

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 01 - Health care as a consumer good

ANSWER:

Yes this is desirable. Medical services have traditionally been organised around professionally defined structures. e-health/ personalised health, whatever terms you like, disrupts this approach and enables individuals to take greater responsibility for the management of their health. The specific delivery of services at present is organised around structural arrangements dating from the industrial era and reflecting organisational principles/management practices from the 1930s at least if we're being optimistic. By using modern technologies to disintermediate/disrupt this structure, new approaches to service delivery are possible. The negative/downside issues lie in two areas mainly. The first will restructure traditional professional knowledge and practice patterns, and the second is avoiding increasing the risk to individuals arising from this restructuring. Avoiding these changes, though, by maintaining existing patterns is hardly progress.

Question 02 - Validity of information

ANSWER:

There are no reasonable grounds for restricting individual's access to information about the state of their bodies or their health. To do otherwise is presumptuous at least and probably unethical. That a certain type of technology is involved is hardly a reason. As far back as 1911, and starting with the first and second official secrets acts in the UK, there have been legislative outcomes that have restricted patient access to information about health and health technologies. I take the view that one must approach the ethics of technology in a technologically neutral manner, that is to say, the features of the technologies themselves are not the focus, but the effects of the technologies and what it enables/provides. In that respect keeping patients from DNA profiling information is little different from not telling them their blood pressure. There is misleading medical/clinical information in standard medical texts and we know that evidence-based clinical practices diffuse very slowly, which of course means that some patients are not getting appropriate care. Having worked on the issue of patient access to health information over the internet for the Council of Europe (there is a recommendation on the subject you may wish to have a look at), I doubt there are good reasons to restrict access to information in general -- apart from the fact this is censorship -- as one is then faced with deciding which information to share and which not. I don't think we're able as

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humans to make these judgements for other people. Again, it is probably unethical to act on information that the patient doesn't know about. Separately, of course, we know that many visits to GPs involve people somatising their health states. But this may reflect anxiety, lack of knowledge, or efforts to get access to healthcare from a system that appears to prefer to ration it. If routine scanning, ECGs, colonoscopies, etc. were more easily available, and indeed upon patient demand, despite the view of GPs that they ought to decide, there may be greater individual understanding of the state of their health.

Question 03 - Prevention

ANSWER:

Undoubtedly it is both the individual's interests and society's that people can take whatever actions are appropriate to enable their better health.

Unfortunately in some respect, one of the founding principles of the NHS (free healthcare in essence) means that patients are insulated from the consequences of their own decisions about lifestyle and care. There are no costs (certainly monetary) to individuals who receive care, fail to alter behaviour and then seek additional care (e.g. smoking as an example). However, as the NHS moves toward greater use of profiling and subsequent allocation of healthcare services based on these profiles (whether from DNA or otherwise) it risks creating a system whereby people will seek to use profiles to receive greater healthcare as access to healthcare will now be linked to a defined entitlement, rather than a generally free service. This shifts the NHS toward an insurance-type model, but which fails to enfranchise individuals. People will then seek to game the entitlement system to get more healthcare. I did a paper for the Department of Health on this issue. The downside is that it monetises the entitlement (since it will sit within budgets linked to individual risk profiles), and people will then seek that to which they think they are entitled.

Question 04 - Who pays?

ANSWER:

The problem the NHS has it doesn't know how to integrate privately initiated healthcare with public provision. This calls for more serious understanding of

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how co-payment systems in insurance-based healthcare systems work. They seem to get good outcomes, equity prevails, and the system doesn't crash! The fail to create a partnership arrangement between the individual and their healthcare provider is caused by the construction of the NHS as a social good, rather than something that helps individuals to be healthy. The social overlay, and there is nothing particularly wrong with this, is that it leads to the situation where deserving individuals are denied care and who then seek to rectify the situation through their own initiative. The NHS punishes people for this, rather than seeking ways to collaborate.

Question 05 - Your experiences

ANSWER:

Yes. I personally like access to health records in a form of my choosing. In one of my reports, I noted that the value of patient-held health records is the notion that the patient is an 'auditor of one'; that is, they are fully committed to the information being accurate and up-to-date. The current Connecting for Health approach is a tired paradigm of a big government project that is what some what call as train wreck in slow motion. Just think of your own experience with credit reports, bank accounts, etc.; the availability of online banking for instance as led to a marked improvement in their accuracy and had the additional benefit of exposing the way that banks clear cheques resulting in their now virtually instantaneous clearing. Health records are little different. I looked at my health record and discovered an error which showed I had a condition only found in women; being male, I drew this to the attention of the doctor, who observed that it was obviously an error. But it was not corrected! Now, in the case of using predictive algorithms and data mining on electronic health records, one will want to ensure that they are accurate, the only way to really ensure that is that each individual owns and controls their records and can therefore ensure their quality. The effect on the health system would be therapeutic. I am also quite keen to explore how to access my health record through my mobile telephone and create a system that individuals can access my record from outside the country when travelling, in case this is required. The technology exists and is currently on trial in Germany. The NHS approach to health records though is insufficiently focused on meeting patient expectations by distinguishing between the whole record and a lesser version. This is just silly, but typical thinking.

Question 06 - Your experiences

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ANSWER:

Yes. I see no reason not to consult online resources for information. On the negative side, I would alert the committee of course to the problem of finding reputable sites with good content. Many, perhaps most, NHS websites fail to meet the HON code of practice. There are some websites, using web 2.0 type approaches, user generated content, which are leading the way toward greater empowerment coupled with improved access to clinical protocols and tests against which individuals can self-manage their care. I was part of a group that developed and launched an interactive digital television channel and put NHS Direct on the TV with direct one to one contact with an NHS Direct nurse through the television. This service was possible in 1999/2000, yet even today, we see really poor quality access to information and advice services.

Question 07 - Your experiences

ANSWER:

No. I am concerned that in the UK in particular there is insufficient regulatory understanding of the need to create a code of practice for online pharmacies. The US has developed a system, which brings some reassurance to the public. I have worked on the problem of counterfeit prescription medicines in particular and there is a specific vulnerability here that needs to be addressed. The risk of failing to deal with this is the trust that underpins the act of dispensing a medicine between the pharmacist and the patient will evaporate and if that were to happen, we would have a very specific problem with trust people would have of their medicines.

Question 08 - Advertising health care products

ANSWER:

I share the concerns of others about inappropriate advertising, whether of medicines or pension products. I see little reason to treat information about medicines differently. Choosing which types of products that fit or not some model of what is acceptable seems a greater problem, than ensuring that advertisements/information is accurate or appropriate. This comes back to my point about being technologically neutral or agnostic. How is one to decide and by what criteria, apart from vague paternalistic fears for patients? That there are likely to be more benefits than disadvantages from advertising seems the way forward as greater profile creates awareness and can lead to understanding and engagement with individuals around their care. Without it, we continue to keep patients in the dark (as someone else has written), and that is not, in my view,

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ethically defensible. I'll add a comment here about self-testing kits as they raise the same sorts of issues. Sense about Science Foundation produced a report on them, and raised fears about patients not understanding how to use them, misunderstanding the results, etc. and in the end arguing for the centrality of a clinical decision-maker (a.k.a. the GP). This is the usual end-point of this sort of thinking, but if we start with the view that individuals should actually be able to be as informed as possible, with professionals deciding what is or isn't acceptable, then you change the issue to one about the ethical defensibility of controlling information itself.

Question 09 - Your experiences

ANSWER:

Yes, I have had telephone conversations with my doctor. Let's not forget that some e-health technologies are quite mundane! I appreciated it and felt that it enabled a more personal relationship as the GP telephoned me; I didn't have to go the practice, sit in a waiting room and wait for some buzzer or light to flash (who thinks this is acceptable? In my personal experience in other countries, the doctor comes to the waiting area and invites you to the consultation.) More generally, though, the wider use of this approach could be very helpful. We just have to get beyond the pilots to real service delivery models.

Question 10 - Who pays?

ANSWER:

Of course it should be provided to folk in rural areas or anywhere else for that matter -- what about being on holiday in the south of France and wanting a consultation (check the European Court on cross-border healthcare)? There is a bit of a problem viewing 'at a distance' as meaning 'rural'. For example, urban areas are excellent candidates for e-health, given traffic congestion. You are framing the issue inappropriately, I think; there already is unequal access. The equity of access to healthcare is not an matter of geography or choice as to where people live, but arises from the structure of how healthcare is organised. The one thing that may flow from wider uptake of e-health is the lowering of current access barriers as services are redesigned. With respect to costs, it is obvious that these are still early days in the UK to make sense of pricing structures for e-health services, given the existing overheads of incumbent providers as a starting point. E-health costs are not incremental but should in the end replace some of what passes for service access. New providers with different overheads and cost structures would replace what is in effect a 19th

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century organisation we fondly call the hospital.

Question 11 - Your experiences

ANSWER:

No.

Question 12 - Regulation

ANSWER:

The way the NHS goes about deciding what technologies it wants to adopt or not is its decision and governed by the activities of NICE. The focus is solely on the needs of the NHS. That the specific requirements of the NHS should determine the wider issues of technology is incompatible with the current regulatory system, which assesses technologies on their merits. The public should not necessarily be inconvenienced by the specific administrative practices of the NHS. Having said that, technologies must meet general requirements for their safety etc. and these are designed to protect the public and are quite appropriate. That the NHS chooses to add additional ones for its own reasons is entirely a matter for the NHS. I would also not wish to overstate the 'stringent evaluations' that the NHS conducts; if they are in the general public interest, then they should perhaps be more a general feature of the regulatory system, within which the NHS operates. But this may not be the case, and may overstate the wider public benefits of NHS practice. There is no contradiction between individuals having access to technologies outside the NHS but within the UK's regulatory environment. The real issue is whether they should be able to access unregulated technologies. The NICE-type reviews are referred to as fourth-hurdles as they introduce additional constraints on the use/uptake of novel technologies. This may not always be in the interest of patients of course. The assumption that all decisions about novel technologies by the NHS are always in the public interest is an interesting assumption worth further reflection.

Question 13 - Responsibility for harm

ANSWER:

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To restate my point about technological neutrality: should there be a general duty not to harm people by giving them bad news? People become distressed everyday when they are told they have cancer by their doctor. How does this differ? People already self-medicate, fail to take their medicines get worried reading the Sun, or whatever. Should we be protected from the Chancellor upsetting us with gloomy financial forecasts? The serious point about the use of predictive models and data mining requires further consideration. Individuals may wish to choose to be or not profiled by such a system; this raises important issues as if the individual has agreed to be profiled then there is obligation to inform (see my report on predictive models for the Department of Health).

Question 14 - Quality of information

ANSWER:

Yes, of course, all efforts should be made to ensure that any information given to the public is accurate, including information provided from NHS sources. Better services are in everyone's interests and are likely to become even more important going forward as genetic information becomes both increasingly precise, and used in personal health decision-making. Take 'thin/fat' genes as an example, and how we could structure appropriate anti-obesity programmes on their basis. There are safeguards already in place to protect consumers; one needs to make sure they apply here. I would add that the NHS should be covered by this, too. That there may not be an actual financial transaction does not mean the NHS is not accountable for providing a decent service (two weeks to get a ECG read???)

Question 15 - Other issues

ANSWER:

One point that is important has to do with identify protection and identify theft. This is particularly relevant in the context of online transactions and securing access to e-health services, and to electronic records. Current NHS based approaches appear to marginalise the patient in the process and control of their health information. Patient-control leads to the auditor-of-one, and greater awareness of the importance of protecting both the information and personal identity. The end result is not just better quality control, but better general oversight of the use of information and organisation of services.