



Medical profiling and online medicine:

The ethics of 'personalised
healthcare' in a consumer age

A guide to the report

NUFFIELD
COUNCIL ON
BIOETHICS

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Introduction

This guide summarises the conclusions and recommendations that are discussed in more detail in the Nuffield Council on Bioethics' report *Medical profiling and online medicine: The ethics of 'personalised healthcare' in a consumer age* (published October 2010).



New developments in medical profiling and online medicine are promised by their providers as leading to a new era of 'personalised healthcare'. These developments include:

- direct-to-consumer body imaging (e.g. CT and MRI scans) and personal genetic profiling as a health check
- the increase in websites that provide health advice, diagnosis, storage of health records, and medicines for sale.

The technologies behind these developments are already being used in positive ways. For example, the UK's National Health Service (NHS) uses approved genetic tests to detect rare genetic disorders. We explore the more controversial uses of these technologies, and the extent to which they really do lead to healthcare becoming more personalised.

Notes in square brackets refer to the chapters in the report.

What is 'personalised healthcare'?

The term 'personalisation' has become very widespread, with many companies, policy makers and doctors claiming that this is the future of healthcare.

We found several meanings for 'personalised healthcare'. For example, it can mean healthcare that is tailored to a person's specific characteristics, or healthcare where more responsibility is given to individuals rather than medical professionals [Chapter 1].

Links with responsabilisation and consumerisation

Some of these types of personalised healthcare correspond with two key social pressures, called 'responsibilisation' and 'consumerisation'. These pressures are not just relevant to healthcare, but present particular ethical challenges for the developments being considered in this report.

'Responsibilisation'

Policy makers in the UK and elsewhere often encourage people to take more responsibility for their own health – to lead a healthy lifestyle and play an active role in managing their healthcare. Developments in medical profiling and online medicine can provide new tools to enable people to take more responsibility for their health.

'Consumerisation'

There is nothing new about being able to select and pay for healthcare in the private sector, but today even public healthcare services are aiming to become more user focused. A consumerist approach to healthcare and the new technologies available have been seized upon by firms offering medical profiling and online medicine services [Chapter 2].

Ethics

The following five ethical values are important when considering developments in medical profiling and online medicine:

- 1 Private information should be safeguarded.
- 2 Individuals should be able to pursue their own interests in their own way.
- 3 The state should act to reduce harm.
- 4 Public resources should be used fairly and efficiently.
- 5 Social solidarity (sharing risks and working together to protect the vulnerable) should inform public policy.

Conflicting ethical values

These ethical values often conflict with one another. All are important and no one value 'trumps' another.

In the following case studies, we examine the benefits and harms in each situation. We then attempt to 'soften' the conflicts between the ethical values by respecting each of them as much as possible and making recommendations that are evidence-based, proportionate and feasible [Chapter 3].



Intervention

If there is broad agreement that a new development in medical profiling and online medicine is likely to cause significant harm, then intervention by governments or other organisations is justified.



Types of intervention

Coercive vs non-coercive

Some interventions involve formal state-specific forms of coercion, such as laws and regulations, while others do not, such as voluntary codes of conduct or education campaigns.

Specific vs general

Some interventions are specific to the product or service in question, while others are more general, for example general professional codes or rules about data protection.

Choosing interventions

The intervention should be proportionate to the problem. Less coercive interventions should be explored first, unless the degree of harm in a particular case merits a more stringent type of intervention.

More general forms of intervention are often preferable to more service- or product-specific ones, particularly where technology is rapidly changing and specific rules can quickly become outdated.

Interventions should also be feasible. There may be times when measures could not realistically be enforced, would be very expensive or could have negative side effects [Chapter 4].

Case studies

Online health information

People have always been able to access health information in newspapers and magazines, but the internet has opened up a range of new possibilities for conveniently finding and exchanging information on health. This can increase people's involvement in their own health and provide them with valuable support from others.

However, it is difficult for people to assess the accuracy of information they are getting online, and they may not know who has access to any personal information they submit. There are no strong incentives for information providers to follow best practice.

The best websites are based on high quality research, originate from an independent not-for-profit organisation, are independently evaluated and continuously updated.

We conclude...

- All websites containing health information should contain key details about, for example, the basis of the information, the authors, funding arrangements, and how any personal data will be used. Websites should seek accreditation from recognised schemes.
- Governments should ensure that high quality health information is available on the internet and doctors should direct patients to these sites.
- Doctors should receive training and advice on caring for patients who use the internet to access information about diagnosis and treatment [Chapter 5].



Case studies continued

Online personal health records

Both public and private healthcare providers are starting to offer online health records services.

Through its HealthSpace website, the NHS currently intends to provide everyone in England with online access to a summary of their medical records, including information about their current and past health problems, medication and allergies.

Several commercial companies, mainly in the US, provide services that allow people to organise their personal health information, integrate health records from different providers, and share them with other people, including healthcare professionals.

These services allow more convenient and patient-centred control of health records. However, there is potential for misuse of stored information.

We conclude...

- Governments should set up accreditation schemes for online health record providers to improve transparency and standards on how personal information is stored and used. Providers of these services should seek accreditation from such schemes.
- During the signing-up process, online health record providers should provide potential users with information about data security and legal rights.
- Responsible bodies in the EU, such as the UK Information Commissioner's Office, should apply European Union data protection legislation to online health records used by people in the EU [Chapter 6].



Case studies continued

Buying medicines online

Online pharmacies can allow people to buy medicines conveniently and privately. Great Britain has a registration system for online pharmacies to help people identify legitimate websites.

The internet can also be used to buy medicines for which people do not have a prescription and which are illegal in their country. People doing this risk buying harmful, fake or low quality medicines and could miss out on advice offered by doctors and pharmacists. It could also lead to an increase in antibiotic resistance arising from misuse of antibiotics.

The extent of any harm currently being caused is not known but the potential for harm is great. As with all online services, the international nature of the problem makes it a difficult area to regulate.



We conclude...

- Registration schemes for online pharmacies, such as the one in Great Britain, should be mirrored in other countries.
- Government websites should provide information about the risks of buying medicines online and how to identify a registered online pharmacy.
- Doctors should receive training and advice on how to deal with patients who may be buying medicines online.
- Governments worldwide should set and enforce regulations on the supply of antibiotics in their country [Chapter 7].

Telemedicine

Telemedicine refers to any healthcare that involves communications technology and an element of distance. It includes patients and doctors communicating with each other electronically, and medical devices being operated remotely.

Although some types of care will always need to be delivered in person, telemedicine has the potential to offer care to people in their own home and increase equitable access to healthcare services.

Telemedicine could have a particularly positive impact in developing countries, for example, by enabling doctors to seek expert opinions from specialists in developed countries. Telemedicine may also have an impact on the 'brain drain' effect of doctors moving from developing countries to work in developed countries.

There has been little research on the impact of different types of telemedicine on doctor-patient relationships or on whether they bring cost savings.

We conclude...

- Public healthcare systems should offer telemedicine services where they can feasibly and cost-effectively help to reduce inequities in access to healthcare. Any impacts on the doctor-patient relationship should be evaluated.
- International agencies should encourage telemedicine networks in developing countries where they are shown to be beneficial, cost-effective and sustainable.
- Developed countries should monitor any impacts of outsourcing their healthcare services to developing countries via telemedicine, for example on the 'brain drain' effect [Chapter 8].



Case studies continued

Personal genetic profiling

Several companies, mainly US-based, now offer personal genetic profiling services for disease susceptibility. After analysing a sample of DNA (e.g. from a saliva sample sent in the post), they claim to be able to tell healthy people about their risks of developing common diseases in future, such as cancer, Parkinson's disease and diabetes. These services can cost up to US\$2000.

The tests might provide reassurance or enable people to take preventative action. However, there are a number of potential downsides:

- The test results can be unreliable and difficult to interpret.
- 'Good' results may lead to complacency in lifestyle.
- Learning about risk of disease could be upsetting, particularly if no treatments are available.
- There is potential for misuse of personal genetic information.
- People may seek unnecessary further tests or advice from their doctor.

The number of people using genetic profiling services and whether this is currently leading to any actual harm is not known.

We conclude...

- Regulators should request evidence for any claims being made by companies about the clinical value of their tests.
- Government websites should provide information about the risks and benefits of personal genetic profiling, including the relevance for insurance.
- Companies should not knowingly analyse the DNA of children unless certain criteria are met.
- Doctors should receive training on giving advice to patients about commercial genetic profiling services.
- Companies should voluntarily provide clear information on the limitations of genetic profiling and what will happen to people's data [Chapter 9].



Body imaging

Commercial companies are now offering people a ‘health MOT’ using body imaging technologies such as CT and MRI scans. They claim to look for early signs of conditions such as cancer and heart disease, and can cost more than £1000.

The tests can put people’s minds at rest, or encourage them to seek treatment and make lifestyle changes. However, there are a number of potential downsides:

- CT scans expose people to radiation, which can be harmful.
- The results can be difficult to interpret.
- MRI scans often pick up ‘abnormalities’ which are actually harmless, but which could lead to unnecessary anxiety and further invasive tests.
- There is potential for misuse of personal health information.

The number of people using direct-to-consumer body imaging services and whether this is currently leading to any actual harm is not known.

We conclude...

- Companies that sell body imaging services as a health check should be regulated to ensure they are meeting standards of quality and safety.
- Direct-to-consumer whole body CT imaging should be banned. Part-body CT scans should only take place if it is in the best interests of the customer.
- Government websites should provide information about the risks and benefits of commercial body imaging, including the relevance for insurance.
- Companies should voluntarily provide clear information on the limitations of direct-to-consumer body imaging, and what will happen to people’s data.
- Doctors should receive training on giving advice to patients about direct-to-consumer body imaging services [Chapter 10].



Conclusions

Personalisation

All the developments in medical profiling and online medicine considered in the report offer increased 'personalisation' to some extent. But many of the claims for more individualised diagnosis and treatment seem to be overstated and should be treated with caution at the present time. For example, commercial genetic profiling and body imaging have the potential to tailor healthcare to the individual, but that potential has yet to be fully realised.

Consumerisation

All the developments considered by the report can lend themselves to the provision of healthcare as a consumer good. We think choice is often a good thing, but to work effectively in healthcare it needs to be accompanied by proper information and advice.

We also need to find ways of balancing individual choice with the principle of social solidarity – i.e. that we should share the responsibility to help people in need.

Responsibilisation

The developments considered in this report can lead to new obligations and expectations for the individuals who use them. For example, online personal health records systems can place new demands on individuals to check their records and ensure their security.

We think responsibility for handling new risks associated with these developments should be placed in the hands of those best placed to manage it. In some cases this is the state, in some cases the medical professional, and in other cases the individual. Each case needs to be considered on its own merits.





Summary

New developments in medical profiling and online medicine are promised by their providers as leading to a new era of 'personalised healthcare'.

'Personalised healthcare' can have different meanings, including healthcare that is tailored to the individual and healthcare that gives more responsibility to the individual.

A number of new developments in medical profiling and online medicine are considered as case studies:

- Personal genetic profiling
- Direct-to-consumer body imaging
- Online health information
- Buying medicines online
- Online personal health records
- Telemedicine

The benefits and harms of each are weighed up, along with the ethical values that come into play, such as individuals being able to pursue their own interests and efforts by the state to reduce harm. We question the degree of personalisation achieved by the new developments and also their implications for 'consumerisation' and 'responsibilisation' of healthcare. Recommendations for policy and practice are made in each case.

Copies of the report and this guide are available to download at: www.nuffieldbioethics.org

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