

Chapter 5

Online health information

Chapter 5 – Online health information

Overview

What is new? 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. Some of this activity is an extension or new formatting of the types of information that have long been provided by newspapers or magazines, but 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. These developments link to our discussion of the issues of consumerisation and responsabilisation in Chapters 1 and 2, because they both allow for more convenient 'consumer-like' or patient-led access to information and because they raise the issue of how and when individuals might be reasonably expected to seek health advice online. They also have the potential to contribute to the other two types of personalisation that we identified in Chapter 1.

Which ethical values come into conflict as a result of this development? The main conflict among the values we identified in Chapter 3 is that between individuals' ability to pursue their own interests in their own way on the one hand, and the values of safeguarding private information and state activity to reduce harms on the other. Another potential conflict arises between the ethical values of safeguarding private information and social solidarity in the form of information pooling for common benefit, for instance in research.

What is the existing pattern of interventions like? There is no overall oversight of information on the internet, though different countries apply their laws to the information on it and how people in their jurisdictions use it. Most of the existing types of intervention in the UK and many other countries fall into the category of 'general governance' measures as described in Chapter 4, with some involving the exercise of state-specific legal power and some involving less coercive measures. The main state-specific legal power relevant to this area is the data protection regime, involving general obligations and prohibitions in criminal law that are enforced by a state regulator. Additionally, the standard codes and rules for medical professionals apply where such individuals are involved with provision of online health information. The main general governance measure falling outside state-specific legal powers is that of the advertising standards regime, and the only service-specific form of intervention that appears to apply to this domain is that of accreditation schemes (which also fall outside the realm of state-specific legal power).

What gaps or shortfalls are there in existing interventions? Existing interventions by the state or third parties do not make it easy for individuals to assess the quality or accuracy of information being provided to them online. Such interventions also do not provide 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. The footloose character of information provision on the internet means that individuals cannot easily ascertain which jurisdiction's laws apply to any given website.

What types of intervention might possibly fill those gaps or remedy those shortfalls? If the main potential harm arises from misleading or poor-quality information and the lack of recognisable quality standards, possible types of intervention might include state provision of good-quality information, voluntary adoption of good practice, third-party accreditation, litigation over allegedly false or misleading claims, and state-imposed standards, including those that could be applied to controls over the internet, if such measures were proportionate and feasible.

What types of intervention do we recommend, and why? Our recommendations are for: (i) voluntary adoption of good practice for websites and forums linked with (ii) good professional medical practice adapted to the modern information age; (iii) the adoption of third-party accreditation of online health information provision; and (iv) state provision of high-quality information and government monitoring of any impact of the 'digital divide'. Our reasons for making these recommendations are that we wish to promote and not restrict the benefits to the public and individuals of online health information, and our inquiries have not produced sufficient evidence of harm to justify the use of coercive state interventions.

Introduction

- 5.1 Health information has been described as including “information for staying well, preventing and managing disease, and making other decisions related to health and health care”.⁸⁶ Our focus in this chapter is the development over the last two decades of enormous amounts of health information on the internet becoming available to, and written by, lay people (see Box 5.1).⁸⁷
- 5.2 Before the development of the internet, people found health information by consulting with their doctor or other health professional; from books, newspapers and magazines; or from family and friends. The internet has quickly become a major source of information for those who have access to it, and it has been argued that the demand for online health information is “unstoppable”.⁸⁸ The boundaries between online health information sites and other aspects of ‘e-health’ discussed in this report, such as online pharmaceutical purchasing (see Chapter 7) and online personal health records (see Chapter 6), are becoming increasingly blurred. Online systems are emerging which, as well as providing online health information, also enable personal health records to be created, stored and updated, facilitate the online purchasing of pharmaceuticals, and can be used for disease surveillance and other monitoring.
- 5.3 Online health information figures in public policy too. For example, in 2009, the then UK Government announced its commitment to provide universal access to broadband services by 2012, as part of its strategic digital vision for the UK, laid out in the *Digital Britain* report.⁸⁹ The report includes themes directly relating to online healthcare provision, stating that the provision of ‘next-generation’ broadband is vital for a variety of applications,⁹⁰ including “e-healthcare in the home” and “internet based health services”, which may offer “greater detail and information about healthy eating, dieting, exercise, diagnosis, treatment and recovery”. Furthermore, the report claims that “nearly a fifth of web users use the Internet as their first port of call when investigating a health concern”⁹¹ (see also Paragraph 5.29).
- 5.4 The use of online health information raises issues of consumerisation and responsabilisation as discussed in Chapters 1 and 2, and such online information has the potential to contribute to all four types of personalisation that we identified in Chapter 1. It is easier for people to search for and find health information that may apply to them, at times and in ways of their own choosing. Some websites purport to offer individualised diagnosis (although we note that many existing websites only sort people by groups based on the information they provide rather than as unique individuals), and they allow people to select the sort of information that aligns with their cultural worldview as a ‘whole person’. And they also lend themselves to ‘responsibilisation’, in the sense of ways in which individuals can be expected or cajoled to take a more active role in their health and healthcare, taking account of official or received views about how to live healthily and behaving responsibly in the sense of consulting online or similar sources of information (for example during pandemics) when deciding whether and when to seek face-to-face consultations with medical professionals.

⁸⁶ Rippen H and Risk A (2000) e-Health Code of Ethics *Journal of Medical Internet Research* **2(2)**: e9.

⁸⁷ We focus on information about conditions, treatments, medicines and devices and not on information about health services. Health information on the internet is of course available to medical professionals too as one of their sources, but we focus on its use by the non-professional user.

⁸⁸ Shaw J (2009) A Reformation for our times *British Medical Journal* **338**: b1080.

⁸⁹ Department of Culture, Media and Sport and Department for Business, Innovation and Skills (2009) *Digital Britain – Final Report*, available at: <http://www.culture.gov.uk/images/publications/digitalbritain-finalreport-jun09.pdf>.

⁹⁰ In this context, ‘next generation broadband’ can be interpreted as referring to extremely high speed internet access technology (when compared to 2008–2009 standards), usually based on fibre-optic technology.

⁹¹ Department of Culture, Media and Sport and Department for Business, Innovation and Skills (2009) *Digital Britain – Final Report*, available at: <http://www.culture.gov.uk/images/publications/digitalbritain-finalreport-jun09.pdf>, pp13, 29, 30.

Types of health information websites

- 5.5 Online health information comes in various forms and one useful categorisation divides them up as follows:⁹²
- general health information provision sites;
 - disease-specific sites;
 - interactive patient group websites;
 - scientific databases; and
 - web tools.
- 5.6 Such information is provided for various reasons, including for commercial purposes and for non-profit reasons such as public policy (for example that aimed at improving the health of the population or at increasing the efficiency of the public healthcare service) and altruistic or collective self-help reasons, such as a desire to help and learn from those with similar health problems.
- 5.7 Information on health-related websites comes in many formats including data, text, audio and video.⁹³ The background of those who provide the content varies to some extent according to the type of website. For example, the general health information provision site WebMD identifies medical writers and editors, physicians and health educators amongst its editorial staff.⁹⁴ Other sites take a more user-orientated, 'Web 2.0', approach (see Box 5.1), whereby content is user-generated, and collaboration, information-sharing and interactivity is paramount, for example in the case of patient sites which are often developed and run by people with a particular condition. Other online health information resources, such as some health-related wikis, involve a collaborative Web 2.0-style approach (at least in terms of the tools with which content is created) but maintain a more traditional relationship between doctors and patients/consumers. For example, AskDrWiki is a site upon which anyone with a proven medical background can provide information (without being a member of the editorial staff).⁹⁵

Box 5.1: Web 2.0

The trend for websites to include, or be entirely based upon, 'user-generated' content is often seen as central to the so-called 'Web 2.0' phenomenon, a phrase popularised after the O'Reilly Media Web 2.0 Conference in 2004. The term is notoriously hard to define precisely, but it is generally accepted to mean the concept of improved communication among both individuals and the programs they use (via open web standards), improved interfaces, interactivity, user-generated content and 'collective intelligence'. Commonly cited examples of Web 2.0 include Wikipedia and YouTube, since they are based on user-generated or uploaded content. This approach can be compared to the 'top-down' content aspects of 'Web 1.0': O'Reilly uses the contrast between 'publishing' and 'participation' to bring out a key element of the difference between Web 1.0 and Web 2.0, but there is much disagreement over the scope of Web 2.0 and even whether it really exists, given the difficulty in defining the term and the fact that some argue that it is simply a marketing buzzword; a concept rather than a clearly identifiable piece of technology. The term 'health 2.0' has been said to connote the "use of a specific set of Web tools

⁹² Adapted from Schwartz J (2008) Logging on for a second (or third) opinion *The New York Times* 29 September, available at: http://www.nytimes.com/2008/09/30/health/30online.html?_r=1.

⁹³ For further information, see: Rippen H and Risk A (2000) e-Health Code of Ethics *Journal of Medical Internet Research* **2(2)**: e9.

⁹⁴ WebMD (2010) What we do for our users, available at: <http://www.webmd.com/about-webmd-policies/about-what-we-do-for-our-users>.

⁹⁵ Those signing up to the website in order to edit entries are required to "submit their medical training, degree, and current hospital or medical school". See: AskDrWiki (2007) AskDrWiki: Editorial policy, available at: http://askdrwiki.com/mediawiki/index.php?title=AskDrWiki:Editorial_Policy.

(blogs, Podcasts, tagging, search, wikis, etc.) by actors in health care including doctors, patients, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize health care, collaborate, and promote health education”.⁹⁶

General health information provision sites

- 5.8 Health information sites provide information about health and diseases, as well as information about lifestyle, medicines and supplements. Examples include dedicated sites such as WebMD and Patient UK, as well as numerous blogs concerning health matters and websites that include health information as part of a wider range of services, such as BBC Health.⁹⁷ Some websites that fall into this category provide mechanisms that facilitate self-diagnosis and the Map of Medicine Healthguides function on NHS Choices allows the user to follow the assessment pathway and “see what your doctor can see”⁹⁸ (Box 5.2).

Box 5.2: Examples of National Health Service (NHS) websites

The NHS Direct website provides a self-help service, which provides appropriate medical advice and information based on answers the user gives in answer to a series of questions about their symptoms. Depending on the answers given, users may be advised to, for example: “Call 999. Your answers suggest you need to dial 999 immediately and ask for an ambulance” or “Your answers suggest that you can safely look after yourself with the care advice on the next page”.

The Map of Medicine Healthguides resource on the NHS Choices website allows the user to follow on flow charts “the ideal, evidence-based patient journey for common and important conditions”.⁹⁹ It is a patient-oriented version of the Map of Medicine, which was originally developed for healthcare professionals.¹⁰⁰ The Healthguides aim to allow patients to “self-educate and engage with care providers about their journey.”¹⁰¹

Disease specific websites

- 5.9 Disease-specific sites focus on a particular condition, and tend to be provided by charities or patient interest groups, or may also be blogs. Funding comes from a range of sources, including charitable donations, governments and pharmaceutical companies. Information might typically be provided about the condition, its cause, the drug treatments and complementary and alternative therapies that are available, as well as providing advice on lifestyle. Examples of groups that have established such websites include the UK’s Alzheimer’s Society and Parkinson’s Disease Society and breastcancer.org in the USA.

Interactive patient group websites

- 5.10 Interactive patient group websites are typically for people with a particular condition to find out information and share experiences with others having the same or similar condition. Online communities such as these can provide helpful support for people, for example by countering feelings of isolation. Some help people with rare conditions to find out information about their particular circumstances from others with experience of the condition. Some are set up by

⁹⁶ Hughes B, Joshi I and Wareham J (2008) Health 2.0 and Medicine 2.0: Tensions and controversies in the field *Journal of Medical Internet Research* **10(3)**: e23.

⁹⁷ See: <http://www.bbc.co.uk/health/>.

⁹⁸ NHS (2010) See what your doctor can see with Map of Medicine Healthguides, available at: <http://healthguides.mapofmedicine.com/choices/map/index.html>.

⁹⁹ *Ibid.*

¹⁰⁰ Map of Medicine (2009) About us, available at: <http://www.mapofmedicine.com/about/history/>.

¹⁰¹ Map of Medicine (2010) New design for Map of Medicine Healthguides, available at: <http://www.mapofmedicine.com/newsandevents/news/2010/healthguides/>.

patients themselves, others by companies, and they are funded in various ways, including advertising and sponsorship from pharmaceutical companies. Some collect data and use it in research or to sell to third parties for research. PatientsLikeMe is an example of a website that enables users to share clinical information on their condition and collects it in a “blinded, aggregated and individual format to [sell to their] partners (i.e., companies that are developing or selling products to patients)”.¹⁰² Such websites can also be used by researchers to give people the opportunity to participate in medical research.

Scientific databases

- 5.11 Scientific databases, including PubMed or clinicaltrials.gov, provide access to research published by scientists or ongoing clinical studies. Some of these sites were originally intended for use by medical and healthcare professionals, but they can of course also be accessed on the internet by anyone.

Web tools

- 5.12 Web tools are designed to help people to manage their condition and generally have an interactive component: for example, automated analysis and results based on the answers to an online questionnaire. A case in point is sugarstats.com, which enables the user to “track, monitor and access your glucose levels and diabetic statistics to spot dangerous trends and better manage your diabetic health”.¹⁰³ Another webtool, MoodGYM,¹⁰⁴ is an “interactive web program designed to prevent depression”, developed by the Centre for Mental Health Research at the Australian National University, that uses diagrams and online exercises with the aim of teaching the principles of cognitive behaviour therapy.¹⁰⁵ The NHS in England offers Healthspace, a website that includes tools that enable the user to enter and keep track of health information such as weight or cholesterol levels (see also Paragraph 6.6).

Benefits and harms

- 5.13 Some potential advantages and disadvantages of online personal health information were set out in Table 3.1.

Potential advantages

- Convenience;
- allows people who want to, to be more involved in their own health and healthcare;
- can empower patients relative to doctors;
- can provide protection from medical malpractice or incompetence; and
- facilitates mutual support.

Potential disadvantages

- Misleading information;
- misinterpretation;
- breaches of privacy; and
- can undermine the traditional doctor-patient relationship.

We explore these advantages and disadvantages further below.

¹⁰² PatientsLikeMe, responding to the Working Party’s consultation. See also: <http://www.patientslikeme.com/>.

¹⁰³ SugarStats (2009) About SugarStats, available at: <http://www.sugarstats.com/about/>.

¹⁰⁴ MoodGYM (2010) the MoodGYM training program/Mark III, available at: <http://moodgym.anu.edu.au/welcome>.

¹⁰⁵ MoodGYM (2010) MoodGYM frequently asked questions, available at: <http://moodgym.anu.edu.au/welcome/faq>.

Reasons people use the internet to access health information

- 5.14 The internet is distinctive because it combines enormous amounts of information with powerful mechanisms for rapid search and retrieval. It enables people to have convenient access to health information in the privacy of their own homes, at the time they wish and for as long and as many times as they wish. Online health sites allow information to be accessed without embarrassment and without needing to talk face-to-face with a doctor or health professional. People may also save money if they would otherwise need to pay for a consultation with a doctor or miss work to do so. There are people who, for whatever reason, have difficulty in accessing the information they need during face-to-face consultations, and health websites may be of great help to them. One study found that the average physician consultation in the USA was eight minutes long,¹⁰⁶ and in the UK the average length of consultation with a general practitioner was 11.7 minutes in 2007.¹⁰⁷ It has been argued that “Given the brevity of the patient-physician encounter, it is perhaps not surprising that patients express a need for more information... ”¹⁰⁸
- 5.15 Using online health information can thus enable individuals to increase their ‘health literacy’ if they want to do so, and to increase their sense of empowerment about their health. Looking up symptoms online may also encourage people to see their doctor early and take other positive action.¹⁰⁹ Given the prevalence of medical errors and misdiagnoses, online information can help people to identify such errors more easily. It may also have beneficial applications for public health, for example in times of pandemics.
- 5.16 There is evidence from the USA to suggest that many people have had positive experiences with online health sites.¹¹⁰ In 2008, the Pew Internet and American Life Project found that 31% of e-patients said they or someone they knew had been “significantly helped by following medical advice or health information found on the internet,” while 3% said they or someone they knew had been seriously harmed by following advice or information found online. Fifty-nine per cent of those internet users who were chronically ill and who had experienced a “health crisis” in the past year had found information online that had then led them to ask their doctor new questions, or seek a second opinion.¹¹¹ However, the author also identified a “generalized fear of misinformation” regarding health information on the internet.
- 5.17 Additionally, a European study found that, in 2005, 30% of internet users across seven countries felt reassurance or relief when accessing health-related information on the internet,¹¹² while 15% stated that they had feelings of anxiety.¹¹³ A 2007 survey found that 36% of Norwegian respondents reported feelings of reassurance or relief after using the internet for health purposes, while 19% had feelings of anxiety.¹¹⁴ The relative perceived importance of the internet as a source of health information has also been studied. One survey,¹¹⁵ again of the

¹⁰⁶ Hardey M (2007) ‘E-health’: The internet and the transformation of patients into consumers and producers of health knowledge, in Lederman LC (Editor) (2007) *Beyond these walls: Readings in health communication* (New York: Oxford University Press), pp154–64.

¹⁰⁷ The NHS Information Centre (2007) *2006/2007 UK general practice workload survey*, available at: <http://www.ic.nhs.uk/webfiles/publications/gp/GP%20Workload%20Report.pdf>.

¹⁰⁸ Sen N (2007) Patient dissatisfaction as a motivating factor in online health seeking *Paper presented at the annual meeting of the NCA 94th Annual Convention, San Diego, CA*, available at: http://www.allacademic.com/meta/p257285_index.html.

¹⁰⁹ Shaw J (2009) A Reformation for our times *British Medical Journal* **338**: b1080.

¹¹⁰ Fox S (2008) *The engaged e-patient population*, available at: http://www.pewinternet.org/~media/Files/Reports/2008/PIP_Health_Aug08.pdf.pdf.

¹¹¹ *Ibid.*

¹¹² The study used a sample of 7,903 people, of which 4,906 were internet users. The countries covered by the survey were Denmark, Germany, Greece, Latvia, Norway, Poland and Portugal.

¹¹³ Andreassen HK, Bujnowska-Fedak MM and Chronaki CE *et al.* (2007) European citizens' use of e-health services: A study of seven countries *BMC Public Health* **7**: 53.

¹¹⁴ Wangberd S, Andreassen H, Kummervold P, Wynn R and Sorensen T (2009) Use of the internet for health purposes: Trends in Norway 2000–2010 *Scandinavian Journal of Caring Sciences* **23**: 691–6.

¹¹⁵ Kummervold PE, Chronaki CE and Lausen B *et al.* (2008) eHealth trends in Europe 2005–2007: A population-based survey *Journal of Medical Internet Research* **10**(4):e42.

same seven European countries as the study mentioned above, found that, in 2007, approximately 47% of survey respondents considered the internet as an “important” source of health information, although direct contact with health professionals was still perceived as the most important source.¹¹⁶ However, there were significant differences between countries in terms of how respondents perceived the relative importance of the internet as a source of health information. For example, in Denmark the internet was seen as the second most important source of health information, behind only health professionals, while in Greece the internet was seen as the least important source, coming behind contact with health professionals; television/radio; books, medical encyclopaedias and leaflets; courses and lectures; newspapers and magazines; family, friends and colleagues; and pharmacies.¹¹⁷

Differences between the sources of information available

5.18 Health information has long been available in books, magazines and other print media. The underlying concept of acquiring information applies to both print material and the internet, but there are some important differences, which include the following:

Print

- It is often easier to determine the author/publisher of printed material and hence establish responsibility and liability.
- Information provided in print media or through radio/television has a ‘static’ nature, as opposed to the potential of websites to be continuously updated.

Online

- The internet can be used to track users’ identities, what other pages they view and where they are located. This information can then be used to target advertising to them.
- Vast quantities of searchable information are rapidly available, much but not all of that information being free.
- Information may appear to be more ‘personalised’ (in the sense of providing more individualised prediction, prevention and treatment, see Paragraph 1.18) when it is returned in response to information submitted by the user (for example, see Paragraph 5.12). That responsive character may lead to perceptions that such information is closely tailored to the inquirer’s personal circumstances, even if that is not always the case.

5.19 The key difference between online health information and information found through print media or via television and radio does not seem to lie in the degree of accuracy in the information available or whether it is free or involves charges, but rather in the way it is accessed. The speed at which an enormous variety of information (well beyond what even the most lavish libraries once contained) may be accessed through targeted, consumer-initiated use of search facilities is far beyond what was previously available. That is why quality problems with online information may have an important impact, even if it is not necessarily true that proportionally more online health information is less accurate than offline information.

¹¹⁶ *Ibid.*

¹¹⁷ The ordering of the last seven items was not stated. See: Kummervold PE, Chronaki CE and Lausen B *et al.* (2008) eHealth trends in Europe 2005–2007: A population-based survey *Journal of Medical Internet Research* **10**(4): e42. It can be noted that, although the authors of the study drew no direct causative or correlative link between internet uptake in a particular country and the level of interest in online health searching, Greece had the lowest uptake of internet access of all the countries surveyed.

Accuracy of information on the internet

- 5.20 Information, whether on the internet or elsewhere, is not all verified for clarity or accuracy. The quality of information available is variable:¹¹⁸ from strictly evidence-based to misleading and even malicious, and the traceability of authorship also varies widely. The development of websites on which people add their own experiences (see Box 5.1) enables people with similar conditions to provide support and information to each other across the world, but raises questions about how personal data is used and sold to third parties, and also frequently relates to non-standard forms of treatment.¹¹⁹ Inaccuracy, misinterpretation or conflicting sources have the potential to lead to confusion, false reassurance or undue anxiety. While these features are not unique to the internet, they may have more significance for other information sources for the reasons given above, and numerous studies have brought out such problems with internet-based health information.
- 5.21 For example, one study showed that approximately one in four patients who used the internet to research forthcoming operations they were due to undergo found the information worrying or confusing.¹²⁰ It has also been shown that many people who look for health-related information through search engines use short, often mis-spelt search phrases and rarely look further than the first page of search results.¹²¹ Another study conducted in 2008, aiming to identify “how effectively students can assess the accuracy of Internet-based material when gathering information on a controversial medical topic using simple keyword searches,” found that 59% of the 34 students who took part reported that they believed the websites they accessed, having used the search terms “vaccine safety” and “vaccine danger” in the Google search engine, were accurate on the whole, despite the fact that over half of those websites were in fact inaccurate on the whole: it was noted that “a high percentage of the students left the [...] exercise with significant misconceptions about vaccines”.¹²² A systematic review in 2002 found that “most authors who evaluated [health website] content found significant problems, criticizing lack of completeness, difficulty in finding high-quality sites, and lack of accuracy”. However, the review also noted that, while online health information quality may be variable “due to differences in study methods and rigor, quality criteria, study population, and topic chosen, study results and conclusions on health-related Web sites vary widely.”¹²³ Studies have also been performed on the adequacy of online health information as it pertains to various fields of medicine,¹²⁴ while others focused on the criteria that should be used to assess information found.¹²⁵
- 5.22 Such studies seem to suggest there is not always a close connection between accuracy and features such as the degree of citation or who provides the information.¹²⁶ They also suggest

¹¹⁸ Bovi AM (2003) Use of health-related online sites *American Journal of Bioethics* **3**(3): W48–52.

¹¹⁹ Although it is by no means clear that the internet is a “major pathway” to patient complementary and alternative medicine usage. See: Broom A and Tovey P (2008) The role of the internet in cancer patients’ engagement with complementary and alternative treatment *Health (London)* **12**: 139.

¹²⁰ Tamhankar AP, Mazari F, Everitt NJ and Ravi K (2009) Use of the internet by patients undergoing elective hernia repair or cholecystectomy *Annals of the Royal College of Surgeons of England* **91**: 460–3.

¹²¹ Morahan-Martin JM (2004) How internet users find, evaluate, and use online health information: A cross-cultural review *Cyberpsychology and behaviour* **7**(5): 497–510.

¹²² Kortum P, Edwards C and Richards-Kortum R (2008) The impact of inaccurate internet health information in a secondary school learning environment *Journal of Medical Internet Research* **10**(2):e17.

¹²³ Eysenbach G, Powell J, Kuss O and Sa E-R (2002) Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review *Journal of the American Medical Association* **287**(20): 2691–700.

¹²⁴ Hargrave DR, Hargrave UA and Bouffet E (2006) Quality of health information on the internet in pediatric neuro-oncology *Neuro-Oncology* **8**(2): 175–82; Selman TJ, Prakash T and Khan KS (2006) Quality of health information for cervical cancer treatment on the internet *BMC Women’s Health* **6**: 9; Bernstam EV, Walji MF, Sagaram S *et al.* (2008) Commonly cited website quality criteria are not effective at identifying inaccurate online information about breast cancer *Cancer* **112**(6): 1206–13

¹²⁵ Kunst H, Groot D, Latthe PM, Latthe M and Khan KS (2002) Accuracy of information on apparently credible websites: Survey of five common health topics *British Medical Journal* **324**: 581–2

¹²⁶ For example, it has been suggested “that features of website credibility – source, [displaying the date of the original document or content posting on the internet], and evidence hierarchy – have only slight or at best moderate correlation with

that the accuracy of online information may vary among different fields of medicine.¹²⁷ But the accuracy of information on governmental health websites was well rated by a 2010 study of 500 websites relating to common paediatric queries, which found governmental websites “gave uniformly accurate advice” and concluded that such websites “should be promoted as the first port of call for parents” looking for paediatric health advice. In contrast, the study found that “sponsored sites [those that pay to appear on the results pages of search engines] universally gave poor information”.¹²⁸ It may of course be that inaccuracies in online information can be corrected through interactive websites of the Web 2.0 type referred to earlier (see Box 5.1). Indeed, Matthew Holt, co-creator of the Health 2.0 conference, suggests that, “In the end, the more people you have in the conversation, the better information drives out the worse information,”¹²⁹ and there appears to be some limited evidence in support of this proposition.¹³⁰

Potential harms to health from using online health information

5.23 There is currently no consistent evidence to suggest that it is common for individuals to suffer harms to their health as a direct consequence of using online health information (see Box 5.3).¹³¹ But we think there is potential for physical, psychological, and possibly financial harms to arise from:

- people believing a particular condition is medical or treatable, when in fact it is not;
- people believing a particular condition is not medical or treatable, when in fact it is;
- people following advice that is inaccurate or misleading;
- people making misdiagnoses; and
- people viewing pages from (or participating in) online patient groups, but being unaware of variations in similar conditions and consequently of the risk that advice given by other patients may not be relevant, or may even be harmful, for them.

accuracy of information”. (Kunst H, Groot D, Latthe PM, Latthe M and Khan KS (2002) Accuracy of information on apparently credible websites: Survey of five common health topics *British Medical Journal* **324**: 581–2).

¹²⁷ For example, a study published in the journal *Cancer* identified 343 unique internet pages about breast cancer by using popular search engines, and found 41 inaccurate statements on 18 sites, representing an error rate of 5.2% and leading to the conclusion that most information about breast cancer that consumers were likely to encounter online was accurate (see: Bernstam EV, Walji MF, Sagaram S *et al.* (2008) Commonly cited website quality criteria are not effective at identifying inaccurate online information about breast cancer *Cancer* **112**(6): 1206–13). That finding contrasts sharply with the study of paediatric websites cited below.

¹²⁸ The study in question set out to determine the quality of advice on websites found through the Google search engine for five common paediatric queries. The first 100 UK-based Google results for each search were classified as being either consistent or inconsistent with current recommendations from the medical profession or as not providing an answer. The study found that “the reliability and accuracy of health information on the internet ranges from poor to excellent, depending on the topic”. Of the 500 sites searched, 39% were found to give correct information in terms of consistency with current evidence-based recommendations, 11% were incorrect and 49% did not answer the question. See: Scullard P, Peacock C and Davies P (2010) Googling children’s health: Reliability of medical advice on the internet *Archives of Disease in Childhood* (published online 6 April 2010).

¹²⁹ Schwartz J (2008) Logging on for a second (or third) opinion *The New York Times* 29 September, available at: http://www.nytimes.com/2008/09/30/health/30online.html?_r=1.

¹³⁰ A 2006 study designed to determine the prevalence of false or misleading statements in messages posted by an internet cancer support group, and whether and how quickly they were corrected by other members of the group, found that of 4,600 postings in four months, ten were false or misleading (0.22%) and of these, seven were identified as such and corrected within an average of four hours and 33 minutes. But the authors concede that the study covered only one internet support group, meaning that the findings may not be generalisable, that only a single reviewer determined the false or misleading nature of the posts, and that reviewer was not blinded to the study hypothesis. See: Esquivel A, Meric-Bernstam F and Bernstam EV (2006) Accuracy and self correction of information received from an internet breast cancer list: Content analysis *British Medical Journal* **332**: 939–42.

¹³¹ Ferguson T and Frydman G (2004) The first generation of e-patients *British Medical Journal* **328**: 1148–9; Smith R (2001) Almost no evidence exists that the internet harms health *British Medical Journal* **323**: 651; Crocco AG, Villasis-Keever M and Jadad AR (2002) Analysis of cases of harm associated with use of health information on the internet *Journal of the American Medical Association* **287**(21): 2869–71; Potts HWW and Wyatt JC (2002) Survey of doctors’ experience of patients using the internet *Journal of Medical Internet Research* **4**(1): e5; Bessell TC, McDonald S and Silagy *et al.* (2002) Do internet interventions for consumers cause more harm than good? A systematic review *Health Expectations* **5**: 28–37.

Such potential harms are of course not unique to information obtained online, but can nevertheless have potentially serious consequences in some cases.

- 5.24 A feature of online information referred to earlier is that it can be viewed without knowing what country it comes from or how the provider of the information in question is funded. While search engines differ to some extent according to where a user is based,¹³² users may not confine themselves to the search engines applicable to their own jurisdictions, and may therefore not be readily aware of the implications of important differences in the way healthcare systems operate, the different measures used for items such as blood sugar levels, the names used for drugs in different countries (see Paragraph 7.8), which treatments are available in what countries, what constitutes common medical practice in one particular country, the frequencies of medical conditions, and whether there is overlap between advertising and independent health information.

Box 5.3: What is the evidence of harms caused by using online health information?

There seems to be rather limited evidence of widespread harm as a consequence of accessing online health information, and no controlled comparisons between harms from online and offline information. Harms reported in the literature we found included the following:

- Inaccurate healthcare information acquired online by parents was “associated with an adverse outcome in a pediatric patient presenting with diarrhea”. But the online information was found to be “congruent” with the advice provided by emergency room staff at a local hospital, so the case showed “how inaccurate information on the Internet can contribute to the consequences of following advice received through face-to-face encounters”,¹³³ rather than demonstrating a direct causative link between the use of online health information and harm to the child in question.
- There was an apparent association between access to online health information and non-adherence to healthcare regimes in a study that found 11.2% of respondents reporting internet-instigated non-adherence and concluded “negative consequences for healthcare adherence behaviour resulting from internet health information utilization appear substantial”.¹³⁴
- An analysis of 1,512 journal article abstracts found three articles describing direct harm arising from following online health information, including two cases of emotional harm as a result of improper internet searches, one instance of kidney failure in a cancer patient who obtained misinformation about the use of medication on the internet, and one example of dogs being poisoned as a consequence of misinformation derived from the internet.¹³⁵
- Interviews with cancer patients suggested that exposure to complex biomedical information, even when it is accurate, can create significant anxiety.¹³⁶
- One survey that found 8% of doctors surveyed reported that some of their patients had suffered physical harm as a consequence of accessing online health information.¹³⁷

¹³² For example, at the time of writing, a search for “heart disease” on Google.co.uk returned different results from those coming from the same search term used on Google.com: the top three results (excluding news stories) for Google.co.uk included the relevant Wikipedia entries, the NHS and the British Heart Foundation; for Google.com, the results were for Wikipedia, WebMD and the American Heart Association.

¹³³ Crocco AG, Villasis-Keever M and Jadad AR (2002) Two wrongs don’t make a right: Harm aggravated by inaccurate information on the internet *Pediatrics* **109**: 522–3.

¹³⁴ Weaver JB, Thompson NJ, Weaver SS and Hopkins GL (2009) Healthcare non-adherence decisions and internet health information *Computers in Human Behaviour* **25**: 1373–80.

¹³⁵ Crocco AG, Villasis-Keever M and Jadad AR (2002) Analysis of cases of harm associated with use of health information on the internet *Journal of the American Medical Association* **287(21)**: 2869–71.

¹³⁶ Broom A and Tovey P (2008) The role of the internet in cancer patients’ engagement with complementary and alternative treatment *Health (London)* **12**: 139.

¹³⁷ Responses were received from 748 doctors, including 375 general practitioners: respondents estimated that 1%–2% of their patients used the internet for health information in the previous month. See: Potts HWW and Wyatt JC (2002) Survey of doctors’ experience of patients using the internet *Journal of Medical Internet Research* **4(1)**: e5.

Use of private information

5.25 As noted earlier, searching for information online may, to a certain extent, enable third parties to track people's identities, which pages they view and where they are located. Such data can be commercially valuable, in addition to the information that people knowingly add to some websites, for example when they are obliged to register to gain access. The balance of advantage and disadvantage to individual users of the information trail that their searches generate depends on their circumstances and their perceptions: they might, for instance, be grateful to be notified of clinical trials relevant for their condition, or upset by being sent targeted marketing for products they think are inappropriate for them. That is why protection of individuals' personal data has to be balanced against other considerations.

Public health possibilities

5.26 Further, searching for online health information and entering information onto websites offers possibilities beyond the individual. Information about which search terms are being entered and which pages are viewed as well as actual information submitted can all, if aggregated in a suitable way, have the potential to be useful for public health, research and commercial purposes.¹³⁸ Examples include infectious disease surveillance, understanding patterns of chronic disease, assessing health behaviour and marketing.¹³⁹ For instance, in 2009, it was shown that by analysing Google search terms related to influenza and its symptoms, researchers were able to predict accurately influenza outbreak in the USA one to two weeks prior to the publication of surveillance reports by the Centers for Disease Control and Prevention, which relied on more typical disease modelling.¹⁴⁰ We return to informing users of health information websites about the use of their information in our recommendation in Paragraph 5.54.

Extent of use

Access to and use of the internet

5.27 It is well known that increasing numbers of people have access to and use the internet, especially in developed countries, as is illustrated in Figure 5.1.¹⁴¹ It is also well known that there is a 'digital divide', with marked variations between socio-economic groups in terms of access to and use of the internet. For example, as of 2008, some 93% of UK adults under 70 who had a degree or equivalent qualification were reported as having access to the internet in their homes, compared with 56% of those with no formal qualifications.¹⁴² However, those over 65 were the least likely to use the internet, with 70% stating they had never used it. Although those numbers seem likely to change (the numbers of over-65s reporting they had never used the internet had been 82% in 2006), the digital divide remains serious for the age group that represents the heaviest users of healthcare, meaning there are important values of fairness and

¹³⁸ See, for example: Google Trends, <http://www.google.com/trends>.

¹³⁹ See: Kahn J, Vayena E and Dzenowagis J (2009) *Ethical, legal and policy issues in the use of electronic health information for public health research and practice*, discussion paper presented at: World Health Organization conference on Internet ethics, law and policy: Issue spotting on the use of electronic health information for public health purposes, 17–18 December 2009, Geneva.

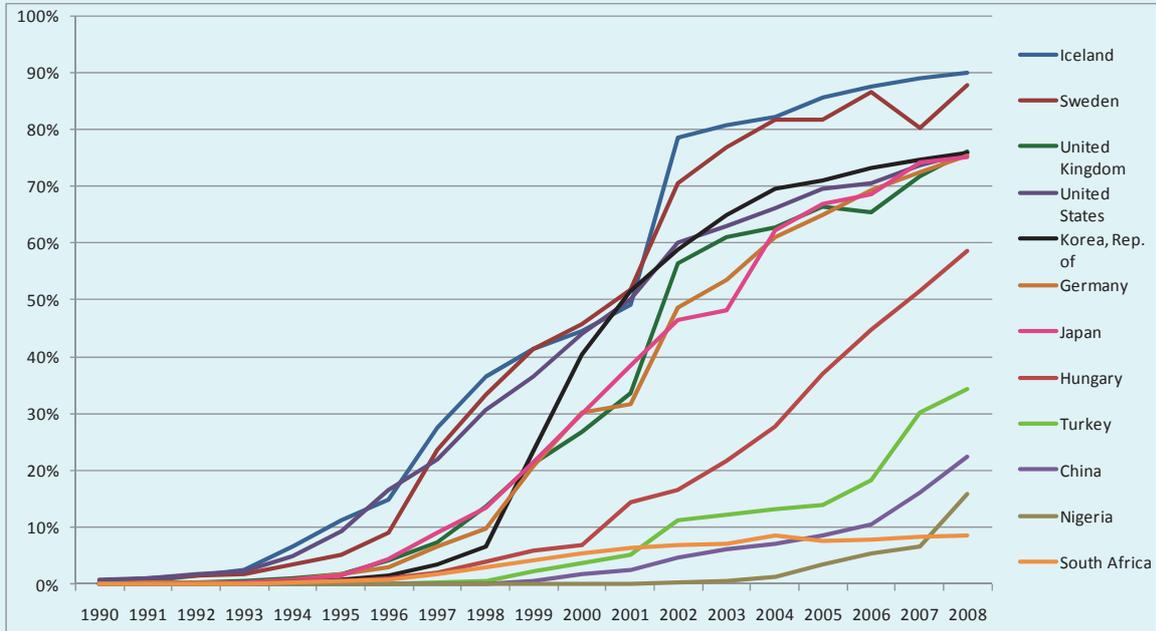
¹⁴⁰ Ginsberg J, Mohebbi MH, Patel RS *et al.* (2009) Detecting influenza epidemics using search engine query data *Nature* **457**: 1012–4.

¹⁴¹ Between 2002 and 2008 in Great Britain access to the internet increased from 46% of all households to 65%. In the USA, between 2000 and 2009, the percentage of American adults with access to the internet increased from 46% to 74%. Additionally, broadband internet access, which enables a far higher rate of data transfer than dial-up access, has become more prevalent. In 2006 in the UK, 40% of households had a broadband connection, and by 2008, this number had increased to 56%. In the USA, from 2000 to 2009, the figure rose from 5%–57%. See: Office for National Statistics (2008) *Internet access 2008 households and individuals*, available at: <http://www.statistics.gov.uk/pdfdir/iahi0808.pdf>; Fox S and Jones S (2009) *The social life of health information*, available at: http://www.pewinternet.org/~media/Files/Reports/2009/PIP_Health_2009.pdf.

¹⁴² Office for National Statistics (2008) *Internet access 2008 households and individuals*, available at: <http://www.statistics.gov.uk/pdfdir/iahi0808.pdf>. This report indicates that 71% of adults in the UK had used the internet within the previous three months before interview and of those, 69% used it every day or almost every day.

autonomy at stake for such information, particularly if those who are unwilling or unable to use the internet for health purposes are likely to be disadvantaged as a result.

Figure 5.1: Internet users as percentage of population in selected countries across the world¹⁴³



Use of the internet for health-related purposes

- 5.28 Some evidence suggests that people see the internet as only one source of information and valued having a range of different types of information about prescribed medicines.¹⁴⁴ In 2007 the Pew Internet and American Life Project found that “experts mattered most when people faced health problems”.¹⁴⁵ Other research has concluded that “online information and advice influence[es] patients’ decision making without threatening their desire to communicate with physicians” and the physician remained “the single most important source of advice on health” despite not being the “first port-of-call” for health information.¹⁴⁶
- 5.29 Figures vary about what proportion of people use the internet to obtain health-related information. In 2008, the UK Office for National Statistics reported that 34% of all recent UK internet users had used it to seek health-related information.¹⁴⁷ The 2009 Oxford Internet Survey found that 68% of British internet users searched for health information online.¹⁴⁸ Figures for other developed countries also suggest that 70% or more of internet users use it to

¹⁴³ Data obtained from World Bank Development Indicators, data derived from International Telecommunication Union, World Telecommunication Development Report and database, and World Bank estimates. See: International Telecommunication Union (2008) Internet Users (per 100 people), available at: <http://data.worldbank.org/indicator/IT.NET.USER.P2>.

¹⁴⁴ MORI Research sponsored by Medicines Partnership (2004) *The public and prescribed medicines*, available at: <http://www.ipsos-mori.com/researchpublications/researcharchive/poll.aspx?oltemid=670>.

¹⁴⁵ Estabrook L, Witt E and Rainie L (2007) Information searches that solve problems: How people use the internet, libraries, and government agencies when they need help, available at: http://www.pewinternet.org/~media/Files/Reports/2007/Pew_UI_LibrariesReport.pdf.pdf.

¹⁴⁶ Sillence E, Briggs P, Harris PR and Fishwick L (2007) How do patients evaluate and make use of online health information? *Social Science & Medicine* 64: 1853–62.

¹⁴⁷ Office for National Statistics (2008) *Internet access 2008 households and individuals*, available at: <http://www.statistics.gov.uk/pdfdir/iahi0808.pdf>.

¹⁴⁸ Dutton WH, Helsper EJ and Gerber MM (2009) *The internet in Britain 2009*, p20, available at: http://www.oii.ox.ac.uk/research/oxis/OxIS2009_Report.pdf.

obtain health related information.¹⁴⁹ In addition to simply seeking information, substantial numbers of people are reported to participate in patient groups and other online communities associated with health information: for example, PatientsLikeMe.com reported that they had over 40,000 members registered with the site.¹⁵⁰

- 5.30 The use of online health information also appears to be shaped by demographics. The 2009 Oxford Internet Survey reported that in Britain women were more likely to look for health information online than men, and the employed and retired to seek more health information than students.¹⁵¹ Perhaps relating to the ‘digital divide’ to which we referred earlier, some research from the USA suggests that older, poorer, less healthy and less educated members of society are less likely to seek health information from online sources.¹⁵²
- 5.31 The medical profession’s response to the rise of online health information seems to have been mixed. Some doctors see the use of the Google search engine as a diagnostic tool as being “laughable and bordering on dangerous”,¹⁵³ while others consider the internet to “encourage early presentation and action that could improve survival and reduce complications from long term conditions”.¹⁵⁴ It may also be that healthcare professionals find the internet useful for finding information themselves.¹⁵⁵ The British Medical Association (BMA) told us that it supported the idea of patients taking more interest in their own healthcare but was concerned about difficulties patients may experience when attempting to identify reliable and accurate information.¹⁵⁶ We return to this problem in our recommendation in Paragraph 5.63.

Current system of interventions

- 5.32 Although there is a system of governance for the basic infrastructure of the internet (notably the domain name system), there is no overall oversight of the information that appears on it. Different countries apply their laws to the information on it and how people in their jurisdictions use it. Governments use a variety of methods to try to control people’s access to information on the internet, and these methods are illustrated in Box 5.4.
- 5.33 Most of the existing types of intervention relating to health information on the internet in the UK and many other countries fall into the category of what we called ‘general governance’ measures in Chapter 4, and of those measures some involve the exercise of state-specific legal power and some do not. As noted earlier, the main state-specific legal power relevant to this area is the data protection regime, and the standard disciplinary codes and rules for medical professionals apply where they are involved with the provision of online health information. The main type of general governance measure that does not involve state-specific legal powers is that of the advertising standards regime. The only service-specific form of intervention that appears to apply to this domain is that of accreditation schemes, which also do not involve state-specific legal power.

¹⁴⁹ In 2007, research into European citizens’ use of the internet for health-related purposes reported that 44% of European citizens, and 71% of European internet users, had accessed the internet for health-related purposes. (Andreassen HK, Bujnowska-Fedak MM, Chronak CE *et al.* (2007) European citizens’ use of e-health services: A study of seven countries *BMC Public Health* 7: 53). In the USA, the Pew Internet and American Life Project estimated that in 2008 75–80% of all internet users in the USA looked online for health information. (Fox S (2008) *The engaged e-patient population*, available at: http://www.pewinternet.org/~media/Files/Reports/2008/PIP_Health_Aug08.pdf.pdf).

¹⁵⁰ PatientsLikeMe.com (2009) Response to the Working Party’s consultation.

¹⁵¹ Dutton WH, Helsper EJ and Gerber MM (2009) *The internet in Britain 2009*, p20, available at: http://www.oii.ox.ac.uk/research/oxis/OxIS2009_Report.pdf.

¹⁵² Cotton SR and Gupta SS (2004) Characteristics of online and offline health information seekers and factors that discriminate between them *Social Science & Medicine* 59: 1795–1806.

¹⁵³ Winthrop TC (2006) This is research? *British Medical Journal* [rapid response to Tang H and Ng JHK (2006) Googling for a diagnosis – use of Google as a diagnostic aid: Internet based study 333: 1143–5], available at: http://www.bmj.com/content/333/7579/1143.full.reply#bmj_el_148937.

¹⁵⁴ Shaw J (2009) A Reformation for our times *British Medical Journal* 338: b1080.

¹⁵⁵ Hartzband P and Groopman J (2010) Untangling the web – patients, doctors and the internet *New England Journal of Medicine* 362(12): 1063–6.

¹⁵⁶ British Medical Association (2009) Response to the Working Party’s consultation.

Box 5.4: Potential methods of intervention applying to the internet

Pre-existing rules: The application of rules relating to pre-existing, well understood activities and the assertion of associated (and often legally uncontroversial) sanctions, such as those criminal penalties that relate to the distribution of child pornography. It is possible to punish criminally those in 'physical' possession of prohibited material in one jurisdiction,¹⁵⁷ i.e. on a hard drive of a computer.

Alternative dispute resolution: Consumer-related international litigation is more effectively managed through alternative dispute resolution, especially small-value internet disputes.¹⁵⁸ This is not because the legal framework to manage it in the courts does not exist, but because (as mentioned below) associated practical difficulties often render such procedures beyond the reach of the average litigant (i.e. cost, translation, time, difficulty in enforcing judgments in foreign courts and so on).¹⁵⁹

Upstream filtering: Filtering imposed from 'above' without the knowledge or consent of those so filtered. An example is mandatory or voluntary internet service provider (ISP) access restrictions of specific internet addresses. ISPs subscribe to, or have imposed upon them, 'no access' lists of specific web addresses which render particular web addresses inaccessible by the average user using the particular ISPs.

Bandwidth management: This may involve rate management of data over networks by ISPs (i.e. restricting the volume of data a particular user can move over certain networks, and therefore the 'speed' with which people can access certain data). This technique can be used to limit the bandwidth of users engaging in file sharing over peer-to-peer networks, for example.

Internet intermediary liability: The enforcement of specific rules on those intermediary entities responsible for providing the physical or software-based infrastructure of the internet and web (telecommunication networks and ISPs, for example) or those who provide access to, host or distribute content (such as search engines, YouTube or eBay and peer-to-peer networks). Examples include criminal responsibility for content that crosses a network; a legal responsibility not to provide access to prohibited items in a specific jurisdiction (such as search engines and Nazi memorabilia)¹⁶⁰ or liability for distributing copyrighted material.¹⁶¹

Monitor and warn: Online activity can be monitored and a user may be presented with a warning that their activity has been monitored.¹⁶²

Notice and disconnection: When an individual breaches a particular rule on what can and cannot be accessed online (such as downloading music in breach of copyright),¹⁶³ they may be warned (for example by their ISP, online or in writing) that their activity has been monitored and that repeat activity will result in their connection being terminated.

¹⁵⁷ Edwards L (2009) Pornography, censorship and the internet, in *Law and the internet* Edwards E and Waelde C (Editors) (Oxford and Portland, Oregon: Hart Publishing), p649.

¹⁵⁸ For example, 41% of respondents to a Eurobarometer who had submitted a formal complaint regarding a cross-border purchase reported they were not satisfied with way the complaint was handled. See: European Commission (2006) *Consumer protection in the internal market: Special Eurobarometer 252 / wave 65.1 – TNS opinion & social*, p32, available at: http://ec.europa.eu/public_opinion/archives/ebs/ebs252_en.pdf.

¹⁵⁹ Hörnle J (2009) The jurisdictional challenge of the internet, in *Law and the internet*, Edwards E and Waelde C (Editors) (Oxford and Portland, Oregon: Hart Publishing), p121.

¹⁶⁰ *LICRA et UEJF v Yahoo! Inc and Yahoo! France* (20 November 2000: Tribunal de Grande Instance de Paris, Superior Court of Paris) 14.

¹⁶¹ *Metro-Goldwyn-Mayer Studios Inc et al v Grokster et al*. 243 F Supp 2d 1073 (CD California 2003).

¹⁶² Edwards L (2009) The fall and rise of intermediary liability online, in *Law and the internet* Edwards E and Waelde C (Editors) (Oxford and Portland, Oregon: Hart Publishing), p81.

¹⁶³ *Ibid*, p82.

Jurisdiction

- 5.34 The use of the internet imposes significant practical (though usually not theoretical) difficulties in determining the geographical location of a particular act and therefore the national law that applies to it.¹⁶⁴
- 5.35 Rules establishing jurisdiction are not part of international law, but are an element of domestic civil procedure,¹⁶⁵ the specifics of which vary between countries. In England and Wales, the process is governed by the Civil Procedure Rules when the litigants all live in England/Wales and a non-EU country, and by the Brussels Regulation (a set of rules applying to this area) when some of the litigants are from the EU. In Scotland, all such matters are dealt with under the Brussels Regulation. Courts in a foreign jurisdiction are under no obligation in international law to recognise and enforce judgments from other jurisdictions, unless there is a bi- or multi-lateral agreement requiring such action (for example the Brussels Regulation in Europe).¹⁶⁶ Contractual obligations may specify the jurisdiction in which subsequent litigation takes place, although different rules apply to consumers and they may have greater freedom in terms of choosing where to bring an action.¹⁶⁷

Liability

- 5.36 We have already noted that health information on the internet, along with many other types of health information, is not necessarily verified for clarity or accuracy. Users therefore need to appreciate that people are free in many countries to post misleading or inaccurate information on the internet that could be accessed by many people across the world. However, should an individual believe they were harmed because they followed advice from an online health information provider, they can in principle take action against that provider under the law of tort in England, Wales and Northern Ireland (see Box 4.1) and in other countries under similar laws. To give an example from another legal domain, there have been successful cross-jurisdiction defamation claims.¹⁶⁸ For an action under tort law to be successful, the claimant would have to demonstrate that they were owed duty of care by the defendant, that such a duty was breached, that the breach caused harm and that damages or other loss resulted as a consequence of that breach. It is likely that the determination of 'duty of care' in these circumstances would be complicated by the nature of the individual or organisation that provided the relevant health information. For example, if the information was provided by a non-medically qualified individual posting on a patient group website rather than being provided on the website of a national health service provider, it may be harder to establish a duty of care. Further, some online health information providers state terms and conditions of use that warn that the information they offer should not replace a consultation with a health professional, and thus seek to limit their liability. Liability for posting misleading, inaccurate or confusing information is further complicated by the transnational nature of the internet as noted above: even where a claim could be made and an appropriate jurisdiction identified, the practicalities of the situation (the extra costs of litigating in an unfamiliar legal system, hiring translators, and so on) are likely to make it difficult for the average internet user to pursue an action even if they were so inclined.

¹⁶⁴ Hörnle J (2009) The jurisdictional challenge of the internet, in *Law and the internet* Edwards E and Waelde C (Editors) (Oxford and Portland, Oregon: Hart Publishing), pp121–2.

¹⁶⁵ *Ibid*, p123.

¹⁶⁶ *Ibid*, p152.

¹⁶⁷ Lloyd IJ (2008) *Information technology law* (New York: Oxford University Press), pp482–4.

¹⁶⁸ See, for example: *Dow Jones & Co Inc v Gutnick* (2002) HCA 56 at 92. Allegedly defamatory content was created in New York, placed on a server in New Jersey and accessed in the Australian state of Victoria. The court held that the claimant, Gutnick, could litigate his defamation action in Victoria, where defamation law was stricter than the USA. The court found that accessibility was sufficient for jurisdiction, provided the claimant had a reputation in that jurisdiction.

Data protection

- 5.37 As we mentioned above in Paragraph 5.25, when using health information websites users may send personal data, either knowingly or inadvertently. Data protection laws are concerned with the processing of personal data, and apply to the services provided by online health website providers, depending on the country in which they are based. For organisations and companies based in the EU, the basis of the legal regime is the Data Protection Directive,¹⁶⁹ which was implemented in domestic law in the UK by the Data Protection Act 1998 (Box 5.5). The scope of the Act is seen as very wide by the UK Information Commissioner's Office,¹⁷⁰ which holds that where an organisation collects or holds information about an identifiable living individual, or where such information is used, disclosed, retained or destroyed, the organisation is likely to be processing personal data relevant to the Data Protection Act.¹⁷¹

Box 5.5: Eight principles of the UK Data Protection Act

- 1 Personal data shall be processed fairly and lawfully.
- 2 Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
- 3 Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
- 4 Personal data shall be accurate and, where necessary, kept up to date.
- 5 Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.
- 6 Personal data shall be processed in accordance with the rights of data subjects under this Act.
- 7 Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
- 8 Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

- 5.38 Although the Data Protection Directive (and the domestic laws individual EU Member States have enacted to implement it) applies only to organisations based in the EU, personal data undergoing (or intended to undergo) processing after transfer which has been collected in an EU Member State cannot be transferred to a country that does not provide an appropriate level of protection.¹⁷² However, commentators have noted that it can be difficult to identify whether or not certain organisations are actually based in the EU: some companies voluntarily fulfil the necessary obligations required by the Data Protection Directive while maintaining that they are not formally bound by the legislation because they are not legally based in the EU. Given that such companies voluntarily comply with the relevant data protection legislation, the legal applicability of the Directive to their operations has not been tested in court.¹⁷³

¹⁶⁹ Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data [1995] OJ L281/31, as amended.

¹⁷⁰ Information Commissioner's Office (2010) Data protection basics, available at: http://www.ico.gov.uk/for_organisations/data_protection_guide/data_protection_basics.aspx. The Information Commissioner's Office was set up to "uphold information rights in the public interest [and] promot[e] openness by public bodies and data privacy for individuals". See: Information Commissioner's Office (2010) About the ICO, available at: http://www.ico.gov.uk/about_us.aspx.

¹⁷¹ Information Commissioner's Office (2010) Data protection basics, available at: http://www.ico.gov.uk/for_organisations/data_protection_guide/data_protection_basics.aspx.

¹⁷² European Union Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data [1995] OJ L281/31 art 25.

¹⁷³ The Working Party's fact-finding meeting with regulators, 23 September 2009.

- 5.39 Mainstream use of the internet has highlighted significant gaps in data protection law as a means of protecting consumers. Such law was originally developed as a way of protecting individuals from misuse of their information by the state or other organisations, and it focuses on identifying ‘data controllers’ and ‘processors’ within such organisations, in a way that is not reflected in the distributed type of information exchange represented by Web 2.0 and similar operations.¹⁷⁴ There have been moves to close such gaps, such as the EU Privacy and Electronic Communications Directive 2002, but the adequacy of those moves can be questioned.¹⁷⁵
- 5.40 It has been claimed that there may be a generational ‘value-gap’ over the protection of certain types of personal data – as reflected, for example, in some users’ apparent (tacit) acceptance of targeted advertising when it is a feature of desired products or services, such as Facebook or Google. It has been questioned whether consent still has a role to play in protecting consumer internet data-protection interests,¹⁷⁶ given that e-commerce and ‘free’ e-services such as social networking services rarely offer any opportunities to negotiate data-use terms. However, society in general still reacts harshly to large-scale data leakage.

Advertising

- 5.41 Direct-to-consumer advertising of pharmaceuticals is prohibited in the EU. However, companies are permitted to include information about their products on their websites (see Paragraph 7.31). More broadly, advertisements on UK websites are covered by the existing UK advertising code, which applies equally to conventional print, radio and television media and originated in the early 1960s as a set of standards imposed by the advertising industry on itself. The Advertising Standards Authority (ASA) broadly seeks “to ensure ads are legal, decent, honest and truthful”.¹⁷⁷ The ASA has a variety of sanctions, such as prohibiting adverts or advertising techniques and requiring advertisers to seek advice before publishing future adverts.¹⁷⁸ The ASA can also refer the publisher of an advert to the Office of Communications (Ofcom), the communications regulator, which has the power to impose financial penalties.¹⁷⁹
- 5.42 We note that some commentators are concerned that advertising of health products and treatments could be specifically directed at particular users without their prior knowledge, based on the pages they have viewed and the information they have entered on patient websites, particularly given that some of these individuals may be particularly vulnerable as a result of a desperate search for information about treatments for their condition, or that of a dependent.¹⁸⁰ We return to this issue in our recommendation in Paragraph 5.61.

Accreditation of health-related websites and tools for users

- 5.43 There are various accreditation schemes for health-related websites. In England, the Department of Health launched a health information accreditation system (the ‘Information Standard’) in 2009 which aimed to ensure that people could identify high-quality health information through a kitemarking scheme. The Information Standard is “a quality filter which helps people to identify reliable information”.¹⁸¹ Organisations that meet the quality criteria

¹⁷⁴ Edwards L (2009) Privacy and data protection online: The laws don’t work? in *Law and the internet* Edwards E and Waelde C (Editors) (Oxford and Portland, Oregon: Hart Publishing), pp472–3.

¹⁷⁵ *Ibid*, pp471–2.

¹⁷⁶ *Ibid*, p487.

¹⁷⁷ See: <http://www.asa.org.uk/>.

¹⁷⁸ Advertising Standards Authority (2009) response to the Working Party’s consultation.

¹⁷⁹ *Ibid*.

¹⁸⁰ For example, a 2009 article in *The New York Times* that claimed RealAge.com receives payments from pharmaceutical companies for the compilation of test results from RealAge.com members and the opportunity to send them marketing messages by e-mail promoting particular products based on the information the members entered. RealAge’s Privacy Policy referred to this practice, but *The New York Times* article alleged that critics believed some users did not seem to be aware of it. See: Clifford S (2008) Online age quiz is a window for drug makers *The New York Times* 25 March, available at: http://www.nytimes.com/2009/03/26/technology/Internet/26privacy.html?_r=2&ref=business.

¹⁸¹ The Information Standard (2010) What is the standard?, available at: <http://www.theinformationstandard.org/standard>.

specified by the Information Standard are entitled to place a quality mark on their materials, including websites and print media.¹⁸² The Department of Health is the 'owner' of the Information Standard, but has licensed the scheme to the outsourcing company Capita.¹⁸³ The Information Standard requires that information be accurate, impartial, balanced, based on evidence, accessible and well written.¹⁸⁴

- 5.44 In the USA, an independent, not-for-profit organisation, the Utilization Review Accreditation Commission (URAC), aims to promote healthcare quality through accreditation and certification programmes. URAC accredits many types of healthcare organisations, including health websites.¹⁸⁵ It reviews a company's operations to ensure that the company is conducting business consistent with national standards. Among other things, URAC claims it has enhanced editorial transparency of online health sites by requiring providers to verify and disclose the credentials of their health content reviewers, and how they conduct verification of credentials. URAC provides a symbol that can be displayed by health websites, showing that the website has met these standards. Accredited health information websites include the BlueCross and Blue Shield Association, Microsoft HealthVault and WebMD.¹⁸⁶
- 5.45 The Health on the Net Foundation Code of Conduct (HONcode)¹⁸⁷ was developed in the mid-1990s by the HON Foundation, a Swiss-based non-governmental organisation. The stated aim was to encourage the dissemination of quality health information for patients and professionals, and to facilitate access to the latest and most relevant medical data.¹⁸⁸ At the time of writing, the HONcode was used by over 7,300 certified websites in 102 countries.¹⁸⁹ The HONcode specifies eight principles for the presentation of medical and health information on the internet (Box 5.6). Where a website conforms to the HONcode, and has applied for certification from the HON Foundation, the website is entitled to display the HONcode logo. The HON Foundation states that the HONcode "does not seek to rate the medical accuracy, validity or appropriateness of the information itself"¹⁹⁰ and the presence of its logo does not guarantee that the information provided on the website is accurate. Applicants must request approval to use the logo and permission is given after the Foundation has assessed the website in question in order to ascertain whether or not it conforms to the standards required. The logo is linked to the HONcode ID Index of registered and approved websites, such that a user who clicks on the logo can ascertain whether the website has had its registration declined or revoked.

¹⁸² The Information Standard (2010) What is the quality mark?, available at: <http://www.theinformationstandard.org/qualitymark>.

¹⁸³ Information Standard (2010) Scheme rules, available at: <http://www.theinformationstandard.org/scheme-rules>.

¹⁸⁴ The Information Standard (2010) What is the standard?, available at: <http://www.theinformationstandard.org/standard>.

¹⁸⁵ URAC (2010) General questions about URAC accreditation, available at: <http://www.urac.org/healthcare/accreditation/>; URAC (2010) URAC's health web site and health content vendor accreditation programs, available at: http://www.urac.org/programs/prog_accred_HWS_po.aspx?navid=accreditation&pagename=prog_accred_HWS.

¹⁸⁶ URAC (2009) URAC directory of accredited companies, available at: <http://www.urac.org/directory/DirectorySearch.aspx>.

¹⁸⁷ Health on the Net Foundation (2010), The HON Code of Conduct for medical and health web sites (HONcode), available at: <http://www.hon.ch/HONcode/Conduct.html>.

¹⁸⁸ Health on the Net Foundation (2010) Our beginnings, available at: <http://www.hon.ch/Global/index.html>; Health on the Net Foundation (2010) Our commitment to reliable health and medical information, available at: <http://www.hon.ch/HONcode/Patients/Visitor/visitor.html>.

¹⁸⁹ Health on the Net Foundation (2010) Our commitment to reliable health and medical information, available at: <http://www.hon.ch/HONcode/Patients/Visitor/visitor.html>.

¹⁹⁰ Health on the Net Foundation (2010) Methodology, available at: <http://www.hon.ch/HONcode/Patients/method.html>.

Box 5.6: Eight principles of the HONcode

- 1 Authoritative – Indicate the qualification of the authors.
- 2 Complementarity – Information should support, not replace, the doctor-patient relationship.
- 3 Privacy – Respect the privacy and confidentiality of personal data submitted to the site by the visitor.
- 4 Attribution – Cite the source(s) of published information, date and medical and health pages.
- 5 Justifiability – Site must back up claims relating to benefits and performance.
- 6 Transparency – Accessible presentation, accurate email contact.
- 7 Financial disclosure – Identify funding sources.
- 8 Advertising policy – Clearly distinguish advertising from editorial content.

5.46 Three other examples of online health information accreditation systems are noted below:

- Discern – a brief questionnaire designed to provide users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem.
- MedCIRCLE – the ‘Collaboration for Internet Rating, Certification, Labeling and Evaluation of Health Information’. MedCIRCLE comprises three European health portals in Spain, France and Germany with the goal of evaluating, describing or annotating health information on the web.
- MedIEQ – a multinational project co-funded by the European Commission. It attempts to automate the quality labelling process in medical websites by providing tools that search the internet to locate medical websites in eight European languages to verify their content against a set of machine-readable quality criteria.

5.47 The value of accreditation or ‘kitemarking’, as applied to online health information can be debated. For example, it has been noted that consumers cope with un-accredited sources of health information (such as newspapers, magazines and television programmes) despite frequent inaccuracies in information provided.¹⁹¹ But it can also be argued that accreditation is an important aid to information-seekers given that “the objective of most quality rating tools...is not to inhibit publication, but to provide a system by which consumers can assess the nature of the information they are accessing.”¹⁹²

5.48 Various agencies, professional or governmental, provide guidelines to help consumers evaluate health information on the internet. For example, the British Medical Association (BMA) provides a checklist of factors to take into account when looking for health information online (such as whether or not the site gives references and sources for the information provided), and offers examples of reputable “medical gateways” (such as NHS Direct) for identifying useful health information.¹⁹³ In the USA, the Food and Drug Administration (FDA) provides a list of questions for consumers to consider and the Medical Library Association provides a users’ guide to finding and evaluating online health information.¹⁹⁴

¹⁹¹ Delamothe T (2002) Quality of websites: Kitemarking the west wind *British Medical Journal* **321**: 843–4.

¹⁹² Wilson P (2002) How to find the good and avoid the bad or ugly: A short guide to tools for rating quality of health information on the internet *British Medical Journal* **324**: 598–602.

¹⁹³ British Medical Association (2008) Health information: Finding reliable sources on the internet, available at: http://www.bma.org.uk/patients_public/finding_reliable_healthcare_information/healthinfonet.jsp.

¹⁹⁴ Food and Drug Administration (2005) How to evaluate health information on the internet, available at: <http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/BuyingMedicinesOvertheInternet/ucm202863.htm>; Medical Library Association (2010) A user’s guide to finding and evaluating health information on the web, available at: <http://www.mlanet.org/resources/userguide.html>.

Softening the ethical dilemmas

- 5.49 For online health information, the main conflict among the values we identified in Chapter 3 is that between individuals' ability to pursue their own interests in their own way (that is, using the internet freely to access the health information they want) and the values of safeguarding private information and state activity to reduce harms. Another potential conflict arises between the ethical value of safeguarding private information and social solidarity in the form of information pooling for common benefit, for instance in research. As described in Chapters 3 and 4, we aim to reduce or soften those dilemmas by recommending practical and proportionate forms of intervention. In some cases we may not consider that any policy change or introduction of interventions is feasible or desirable, but still think that the developments in question merit comment. That latter consideration applies particularly to restrictions on the way the internet is to be used, given the practical difficulties described earlier.
- 5.50 As we have indicated, some forms of online health information can help people increase their understanding of their own bodies, health and illness, and to become more involved with and take more control over their healthcare if they want to, for example by using some of the interactive tools available for managing chronic conditions. Indeed, good-quality health information can be argued to be key to enabling individuals effectively to pursue their own interests in their own way. Information on the internet can be accessed in private and at the user's convenience, and when it is accurate it can also help people to decide when face-to-face professional health advice is necessary and when it might not be. Patient group websites have the potential to be an especially valuable source of information and indeed a new form of solidarity for people with a particular condition who want to share experiences with others in similar situations. As mentioned earlier, information pooled from internet sources can also be used to convey public health benefits and as a source of research data that may be a common-pool resource for the future.
- 5.51 As noted earlier, there is little evidence that online health information has led to serious or widespread harm. Nevertheless, such harm could arise from individuals receiving false reassurance or suffering undue anxiety, as a result of inaccuracy or misinterpretation of information obtained online, as we have suggested above (see Paragraph 5.20). So we aim to reduce the risk of such harms while not restricting the corresponding benefits to individuals and wider society.
- 5.52 We think the lack of evidence of harms means that attempts to prohibit the publication of, or access to, online health-related information would plainly not be proportionate at this time. We argued in Chapter 4 that it is only proportionate to recommend interventions relying on the state's special legal powers (to compel, prohibit, permit or punish) when the harm justifies the use of such powers, so in this case our recommendations involve actions that do not rely on those powers. We are specifically concerned with finding forms of intervention that aid people to pursue their own interests in their own way by enabling them to assess more easily the quality of the online information they are receiving. Our aim is to help encourage a climate in which more providers of online health information follow good practice and more users come to expect such practice of the sites they visit. Our recommendations below therefore involve voluntary adoption of good practice for websites and forums, good professional medical practice, third-party accreditation and government monitoring of any impact of the 'digital divide'. In line with the approach set out in Chapter 4, we have recommended general governance measures except in situations where only a product-specific measure would achieve the desired outcome.

Content of websites

- 5.53 Given the importance today of online health information, as noted earlier (see Paragraph 5.17), we are concerned that it is not always easy for individuals to assess the quality or accuracy of such information. There are no strong incentives for information providers to follow 'best practice' in terms of the information they provide to users of their websites. It is also difficult for

people to ascertain the origin of a website and the information on it, including which country the information provider is based in. Even though patient group websites may be highly valuable in some cases, as we have also noted earlier, there is a risk that users of these sites may not be aware that advice for one person may not be appropriate for another person, even if their condition appears similar. We therefore think that users of online health information would be assisted by higher quality information and more transparency about the nature of websites.

5.54 To facilitate individuals to pursue more easily their own interests in their own way, we recommend that all websites, including patient group 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 (for further detail see the recommendation in Paragraph 5.61 below);**
- **where the provider(s) of the website are based; and**
- **funding and advertising arrangements.**

Advertisements should also clearly be distinguishable as such.

5.55 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. For example, in the UK, 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.¹⁹⁵

5.56 **In line with our ethical value of the state making efforts to reduce harm (see Chapter 3), we recommend that states should provide high-quality health information on the internet or ensure that such information is available, and that healthcare professionals should draw their patients' attention to these sites. How exactly this recommendation is to be carried out is a matter for each health system: but, within the UK, we think the UK Government Departments of Health have a special responsibility to ensure that their websites meet the criteria above, given their public funding, reputation and public role and the fact that they are trusted by the public.**¹⁹⁶

5.57 While recognising that accreditation of websites has its limitations as a tool of intervention (see Paragraph 5.47), 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 information, and that accreditation initiatives run or sponsored by the state are one way in which the state can reduce harm in this domain.

5.58 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

¹⁹⁵ We note that these websites are also used to some degree by residents of other countries. The NHS Choices website, for example, typically receives approximately 10% of its traffic from non-UK countries. (Information supplied by the Department of Health).

¹⁹⁶ One NHS survey, for example, found that 46% of internet users would be "much more likely" to trust a health information website run or licensed by the NHS, while 32% would be "a little more likely". (Information supplied by the Department of Health).

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.

- 5.59 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 the climate we described in Paragraph 5.52 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.

Use of information

- 5.60 People find comfort, and indeed solidarity, through exchanging experiences with others in similar situations on patient group websites. But such advantages can conflict with the value of safeguarding private information, since users may not know who has access to data about their internet use or access to the information they provide, and under what conditions and for what uses. While organisations with websites based in the EU are subject to the data protection regime described earlier (see Paragraphs 5.37–40), others may fall under different jurisdictions. We are concerned that many people are not aware that it could be possible for third parties to identify (to some extent) individual users, using information that does not appear to identify them directly,¹⁹⁷ such as which condition they have or which hospitals they have attended, especially when combined with information they provide in other formats, such as social networking sites.
- 5.61 As well as information about how their content is derived, we recommend that health information websites, including those of patient groups, should also state whether and how they use, store, pass on or sell personal information (including the record of searches carried out and pages viewed) to third parties, in language that lay people can understand. We recommend that all use and passing on of data should require ‘opt-in’ by the user. Including information about all these aspects of using and passing on information should also be a requirement of any accreditation scheme (see also Paragraph 5.58).¹⁹⁸

Doctor-patient relationship

- 5.62 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.¹⁹⁹ Doctors and other healthcare professionals may increasingly be called upon to advise patients about the quality of the information they obtain online. The doctor-patient relationship might change because patients come to identify an appropriate course of action for themselves, perhaps one their doctor might not have thought of. On the other hand, there are potential problems associated with more health information available online that healthcare professionals will need to manage carefully. For example, professionals might find

¹⁹⁷ For a discussion of the possibility of ‘de-anonymisation’, see: Narayanan A and Shmatikov V (2008) Robust de-anonymization of large sparse datasets *Security and Privacy – EEE Symposium on Security and Privacy*, pp111–25, available at: http://www.cs.utexas.edu/~shmat/shmat_oak08netflix.pdf; Singer N (2009) When 2+2 equals a privacy question *The New York Times* 17 October, available at: http://www.nytimes.com/2009/10/18/business/18stream.html?_r=1.

¹⁹⁸ This is already a feature of the HONcode. See: Health on the Net Foundation (2010) Principle 3: Confidentiality – guidelines, available at: http://www.hon.ch/HONcode/Guidelines/hc_p3.html.

¹⁹⁹ Royal College of Physicians (2010) *Future physician: Changing doctors in changing times – report of a working party* available at: <http://bookshop.rcplondon.ac.uk/details.aspx?e=314>.

their judgments increasingly contested by patients in the light of information and advertising they have found on the internet. Patients might request treatments they have seen that are not provided by their public healthcare system or insurance scheme, such as certain branded pharmaceuticals rather than generic products. Such responses may well increase as a result of more direct advertising of pharmaceuticals and marketing material becoming available online to people in many different countries. Again, the values of individuals being able to pursue their own interests in their own way and of the state making efforts to reduce harm can come into conflict, and we make some recommendations below for measures that would soften the dilemmas that might arise.

- 5.63 **We recommend that organisations responsible for the training of healthcare professionals and professional standards (such as medical schools, Royal Colleges and the General Medical Council in the UK) 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. Some patients will be well informed but others will not have gained additional information in advance of their consultation. Indeed the same patient may be more or less informed by good-quality information on different visits. Other patients will have found misleading or confusing information about which they require advice. Healthcare professionals should also help patients to recognise that bringing a large amount of irrelevant or inaccurate health information might lead to a less productive consultation.**
- 5.64 **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 the National Institute for Health and Clinical Excellence (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.**

The digital divide

- 5.65 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 harms to any particular group in society.
- 5.66 **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.**

Future impact

- 5.67 Accessing online information about health seems likely to increase as more people go online across the world and more health-related websites appear. Elderly people on average use healthcare services more than other age groups, and we know that elderly people do not currently use the internet as much as younger people. It may well be that as people who are now middle-aged and younger get older, they will continue to use the internet in whatever future form it takes, especially for health-related searches – but that is speculative.
- 5.68 Health sites on the internet may well be a magnet for the ‘worried well’: but it also needs to be recognised that many people are vulnerable and desperate for help at the time they look for health information. That vulnerability, combined with opportunities for profit from selling people health-related products – as well as from selling the information people provide (sometimes unwittingly) to companies and organisations with a commercial interest – means there are risks of exploitation. We do not think the risks are imaginary, but they must be assessed alongside the real benefits that open access to high-quality, peer-reviewed, evidence-based health information can bring to individuals and to health services. Should evidence emerge of serious harms being caused directly from internet health information, more intrusive interventions than those we have recommended in this report would be justified (see the possibilities available in Box 5.4). Policy makers also need to be aware that the internet can be used by groups to mobilise support for particular health conditions, and such activity may mean that certain groups – those with good access to, and knowledge of, the internet – may receive a lot of attention among the public, in the media and elsewhere while others can be overlooked.