. Do you think more should be done to improve the quality and usefulness of body imaging and DNA profiling services? **No**

If yes...

Who should pay? Should there be publicly funded investment, or should private companies be left to develop better methods?

If no...

Is it sufficient to rely on the so-called 'buyer beware principle' in such cases, by putting the onus on the purchaser to find out about the quality and associated risks of the product they are buying?

Caveat emptor is the only way forward – the Government has enough problems funding the NHS, without trying to regulate a market which may or may not develop.

Other issues

Question 15

Are there any other issues we should consider?

The safety of the techniques should be a concern of Government. Only techniques of proven safety, within appropriate limits, should be allowed to advertise. Obviously, policing advertising on the internet is a problem but the idea would be to make it clear that certain techniques are safe – those that are not endorsed on a particular NHS webpage would be considered unsafe. Obviously, where certain tools are already used within the NHS, they would be considered safe but there may be limits to how often a technique should be used, as there have been with X-rays for some time.