

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: individuals have differing personal values which define their choices and perceived needs in everyday life and their tolerance of risk in calculating risk taking behaviours - hence these differing personal values of acceptance of medical risk equate to some persons needing greater reassurance to maintain their holistic "mental health". However if true quantities of risk and benefit are not presented in a format the "consumer" understands this arrangement of having these products and services available as consumer goods is nothing worse than the actions of a confidence trickster

Question 02 - Validity of information

ANSWER:

Yes: a line needs to be drawn to clearly mark out and define what is "clinical advice" and that which could be defined as popular comment or journalistic comment

Question 03 - Prevention

ANSWER:

No: duress to undertake medical tests would be reminiscent of Nazi Germany and seem like the beginnings of "Big Brother: 1984". Where genetic factors could be clearly rectified, corrected or modified people should be given information and the opportunity to seek testing via organisations such as the NHS that consider "public health" rather than profits. Individuals must be allowed to exercise choice as best suits their individual acceptance for their personal toleration of risk and uncertainty

Question 04 - Who pays?

ANSWER:

Yes: however people should not be able to queue jump stages in a normal "NHS" wait. We do not want to see that the rich buy key slow stage tests but return to the public sector for other elements or follow up. For example: I believe that within Fife in Scotland the orthopedic service operate under the principle that the wait in the NHS is the same for everyone. Even if some one is diagnosed privately with arthritis and is deemed as needing a replacement knee

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joint operation. That person once they enter the NHS has to join the back of the queue and progress through the very same stages and wait as everyone else - they are unable to by-pass the time consuming early stages and jump straight into a public funded operation having undertaken part of the process privately.

Question 05 - Your experiences

ANSWER:

No: the factors that would influence my decision would be: security, speed of access and speed of the process (internet connexions can be very slow within the NHS with many computers serviced through one IT department), reliability of connexions as well as software, good training provision, and finally I would only use it if it had universal use and acceptance by the medical profession

Question 06 - Your experiences

ANSWER:

Yes: Unfortunately online flow chart assessments such as those that patients can take with NHS24 online have not yet developed to a level that equates to a medical opinion. Understandably they have to err on the side of caution. This inevitably means large numbers of people may be unnecessarily seen face to face in inappropriately urgent appointments.

Question 07 - Your experiences

ANSWER:

No: I would never do this as part of the process is the advice received by the doctor administering the prescription

Question 08 - Advertising health care products

ANSWER:

No: There is always a bias in the presentation of information. Adverts use not only written or spoken words to convey messages, they use a variety of other techniques with visual images and voice tone and a number of NLP (neuro-linguistic programming) techniques that serve to give a pseudo-hypnotic or trance like suggestion to the viewer or listener. A better option would be for drug companies to pay into a fund run by SIGN and NICE that would develop adverts on the companies behalf with their inhouse advertisers to create an appropriate information "advert"

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Question 09 - Your experiences

ANSWER:

Yes: I have used online x-rays, blood results, emailed consultants for opinions and telephoned consultants for advice as a doctor. I have also undertaken telephone consultations with patients for simple problems but always have the opportunity to convert a telephone call with a patient into a face to face discussion

Question 10 - Who pays?

ANSWER:

Yes: Telemedicine will always be inferior to face to face medicine. Remote areas should aim for an equal access to medical provision compared to that found in cities. Otherwise we may see a health migration to the cities.

Question 11 - Your experiences

ANSWER:

No: 1) true reliability, sensitivity and specificity of results 2) Films such as GATTACA take this to one extreme of a possible outcome 3)How would a "consumer" be counselled on the out come of the test - or would the NHS have to pick up the pieces for people distraught from a postal result?

Question 12 - Regulation

ANSWER:

No: The product should be consistent and reliable through all sources

Question 13 - Responsibility for harm

ANSWER:

Yes: if a pregnancy test fell below the advertised accuracy level due to fault or misinformation the manufacturer should be held responsible. Surgeons must gain informed consent and discuss risks before operations. These DNA profiling and body imaging tests should have the same safe guards

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Question 14 - Quality of information

ANSWER:

Yes: both private and public organisations should have a vested interest in improving services

Question 15 - Other issues

ANSWER:

1) who "owns" genetic/body scan reports? - the patient, the company providing the test, the NHS 2) all test results should be legally obliged to be recorded in NHS notes in a standard format to enable comparison and interpretation 3) who owns a "genetic profile" or a "genetic code" if a company sequences my particular eye colour (or my personality?!) do I "own" that code or profile if I ever needed it regrown (assuming advances in science) or would that company own it for eternity? Could the company sell my traits/organs created from my genetic code to other customers? 4) who can share an individuals test results - i.e. data protection law extension? 5) in the event of a company going "bust" should information be taken over by a government/NHS organisation or can another company buy it? If a company can buy that information will it be only for UK companies and would the information only be stored in the UK on UK patients under only UK law? 6) should these companies be inspected by the Care Quality commission (as is the standard for NHS organisations)? 7) should all tests and protocols and methods of relaying results be approved by and ethical committee?