

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?

If yes...

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

If no...

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

I believe that commodifying such items should place a legal burden of responsibility on the provider to ensure that the purchaser has full capacity to understand and appropriately use the service. Since that would massively reduce the profit for the providers I think it likely they would evade such responsibility. In such circumstances I believe the exploitation of ignorant people through misleading advertising is very likely. The benefits are limited and the possibilities for mischief infinite.

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?

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?

See Above. The technical knowledge as to the benefits of such investigations is beyond that of the non specialist. Having the tests without a good clinical reason will not reassure the hypochondriac and may falsely reassure the uninformed without the necessary

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understanding. The both constitute opportunities for the commercial exploitation of health anxiety.

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?

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?

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?

The greatest contributor to ill health is financial and cultural inequality. The responsibility for reversing that rests clearly with the government and with the richer members of society who can easily afford additional health care. People should be encouraged to take personal responsibility but none of us are able to read peoples motives or the drives/deficiencies that lead to unhealthy behaviour. In such a situation I do not believe anyone

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has the right to exclude others from healthcare unless they constitute a direct risk to those providing that care.

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?

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)?

Clearly all minor abnormalities cannot be included but as a general rule those abnormalities that have significant, remediable or manageable health implications should be made available through the health service. The mode by which a person becomes aware of a significant condition should not restrict the availability of help free at the point of delivery.

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)?

Question 5 Your experiences

Have you used online health recording systems such as Google Health?

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?

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Privacy, Privacy, Privacy. I don't trust Google and I don't trust ANY government department to safely look after everything that I tell them.

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?

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?

NHS direct several times – always helpful. No negative effects.

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?

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?

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I wouldn't. There is no way to guarantee the integrity of the drugs provided.

Question 8 Advertising health care products

Do you think it should be permissible to advertise prescription drugs direct to consumers?

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)?

No

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?

False representation, lack of protection, high likelihood of deliberate deceit. Although there are sometimes such problems with prescribing doctors I think the likelihood is much lower and there are remedies through professional certification and the law which will not be available through these other systems. The right to free choice is no use to a person terrified or poisoned by that choice.

Question 9 Your experiences

Have you used information technology to access individual health care expertise at a distance?

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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?

So long as one can have confidence that the person is who they say they are I would have no problems with telemedicine.

Question 10 Who pays?

Should remote access to GP services be provided through telemedicine for those in remote and rural locations?

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?

The public purse should bear the cost – free at the point of delivery. It would be a lot cheaper than sending out a doctor.

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

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Have you used the services of a body imaging or DNA profiling company (see Annexes 4 and 5 for examples)?

Never.

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?

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?

No – all should be stringently registered.

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?

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.

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I don't know – too complicated. But equality of arms is the default position

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?

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?

The same circumstances as in the NHS. Duty of care is the basis of the argument.

If no...

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

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?

If yes...

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

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I see no need to encourage the development of these services at all for the reasons given above. If a decision is taken that their continuing existence is proper then they should be required to provide information and support at the same level as state funded systems. Bleating about commercial viability should receive a very dusty answer; they are there for the shareholders, not the public – who therefore need statutory protection.

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?