

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:

I think this is a negative thing - this development is not desirable. I have a chronic health condition and speak to others with this condition in other countries. In the US where this is the norm, and drugs are advertised on TV, there are many people in terrible trouble because they cannot afford their medication. If this situation does occur I believe that the price should be determined by an independent body - not including anyone from a pharmaceutical company or anyone who could be perceived as benefitting financially from the sale of medicines - and the price they agree must be adhered to. I think it is immoral for a company to make profits from sick people and it is wrong that rich people would be able to afford better treatments than poor people.

### Question 02 - Validity of information

#### ANSWER:

I think there are grounds for restricting access to these sorts of services. They can make people very afraid and possibly make them think they need expensive treatments when they in fact do not. These treatments medicalise healthy people.

### Question 03 - Prevention

#### ANSWER:

I think there are more appropriate ways in which people can take responsibility - common sense ways such as exercising, eating a balanced diet and not driving their cars unless it is really necessary. I do not believe financial incentives are

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appropriate - these must eventually be withdrawn and if the only reason people were having a healthy lifestyle was for the money, then they would go back to their bad habits when the money was withdrawn. Information is important but it MUST be non-judgmental. If it is presented in a judgmental way people will not accept it. The information must be presented along with whatever support is necessary for the person to make the lifestyle change. I think it is acceptable for the taxpayer to pay the higher cost for later treatment - if they do not the only alternative, taken to the extreme, is a society where everyone only pays for themselves and there is no communal feeling - no health service, no welfare state, no public parks or libraries. That would be an awful place to live since nobody would care for anyone except themselves. I think the NHS, for all its imperfections, is incredibly valuable and it is so important that the principle remains that people pay for each other. Once you start down the road of not paying for the obese, for smokers, for people who do dangerous sports... where do you stop? Almost everything that lands people in hospital could be said to be self inflicted in some way. If you are paying in taxes for others but you are healthy yourself and do not use the health service, you should feel very lucky, not mean and stingy. If you have perfect health you are a very lucky person. You don't know when some condition or accident will strike you and you might have need of the health service you did not want to pay for.

#### Question 04 - Who pays?

#### ANSWER:

In general I would say that the state should pay as that is the principle of the NHS. If the individual consults a doctor and the doctor deems it necessary to perform the follow-up service, then yes the NHS should pay. I object to charging patients.

#### Question 05 - Your experiences

#### ANSWER:

I have not used these systems. If I was to use them in future I would need to be 100% sure (in the case of private services like Google Health) that the company

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did not use a targeted ad service like Phorm. I would not want my private health information to be used to push products at me. I would need to be sure that my information would be 100% private and would never be seen by anyone except me without asking my permission first.

#### Question 06 - Your experiences

##### ANSWER:

Yes I have. I wanted some reliable advice on my health condition. The main thing influencing me was the unavailability of doctors outside work hours. I would have gone to the doctor if I could but I cannot get an appointment with a named doctor within several weeks at my surgery, and emergency appointments can be unreliable since you don't know the doctor, there is no continuity of care and no guarantee they will listen to you or be sensitive. I have found the NHS Direct site helpful with general problems, eg burns and flu. But with problems specific to my health condition it is not good. I rang the NHS Direct phone line and the doctor would only give me very general advice. It was also very frustrating since I was passed to 3 or 4 people and had to tell each of them lengthy personal information before I spoke to a doctor. I was very ill at the time so the experience was even more frustrating.

#### Question 07 - Your experiences

##### ANSWER:

I would not purchase drugs online. I get free prescriptions so there would be no point in paying for the drugs online. I would definitely not purchase drugs online for a relative or friend.

#### Question 08 - Advertising health care products

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**ANSWER:**

I do not think it should be permissible to advertise prescription drugs direct to consumers. I am not confident that GPs have my best interests at heart all the time - they often choose a generic or cheaper drug rather than brand names, for example. But I think their involvement is important as despite the cost problem, they will try to get the best drugs for patients. I think advertising DNA profiling or similar services should also be prohibited.

**Question 09 - Your experiences**

**ANSWER:**

I have not used these services. But if I had the choice I would use them. It would be much more convenient. Provided my work had the facilities, I could go to a private room and have my consultation there. Travelling to the doctor is a big problem for me since it means more time off work. It often means that I have to take whole mornings or afternoons off work when the actual consultation is quite short. And appointments are only in work hours so it means large amounts of time off work. Another factor with travel is that if the bus is delayed even by a few minutes, my appointment is cancelled. Telemedicine would avoid that.

**Question 10 - Who pays?**

**ANSWER:**

I think, as I have said in previous questions, that NHS care should be free at the point of use and that charging patients is wrong. I think there must be ways of saving money in other areas (eg GP salaries) in order to afford this type of important healthcare cost.

**Question 11 - Your experiences**

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**ANSWER:**

I would want to know how accurate the results were - eg if they found a gene for something, how likely is it that the gene would cause the condition? I would want the service to be approved by the NHS or another reliable body. I would want to know it was a not for profit organisation - I object to people making profit from peoples' fear and illness.

**Question 12 - Regulation**

**ANSWER:**

I think more regulation should be imposed on private providers. A voluntary code would not be good enough - it would have to be compulsory. Advertising should be banned. Breaches of rules should result in the service being banned until it could show clearly that it was acting within the rules for a set period - ie they couldn't just make a temporary bodge to get past the rules. Labels should be clear and comprehensible to a layman - no hiding things in fancy technical jargon.

**Question 13 - Responsibility for harm**

**ANSWER:**

This is a difficult line to draw. I think the providers should be able to demonstrate they have acted in a responsible way - eg, making it clear how likely a gene is to lead to a medical condition, having some counselling prior to the imaging/profiling to determine if the person is psychologically stable enough to undergo it and support afterwards. If for example several close relatives of a person have had a form of cancer and passed away, and that person is finding out if they have the gene for that cancer, the person should be given counselling

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by a qualified professional. There is also a responsibility on the patient to disclose that sort of information and tell the company whether they have had any sort of mental health issue in the past which could affect them when they receive the results. If the company are not aware of a mental health condition or family experience, and that then leads the person to some sort of harm, the company cannot be held responsible if the circumstances were not disclosed to them beforehand. Any publicity material should not be scaremongering or distressing or likely to trigger any negative feelings.

#### Question 14 - Quality of information

#### ANSWER:

There is some responsibility on the purchaser. But the seller should be able to prove they have done their best to provide useful and good quality results.