

## Background

People have always been able to access health information in newspapers, books and magazines, but the internet has opened up a range of new possibilities for conveniently finding and exchanging information on health.

Many people now treat the internet as a first, or at least a major, source of health information and advice. 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 post.

### What to look for

The Council's report (see [www.nuffieldbioethics.org/personalised](http://www.nuffieldbioethics.org/personalised)) states that the best websites for looking up health information are:

- Based on high quality research (e.g. from research published in a respected, peer-reviewed journal).
- Originate from an independent not-for-profit organisation.
- Independently evaluated.
- Regularly updated.

### Suggested further reading and resources

- *Medical profiling and online medicine, the ethics of 'personalised healthcare' in a consumer age* - Chapter 5: Online health information. Available at [www.nuffieldbioethics.org/personalised](http://www.nuffieldbioethics.org/personalised) (click on 'chapter downloads').
- Video: Introduction to the 'Information Standard' (up to 1min 28s is the most relevant). <http://bit.ly/infomationstandardvideo>
- News article: 'Finding health information on the internet' (15 October 2010) <http://bit.ly/findinghealthinformation>

## Teaching notes

### Activities

This exercise could be carried out as individuals or in pairs, during class time or as homework.

1. Students choose a health issue that interests them, and an appropriate search term for finding information and advice on that health issue.

Using the form provided, they search for information from three different websites. Each website should be of a different 'type', e.g.:

- General information sites
- General health information sites
- Medical research charity websites
- Blogs
- Patient interest groups

Students then assess whether they think that the following three criteria are met on each website (adding a tick or cross to the form). A worksheet is provided on p.3.

- Based on high quality research?
- Independent not-for-profit organisation?
- Continuously updated?

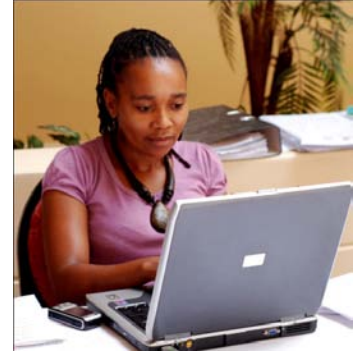
Students must note down three or four 'key health messages' that they found about the condition they searched for, in order that they could briefly explain to other people what they found online.

Students then rate the sites in order of a) how helpful they found the information b) how trustworthy they think the information is, and give reasons for their ratings.

2. Distribute the provided list of harms and benefits of using health information websites (p.4). Students then match each benefit / harm to one or more of the ethical values (p.5&6) that are relevant to personal genetic profiling.

## Comparing online health information

- Choose a health issue that interests you, and an appropriate search term for finding information and advice on the subject.
- Using the form provided, search for information from three different websites.
- Add a tick or cross to the form to show whether you think the criteria are met on each website.
- Note down three or four 'key health messages' that you found about the condition you searched for.
- Rate the sites in order of a) how **helpful** you found the information and b) how **trustworthy** you think the information is.



<b>Website name</b> →			
Based on high quality research?			
Independent, not-for-profit organisation?			
Continuously updated?			
Rating – how helpful?			
Rating – how trustworthy?			
<b>Notes</b>			

## Summary of potential benefits and harms

Decisions about ethics often involve weighing up the potential benefits of an action or situation against the potential harms. The views of everybody affected by the decision should be taken into account. In some cases, certain actions are considered unacceptable whatever the potential benefits.

Potential benefits	Potential harms
Access to information at a time and in a form that the patient can choose.	Danger of accessing misleading information, as online content is not regulated.
Improved individual understanding, responsibility for, and management of health and healthcare and risk.	Danger of misinterpretation of information leading to unnecessary anxiety, with possible adverse consequences.
Advantage for doctor-patient relationship from improved patient understanding of healthcare.	Potential breach of privacy by companies tracking users searches, e.g. for targeted advertising'
Supportive relationships between individuals with similar health risks or medical conditions to user.	Undermining of doctor-patient relationship by challenging professional authority.

## Applying ethical values

When weighing up the potential harms and benefits of developments in personalised healthcare, it is important to consider the following five ethical values. These ethical values often conflict with one another but all are important and no one value 'trumps' another.

Which of these five ethical values do you think are relevant to each potential harm or benefit identified for health information websites?

### A. Privacy

**Private information should be safeguarded.**

*In a nutshell: People should be able to keep information about themselves and their health private and free from unauthorised access or use if they so wish.*

The increasing amount of personal information that is available and can be tracked on the internet raises issues about the scope and limits of privacy and confidentiality for people using the internet to find health information or to buy medicines online. The same goes for genetic testing where information about an individual, such as a predisposition to disease, may be of crucial relevance to his or her family.

### B. Autonomy

**People should be free to pursue their own interests in their own way.**

*In a nutshell: People should be free to make their own decisions about what happens to them.*

It is widely believed that, unless there is a good reason not to, individuals should be able to make decisions for themselves and pursue their own interests in their own way.

Individuals can be thought to be the best judges of their interests, and so are likely to make better decisions in matters concerning their healthcare than others would for them, even though in practice, people rarely take decisions without consulting others they trust.

(Continued overleaf)

### C. Maximising welfare

**The state should act to benefit people as much as possible.**

In a nutshell: *We need to help as many people as possible, while reducing harm as much as we can.*

Most governments restrict personal autonomy to some degree, or try to steer people's behaviour, in order to prevent them causing harm to themselves or others. One example of a legally enforced restriction is that people who don't wear seat belts in cars are subject to penalties. Less strict policies aim to 'nudge' people's behaviour without pushing them, for example, providing people with facilities for recycling rather than making it compulsory.

Some personalised healthcare services may be partially restricted. For example, to maximise the welfare of younger people, genetic profiling services can generally only be accessed by people aged 18 or over.

### D. Fairness

**Public resources should be used fairly and efficiently.**

In a nutshell: *Everyone should have access to healthcare, not just people who can afford it.*

While individuals might be entitled to spend their own money wastefully or carelessly if they choose to do so, there is normally considered to be a special obligation to spend limited public resources as fairly and efficiently as possible.

New developments in medical profiling and online medicine could affect the resources available in public healthcare systems. For example, people may seek follow up appointments after they have had a genetic profiling test, and so add to NHS costs. On the other hand, people may find health information from trusted online sources rather than requiring an appointment with their GP, thus saving the NHS money.

### E. Solidarity

**Public policy should encourage sharing risks and working together to protect the vulnerable.**

In a nutshell: *We're all in this together. We should help other people in our communities.*

It is often argued that the NHS, and similar systems of publicly-funded healthcare, embody a valuable notion of shared responsibility and of pooling risks in a way that protects the vulnerable. The principle of solidarity also involves the idea of equity in society e.g. that everyone deserves at least a minimum standard of care, support and financial security.

Some argue that this sense of solidarity is important and that trends towards 'personalisation' in healthcare will damage it.