

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:

Essentially yes. Blurring of the distinction between public health and medical treatment aimed at the individual is one of the main changes in health care in recent years. It has become increasingly blurred with the introduction of government targets and as resources are aimed at community > individual. Allowing patients to access treatment/tests based on individual need (as opposed to perceived group need) helps to restore that balance. Clearly there needs to be some level of control and licensing - quality issues, cumulative risks (e.g. x-rays), information sheets etc... This would be in line with other commodities e.g. food safety. Perceived need by the individual will vary on a host of personal factors (need for prompt return to work, social pressures etc.). Issues around "social justice" are a concern, but individual health "benefits" based on an ability to pay are already widespread. In this context "medical" care should perhaps include e.g. physiotherapy and private payments are one way of helping to keep adequate numbers of trained physiotherapists.

Question 02 - Validity of information

ANSWER:

Yes. As recently described, it is possible to obtain DNA profiling on a third party without that person's consent. This is unacceptable. The implications of profiling of children at the request of e.g. a parent would also need to be carefully thought through. Dilemmas arising from equivocal tests/false negatives need to be resolved by the provider of the service (perhaps with the help of attached counsellors) rather than the NHS. One of our greatest health problems is that people find it very difficult to live with uncertainty - it often lies behind the request for a test. There also needs to be an ongoing record of tests involving irradiation. Providers of imaging services should not try to "cover" themselves by simply raising possibilities and suggesting further tests unless these are clearly appropriate. If the test is unsatisfactory for technical reasons they have some obligation to repeat free of charge. Information should be vetted but since the NHS screening programmes tend to overstate the value, underestimate the drawbacks and put pressure on individuals to take part, it might be difficult to be too critical about advertisements for the private sector.

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Pre-testing counselling should include about effects on life insurance etc...

Question 03 - Prevention

ANSWER:

No. This answer also covers some later questions. Currently much of the screening provided is not adequately evidence based and/or is used inappropriately e.g. using age as a basis rather than individual risk factors. (Screening all males of a certain age for abdo aneurysm -AAA - but not high risk females is perhaps an obvious example). The cost of prevention screening and early operation can often outweigh any overall financial saving of non-prevention. Higher risk individuals who are outside the criteria chosen will be disadvantaged as resource priority is directed to those meeting the chosen criteria. This happens for example with some cancers when the guidelines for rapid access are implemented but many patients present outside the guidelines. Political gain or response to particular pressure groups seem to be responsible in some instances. NHS facilities are stretched increasingly to pay -financially and in resources - for the care of lifestyle diseases, particularly those related to obesity and alcohol. Smokers were at least financially neutral for the UK - earlier death and tax etc - despite the studies showing the NHS "cost" for smoking related disease. Total cost to Society should also be considered not just NHS costs. Obesity and alcohol abuse have much in common - both have a genetic loading, both have major social and NHS implications and with both the individual has to take control for effective treatment. Society needs to adopt a similar approach to that adopted towards smoking. Taxation could be used, increasing the tax on alcohol and outsize clothes etc... These are issues for Society not Medicine, but the costs of obesity to the NHS need greater emphasis. It could be argued that if the majority become obese then it is appropriate for the NHS to provide care without comment, but by condoning obesity perhaps Society is failing in a moral duty? It would be unreasonable with most screening programmes on adults to expect a payment from those opting out. Screening is very different from, for example, vaccination, in its potential benefits for the individual rather than individual and community. The whole area needs re-thinking. Apart from detecting new disease we also need to consider those disease where early treatment may help stop progression - early rituximab for rheumatoid arthritis may prove an example. As a recently retired hospital specialist I have not opted into screening programmes which many would see as "reasonable" for me but where I have serious doubts about the overall value. There needs to be greater integrity in looking at the cost of screening programmes - unnecessary treatments, false positives and long term costs to

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the country etc... need to be weighed in the balance , as well as the inconvenience and anxieties raised. Of course one could give the cost of the screening to the individual who chooses not to have screening but take the money back if he then develops the disease in question....

Question 04 - Who pays?

ANSWER:

See earlier comment. Yes. In some instances there will have been a failure of resources or competence by the NHS and the privately funded test has produced a positive test showing significant disease warranting treatment, possibly urgently. In some centres roughly half of patients with certain cancers will present outside the guidelines for rapid access - and these patients may have been disadvantaged further as they will be pushed down the waiting list by those seen as "urgent" (despite many being a very low risk). At the other extreme, inconclusive results and reports can be an undue burden and the test centres should be responsible for initial counselling and possibly further tests to help resolve uncertainty. This is an area that needs to be explored more fully as I do not think we have adequate data currently and there are a number of alternatives.

Question 05 - Your experiences

ANSWER:

No , but see these as having a place for holding data which I choose to be held. Particularly as regards advance decisions /directives, I have been looking into opening an account with one of these systems and see them as preferable to the proposed NHS database. The Firm MedicAlert could develop its services in the UK. Although my own medical records are very thin I object in principle to the proposed NHS centralised "spine" with real concerns about how the information may be used in future and see this as not primarily aimed at individual care.

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Question 06 - Your experiences

ANSWER:

Yes : both for self (patient a number of times) and in my work as a hospital doctor. Sites for the most part accessed through Google or e.g. Medline. In general I have found these an excellent resource. Often pretty obvious which sites are poor/ motivated by ulterior motives. Informed consent at hospitals is often something of a misnomer and internet searches better value in terms of what to expect and recovery/physio treatments. I have always encouraged patients to carry out searches and to let me know if anything comes up with gives them concern etc... For an operation I had earlier this year, I did a fairly detailed search and could obtain information not forthcoming from my "carers" and also realised some of the gaps in the "evidence" for the value of the procedure. For a previous operation (orthopaedic) I used the net to provide my physio-therapy regime - and was fully active again some months before the normal expectation. The prompt surgery would not have been available through normal NHS channels. On a 10 year follow-up from another orthopaedic procedure I seem to have had a brilliant response but gather it is not now available in the NHS. In both these instances the failure of the NHS approach would seem to stem from poor patient selection in the trials rather than just from ineffectiveness. Some of the patient group websites are quite outstanding. I used to be a medical adviser to a major patient group and am very aware just how poor is the information provided in some clinics. I have ambivalences about and have not yet used - on-line pharmacies: partly quality issues but also clinical. I think the range of drugs now available in the UK off prescription has been a major advance. On occasion I have taken OTC drugs at a prescription dosage. I deplore the negative attitude of many doctors in trying to discourage this trend to increase drugs available OTC and question their motives. I have some misgivings about OTC antibiotics but find pharmacists are often more critical in providing them than some doctors. I would rather expect patients to have at least tried OTC remedies.

Question 07 - Your experiences

ANSWER:

No - but because lack of need and my uncertainties about purity of compounds available. In general in recent years the range of drugs available in the UK OTC (over-the-counter) has become much wider. It is easy enough to increase the dose to one which might be recommended medically - but might prove expensive if taken regularly. Similarly drugs needed for a travel pack can often

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be obtained from a GP on a private prescription. GPs are under much pressure to restrict prescribing of certain drugs and I can envisage circumstances where I might be tempted to obtain these over the internet for a specific indication. In some countries UK prescription only drugs are available OTC and my experience of those buying drugs in this way has been that it has been done appropriately and responsibly. As with most drugs the few who abuse the system will dictate what happens. At least if someone takes something bought over the net in this way, it is their responsibility and perhaps we should accept that. People buying a knife may cut themselves.

Question 08 - Advertising health care products

ANSWER:

No, but ambivalent. Some of the advertising I have seen abroad on television has been responsible but much of it seemed inappropriate. In general I think the informed patient can access information about new drugs and treatments from several sources and the ill-informed are likely to be misled by some of the commercial claims. Good patient groups can play a crucial part and with adequate guidelines now it is relatively unlikely that prescribers will be greatly ill-informed. With qualifications as outlined earlier I have no objection to imaging centres (or private health insurers) advertising but the adverts really do need scrutiny about just what is on offer. I have had serious misgivings about some of them. Genetic variation in drug metabolism is a fascinating area but sometimes its practical (as opposed to scientific) value is overstated and all that is needed is care in prescribing and assessment of response +/- blood levels. Yet I have known of doctors who insist on genotype assessment even where the evidence suggests it is not needed. Not a responsible use of resources and in these circumstances it would seem reasonable to ask the patient to pay. This is very much a "watch this space" area and is likely to be crucial for some drugs.

Question 09 - Your experiences

ANSWER:

No* but I have consulted (as a patient) by telephone. I would have no objection to using IT technology in this way. Much depends on why I was seeking an opinion - for "technology" / identification of e.g. skin lesion or for an ailment where interaction, attitudes and non-verbal clues etc more relevant. In general

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would prefer not to travel - but would also be influenced by what I knew about the "specialist" at the other end. 30+ years ago I tried an early computerised diagnostic programme in a research institute. I did not like it and disagreed with the answer given - time showed that the computer was quite correct! Also some experience of "tele-medicine" off site and its value in teaching.

Question 10 - Who pays?

ANSWER:

No. Mainly because many GP consultations need face to face assessment. Clearly a place if available but depends on the complaint. A home visit (not necessarily by the GP) might be more appropriate in overall assessment particularly for the frail elderly. In some remote areas (or in my case, not quite so remote) can have technical problems - poor telephone lines, no or limited broadband etc... Recent government plans may help to overcome this. For many years I have been irritated by those who moan about every case of so-called post code rationing - this has always existed for those of us in remote or semi-remote areas e.g. as regards ambulance response times , access to hospitals. Life has its inequalities - where we live has compensations which outweigh the inconveniences, but that may change. Our GP surgery is about 10miles away, but many problems can be resolved over the phone. I accept the cost of a visit (car or taxi) - no public transport - but the need to plan ahead for when I cannot drive.

Question 11 - Your experiences

ANSWER:

No. I might choose to body imaging services if I was felt these were clinically warranted but there was no local service or it was felt that I did not meet NHS guidelines. There might also be circumstances where I might want to have a preliminary result before seeking more formal medical advice or going to a hospital where I have worked for 30 years. Ideally, I suppose I would like a copy of the scan downloaded so that I could look at it and discuss with those whose opinion I trust. During these 30 years I have had several investigation lists each week and am aware there is an enormous gap in public awareness of what a test can or cannot achieve. Those with health anxieties need more than just tests to help to resolve the underlying problem when this is anxiety rather than a particular symptom.

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Question 12 - Regulation

ANSWER:

No. This is a relatively new area Testing should be carried out in NHS and private sectors with equal accuracy and with high standards of ethical practice. Private labs should be licensed and the system audited with penalties as seen appropriate. Where there is a new test then the potential inaccuracies should be discussed beforehand. If necessary the commercial sector should refer for outside counselling first. The difference is that the NHS should ration the service to those tests which have a clear clinical relevance. There needs to be a tighter code of practice as regards advertising. Competition between private providers should help to keep costs down but there might need to be intervention if there is evidence of price-fixing.

Question 13 - Responsibility for harm

ANSWER:

Yes BUT only where there has been marked negligence in the provision of the service (so perhaps my answer should be "No"). This raises a problem with much NHS or non-NHS testing . Since the probability of many test results is normality many patients and doctors have a "let's just check that everything is OK?" approach. Unexpected findings will sometimes come to light and the effect of these can be life-altering. This applies to almost all tests. Perhaps if a patient has a bad experience with his prostate biopsy when a PSA test has given an equivocal result then whoever has sought the test should have some responsibility. This may be the doctor - but sometimes it is the patient pressurising for the test. If the patient goes to a test centre on their own initiative then that is their responsibility - but one would expect it to be an approved centre which has a protocol for explaining the nature, purpose and limitations of the test etc....

Question 14 - Quality of information

ANSWER:

Yes There should be nationally approved standards of practice which are audited. Proof of these standards being maintained should be necessary for having a licence to practice. The private sector should budget for the cost of this in deciding on its fees. There could be a place for a division of expenses

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with some of the inspection being funded with public funds - for example if the private laboratory takes on subcontracted NHS work.

Question 15 - Other issues

ANSWER:

Private scanning and genetic testing is a fairly small part of overall health care. They can provide a useful safety valve for failings in the NHS - whether there is a shortage of resources or a misuse (e.g. inappropriate requests). We really need more thought about what we are trying to do in health care. There is a lack of adequate data in trying to assess the value of various screening programmes and of CT/MRI scans. Chosen outcome measures may not be those which most concern the patient. This also applies to the choice of modality for screening - for example some patients might prefer to have a virtual colonoscopy rather than going straight to colonoscopy, for reasons varying from fear of discomfort to convenience etc... The true costs are often underestimated and the benefits overestimated. Attempts to limit private access to these services is likely to be self-defeating as many of those involved will simply look to Europe, where high quality scans can be obtained at a much cheaper rate that would often cover the cost of travel. A one size fits all approach to health care is not appropriate. It is unclear that the use of private facilities will deprive the poorer social groups of health care - the extended NHS already favours the motivated middle classes. Just how one spreads equality of health care to the non-users is a separate and much wider issue which needs addressing.