

Information Strategy Team
Department of Health
7th Floor
New Kings Beam House
London SE1 9BW

Dear Sir or Madam

Liberating the NHS: An information revolution

I am writing in response to your consultation 'Liberating the NHS: An information revolution' on behalf of the Nuffield Council on Bioethics. The response draws primarily on the Council's recent report *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*, which can be downloaded at: www.nuffieldbioethics.org/personalised.


The report was produced following a two-year inquiry of a Working Party chaired by Christopher Hood, Professor of Government at the University of Oxford, and which included members with expertise in medicine, science, law, philosophy, ethics, and health policy. To inform its deliberations, the Working Party held a public consultation and a series of 'fact-finding meetings' with scientists, providers of healthcare services and regulatory bodies.

This response also draws on the Council's 2009 report *Dementia: ethical issues*, available at: www.nuffieldbioethics.org/dementia.

Paragraph numbers on brackets refer to paragraph numbers in the Council's reports.

I hope that this is a helpful contribution to the inquiry. Please let us know if we can be of further assistance.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Hugh Whittall'.

Hugh Whittall
Director

Response of the Nuffield Council on Bioethics to 'Liberating the NHS: An information revolution'

General points: responsabilisation

It is suggested throughout the consultation paper that information can be a means of helping people to take greater responsibility for their own health and well-being. Seeking to encourage – and in some cases demand – greater responsibility from individuals or their families is a process that has been dubbed 'responsibilisation' by some social scientists. While attractive from many viewpoints, it should be noted that the notion of responsabilisation through new technology raises important ethical issues as well. On the one hand, responsabilisation stresses the value of allowing people to act as educated and empowered individuals, knowing more and able to increase their capacities to make informed decisions about the management of their health and illness. But on the other hand it may involve increased obligations and expectations on individuals to take this active role, requiring increasing skills in terms of self-education, and the need to make trade-offs between different options in terms of their relative costs and benefits. Individuals may choose to reject rather than embrace such responsibility and not all patient groups have equal access to the internet and its power of communication (Medical profiling and online medicine report: para 2.13-2.19).

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

Over the past decade or so people have increasingly used the internet to search for, exchange and post health information on various types of websites, including those run by governments and charities, patient group websites and individuals' own sites and blogs. The existence of search engines and group networking sites opens up new possibilities, and raises the issue of how people can ensure they are receiving good quality, validated information.

It is currently not easy for individuals to assess the quality or accuracy of information being provided to them online. There are few strong incentives for information providers to follow 'best practice', for example by informing users of the ways in which information provided might be stored, passed on or sold.

Content of websites

We recommend that the Department of Health should provide high-quality health information on the internet or ensure that such information is available. High-quality websites should include at least the following information prominently in language that lay people can understand:

- where the information originates and what it is based upon;
- which individual or organisation is the author of the information;

- how any information provided by users of the website will be used, stored, passed on or sold;
- where the provider(s) of the website are based; and
- funding and advertising arrangements.

Advertisements should also clearly be distinguishable as such.

We think the best websites contain information that: (i) is based on high-quality peer-reviewed studies; (ii) originates from an independent not-for-profit organisation with no commercial interests, and (iii) is independently and widely evaluated and continuously monitored and updated. We judge the NHS websites and those of the National Institute for Health and Clinical Excellence (NICE) to be examples of websites that generally meet these criteria.

Doctor-patient relationship

We have come across some anecdotal evidence that increasing numbers of patients are presenting to their doctors having read health information on the internet. Such a development can in principle lead to more involved, knowledgeable, empowered patients and improved understanding between doctor and patient. A recent report from the Royal College of Physicians found that patients' relationships with their doctors were changing, that such change may be related to increased access to online health information, and that doctors need to respond to such developments.

We recommend that organisations responsible for the training of healthcare professionals and professional standards should train and advise healthcare professionals on caring for patients under the new circumstances in which patients increasingly use the internet to access health information.

With regard to patients who request treatments they have seen that are not provided by the public healthcare system, we recommend that the bodies that issue guidance on treatment (such as NICE in England and Wales) should support doctors by providing information to enable them to explain to their patients their decisions and recommendations for treatment. This should include why particular treatments are selected over others, and why certain treatments are not provided for some or all patients by the public healthcare system (Medical profiling and online medicine report: para 5.62-5.64).

Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?

Many developments in telemedicine offer potential benefits to patients, in terms of convenience, access and privacy in some cases, and they can also improve patient outcomes. The interactions between healthcare professionals and patients can change as a result of telemedicine services, and have the

potential to result in both benefits and disadvantages for patients and healthcare professionals. But those changes seem to depend heavily on context, technology and perhaps individual characteristics as well, and there has been little empirical research conducted to date that investigates the impact of telemedicine on doctor-patient relationships. Such research is important to assess likely effects if telemedicine comes to be applied on a larger scale than it is at present. In the light of our value of efforts by the state to reduce harm, we recommend that public healthcare providers should carry out an evaluation of any impact upon the doctor-patient relationship for every telemedicine service that is implemented (Medical profiling and online medicine report: para 8.39-8.40).

Applications of telemedicine involving monitoring and feedback functions may mean that some people are given immediate warnings that their conduct – whether it be by behaviour, diet, or non-adherence to treatment – is potentially harmful to their health. (For example, a glucose or alcohol monitor can be linked to appropriate warnings.) Such applications make it possible for willing individuals to become more involved in their health and healthcare and may give them information they need to make responsible decisions about their health. However, people may also find themselves held more responsible by healthcare professionals for poor health outcomes that might be ascribed to their own actions in the light of such information and alerts. ‘Responsibilisation’ can thus cut several ways. We consider that healthcare professionals should not rely on monitoring and feedback devices as the basis on which to make decisions about denying treatments to patients. Instead, healthcare professionals should use the information gained (as they do for other sources of information) to help them in working with the patient to provide him/her with the most suitable care available in that healthcare system (Medical profiling and online medicine report: para 8.41-8.42).

Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.

Online personal health records have the potential to empower patients and to increase convenience, safety and efficacy. We have found no evidence of any actual harms having been caused by the use of such records, but we see potential risks over the confidentiality and security of health records. We do not wish to prevent people from gaining the benefits of these services, but we want to ensure that users are able to verify that a system is of high-quality and offers suitable safeguards for their personal information.

Enabling patients to access and add, but not delete or edit, health information to an online medical record held by healthcare providers is a sensible measure, provided information originating from the patient can be identified, and provided the system is designed to help both doctors and patients (such as building in limits to the amount and type of information that can be added, to avoid

unnecessary burdens on medical professionals to take time in reading through records to protect themselves against possible malpractice suits) and care for their patients. Medical record systems that allow these additions can help both patients and health professionals without compromising subsequent decision making by health professionals (Medical profiling and online medicine report: para 6.29).

Online health records offered by the NHS and private companies based in the UK are subject to the same data protection legislation as other types of health records and stores of personal information. However, as the House of Commons Health Committee noted in 2007's *The electronic patient record*: "Increasing access to patient data also brings new challenges for safeguarding patient privacy... There is a difficult balance to be struck between the need to protect privacy and the opportunities for research, between safeguarding individual rights and promoting the public good."

Providers may wish to share the information and data they hold with third parties (such as research institutions or pharmaceutical companies), and users may not always be readily aware of such information-sharing arrangements. The EU Data Protection Directive includes the processing of data about an individual both by an organisation established in an EU Member State as well as by an organisation that makes use of equipment for data processing in an EU Member State, so many of the potential harms of online personal health records should be protected against in the EU, and other countries with similar legislation, by data protection laws, provided such laws are adequately enforced. But it is not clear that providers based outside such jurisdictions are in practice always covered by the legislation that applies in the countries where their users are based. We recommend that responsible bodies in the EU, such as the Information Commissioner's Office in the UK, take as a premise that EU data protection legislation applies to online health records held by people who upload and edit their information in the EU.

As an additional safeguard, we would like to encourage what we see as good practice for the process by which individuals join online personal health records systems. We believe that routinely providing the kinds of information set out below would help users to assess whether their private information was being safeguarded. We also think that providers should routinely make it easily possible for their users to store their own local copy as an additional safeguard against its loss.

We recommend that providers of online personal health records should design a joining process for new users that includes information about the following, which the user should actively view and 'opt-in' to:

- arrangements for data security (the possibility of a change to the administration of the company);

- whether and how their personal information will be used, stored, passed on or sold to third parties (and the limits of any anonymisation process that may be applied to such information);
- examples about how personal information could be used, such as whether or not the user might receive information/advertising from pharmaceutical companies on the basis of the information they have entered;
- the advisability of the user downloading and storing locally a frequently updated copy of their health record as an additional safeguard against its loss; and
- users' rights under data protection legislation.

The above information should all be presented in accessible language that lay people can understand, and advertisements should clearly be distinguishable as such. The providers of online health record facilities should design an easy method for their users to back up and print out copies of their record to ensure against its loss (Medical profiling and online medicine report: para 6.30-6.34).

We also recommend that public healthcare services should develop an accreditation system for online health record providers. Further details are provided under Q30 below.

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?

Q11: What additional information would be helpful for specific groups?

The long-term conditions model is provided in the consultation document as an example of shared decision making that can lead to better care outcomes. We discuss the importance of information and communication in the Council's report *Dementia: ethical issues* (2009).

There is ample evidence that, in many cases, people are presented with a diagnosis of dementia and simply told to come back in a year's time. It was argued forcefully in one of our fact-finding meetings with people in front-line dementia care that such a lack of information and support in the immediate aftermath of diagnosis is simply morally wrong. We agree. Access to supportive care, including appropriate information, emotional support, and a variety of forms of practical support, is essential for people to live well with dementia, making the most of all their retained abilities.

People also need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services that people with dementia and their families may potentially use. We suggest that an important element will be the identification of a single individual to liaise with the person with dementia and their family, and with whom a trusting relationship can develop. We welcome the proposal in the English dementia strategy to pilot possible models of 'dementia care advisers', whose role would be to help people

diagnosed with dementia access appropriate services and support. We suggest that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible (Dementia report: para 3.27).

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

Carers will often know the person with dementia better than anyone else, and hence are likely to be well placed to advise on their particular support needs. However, they do not necessarily know about the nature or progression of dementia, nor what care interventions are possible. Support is therefore needed from professionals who do possess such knowledge. Conversely, health and social care professionals will be familiar with care planning, care provision and caregiving, but unfamiliar, at least initially, with the personal history, references and values of the person with dementia. It is therefore crucial that professionals and carers work together in genuine partnership, in order to ensure that people with dementia benefit from their joint expertise and joint knowledge (Dementia report: para 7.20).

Q13: What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?

The consultation document states that assistive technologies, such as telehealth and telecare, support independent living, and that through remote monitoring, they can support people with challenging long-term conditions to continue with their everyday lives

Careful consideration should be given to the fact that certain groups for whom telemedicine applications could be considered – for example, people with dementia and people with learning difficulties – may have special healthcare needs and may have impaired capacity for informed consent. The values of individuals being able to pursue their own interests and efforts by the state to reduce harm to individuals therefore shape our recommendations on this issue.

We recommend that providers of telemedicine services observe the following conclusion made in relation to assistive technologies by the Nuffield Council on Bioethics in its 2009 report *Dementia: ethical issues*. Where a person with dementia lacks the capacity to decide for themselves whether to make use of a particular technology, the relative strength of a number of factors should be considered on a case-by-case basis, including:

- the person's own views and concerns, past and present, for example about privacy;
- the actual benefit which is likely to be achieved through using the device;

- the extent to which carers' interests may be affected, for example where they would otherwise have to search for the person with dementia in the streets at night; and
- the dangers of loss of human contact.

There may be similar problems in deciding whether or not a person with learning difficulties has appropriately agreed to use telemedicine. We recommend that providers of telemedicine services take into account the following issues when making these decisions:

- effective provision of information;
- privacy;
- issues of response bias; and
- the potential for unintentional coercion (Medical profiling and online medicine report: para 8.36-8.38).

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and 'intermediaries'? Would factors such as cost and bureaucracy outweigh any benefits?

Accreditation of online health records

We recommend that public healthcare services should develop an accreditation system for online health record providers and promote it appropriately. In the UK the responsibility for developing such a system should fall on the Government Health Departments. We recommend that providers of online personal health record facilities should seek accreditation. Such an accreditation system should include requirements to include the following information prominently in lay language:

- the operator of the services;
- location in which the operator is based;
- how information provided by users will be stored, passed on or sold;
- arrangements in place to ensure the security and confidentiality of data and information if the operator went into administration or changed hands;
- the possibility that changes to terms and conditions could be made after initial sign-up and how the user will be informed; and
- funding and advertising arrangements

Advertisements should also clearly be distinguishable as such. We also think it is important that companies establish systems to safeguard the confidentiality of the data they hold were they to change ownership or go into administration (Medical profiling and online medicine report: para 6.27).

Accreditation of health websites

While recognising that accreditation of websites has its limitations as a tool of intervention, we nevertheless conclude that stringent accreditation can have a valuable role in the digital age in helping people to identify the more trustworthy sources of health information, and that accreditation initiatives run or sponsored by the state are one way in which the state can reduce harm in this domain.

We recommend that accreditation schemes should: (i) be fit for purpose; (ii) set criteria for websites specifying that they need to state, in language that lay people can understand, where their information originates, authorship and funding arrangements; (iii) set criteria about identifying advertisements appropriately; (iv) set criteria about informing website users of how their information will be stored, passed on or used; (v) be used to drive improvements over time; and (vi) be kept under review.

We recommend website owners should take the measures necessary and seek accreditation from recognised schemes. We also recommend that websites should display accreditation certification on their home pages, and that government health department websites should include prominent information about these schemes. This would help to generate a climate in which more providers of health information on the internet follow best practice and more internet users come to expect this of the sites they visit (Medical profiling and online medicine report: para 5.54-5.59).

Q31: How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

We recognise the differences among people in their access to, and ability to use and understand, the internet and the information it can provide (commonly referred to as the 'digital divide'). We are concerned in particular that the heaviest users of healthcare services – the elderly – tend to use the internet less than other age groups. Furthermore, significant amounts of high-quality information (such as the original texts of papers in scientific journals rather than the glosses put on them in promotional material) are available only for payment rather than freely, and that particular market divide may grow. Also, further advantages may accrue to those with more education and other resources who use the internet to lobby for particular causes. Consequently, those who are elderly, less educated and less well off are potentially triply disadvantaged in this informational divide. But at present there is no real evidence about whether this divide is causing any specific harm to any particular group in society.

We recommend that government health departments should take seriously the ethical values of social solidarity and reducing harm by monitoring whether the

'digital divide' is differentially affecting doctor-patient relationships, access to care and type of care received by different socio-economic groups (Medical profiling and online medicine report: para 5.65-5.66).