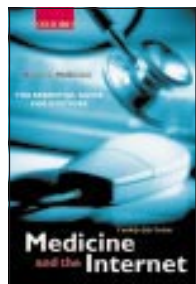


reviews

BOOKS • CD ROMS • ART • WEBSITES • MEDIA • PERSONAL VIEWS • SOUNDINGS

Medicine and the Internet: The Essential Guide for Doctors

Third edition
Bruce C McKenzie



Oxford University Press,
£19.50, pp 320
ISBN 0 19 851063 2
Published on 21 March

Rating: ★★★

Whatever the quality of health information on the internet—and the problems associated with its evaluation are well reviewed—there is no doubt that the best resources for understanding the internet are on the internet itself. Doctors might be forgiven for not having indulged in the kind of playful use of the internet that eventually leads to expertise. However, it is questionable whether any book can shortcut this process. Paper still has its advantages, but it's at its most useless

describing the internet; it is better just to get on and surf.

This book eschews making practical points about any particular client software. In sticking to its generic guns it wisely avoids advocating any individual platform, but also misses the opportunity to provide the necessary shortcuts and tips that would make using internet software more bearable for busy health professionals.

The discussion is organised around application areas: clinical care, continuing medical education, publishing, commerce, and so on. The contributors provide concise overviews of how the internet is currently used in medicine. There are valuable referenced discussions on the potential (and pitfalls) of using the internet to communicate with patients, other professionals, and in research.

No book covering the internet can be comprehensive. That means that the most important function of any such book should be to describe strategies for exploring it, but it is not until page 204 that the best search engine, Google, is mentioned, and its most interesting competitors (Teoma, Daypop, Vivismo) are not mentioned at all.

The internet is changing publishing, and the description of internet access to most journals as being like “a helpful librarian

leading you down a maze of corridors to the information you need, then asking you to pay for it” is apt. Will scientific authors really continue to give their work to publishers for free and then pay to get it back? “Of course for journals to survive they have to charge,” conclude section authors Godlee and Tamber. However, they shrink from one obvious conclusion—that paper journals may just die. It is perhaps ironic that there is no website of this book, something that is now routine in computer book publishing.

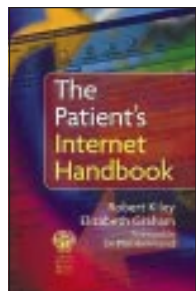
Paradoxically, I think this book will be more useful to technical people outside medicine than doctors themselves. An intranet developer could scoop a sample of the links and make an evidence based resource in a morning, for example. Software developers could use it to review the kind of applications and resources that have already proved valuable in medicine, and develop and extend those ideas in their own products.

Overall, though, the authors are to be congratulated: this is a cut above most medical internet guides in its ambition and scope, and orders what can often seem a chaotic field in a clear and educational manner.

Douglas Carnall *general practitioner, London*
dougie@carnall.org

The Patient's Internet Handbook

Robert Kiley, Elizabeth Graham



Royal Society of Medicine
Press, £9.95, pp 302
ISBN 1 85315 498 9

Rating: ★★★

Whether you're a patient or a health professional, *The Patient's Internet Handbook* can guide you through the internet's seven million websites to find quality health information at the touch of a button.

This book is designed to help patients ask the right questions at their next consultation and it begins with the basics of getting started on the internet. With clearly defined chapters and detailed examples, you can find out about

local support groups, professional information—including treatments—concerning a hundred common medical conditions, current evidence based research on a chosen topic, or compare hospital appointment waiting times.

I have shared tips and experiences with others who, like me, have eczema, and I have accessed the Royal Marsden Hospital's information on treating different types of cancer. And I discovered that my son was one of a total of 16 550 attendees to accident and emergency at my local Whittington Hospital between July and September last year.

I can now perform tricky advanced searches on the Medline database. However, I disagree with the book's statement that randomised controlled trials “produce more reliable conclusions” and would have liked more information on qualitative research sources.

Most women's first prolonged contact with healthcare professionals happens when they have their first baby. The dedicated chapter on this, with a special mention for the excellent National Childbirth Trust's website, responds well to this information need. And did you know that several interactive

tools can help you estimate your next ovulation date, create an online birth plan, find additional baby names, or tell you if you're going to have a boy or a girl (if your tummy looks like a watermelon, it must be a girl)?

This last tool should not be taken seriously, warn the authors, who offer necessary tips on how to evaluate the quality of health information on the internet and how to avoid the many sites with misinformation, which promise scams such as “slimming soap to wash away your fat.” Some sites even give outright dangerous advice, for example the promotion of hydrazine sulphate, an unproven cancer treatment, to people with cancer.

The idea of this handy guide is not to turn people into hypochondriacs (or cyberchondriacs) or to replace the advice that patients can get from their general practitioners. Instead it is to help people learn to treat the internet as a useful tool in order to become better informed patients and perhaps better informed doctors and health professionals too.

Cathy Neale *postgraduate student in health studies, Middlesex University*

The Regulation of Privacy and Data Protection in the Use of Electronic Health Information

An International Perspective and Reference Source on Regulatory and Legal Issues Related to Person-Identifiable Health Databases

Roberto J Rodrigues, Petra Wilson, Stephen J Schanz



Pan American Health Information, pp 217
To order, email rrodrigues@paho.org

Rating: 0

My first reaction on leafing through this book was excitement—at seeing sections on the law and practice of medical informatics in dozens of countries. E-medicine throws up many hard regulatory problems, and we should not all have to waste time reinventing the same square old wheels. For example, I am writing this in Boston, and last night had a debate with local medical ethicists about the definition of anonymous data. The United States is now learning the hard way about many of the problems with de-identifying data—and, in particular, how easy supposedly anonymous records can be to re-link with patients—that were debated in Britain in the mid 1990s and in Iceland shortly afterwards.

However, on a closer reading, this book is deeply disappointing. It may well be enlightening for healthcare IT professionals to compare notes internationally, but this book is not the vehicle for delivering that enlightenment.

Chapters one to three provide a discussion of basic medical informatics leading to some definitions. This discussion is generally weak. Terms such as “security,” “confidentiality,” “privacy,” and “access control” are given multiple inconsistent definitions and explanations within the same chapter, and then used inconsistently in the rest of the book. The multiple meanings of terms such as “trust” do not seem to be understood at all.

Chapters four to six sketch the international regulatory framework. This section appears aimed at explaining the origins and concepts of European data protection law to an American audience,

Items reviewed are rated on a 4 star scale (4=excellent)

and seems to do a moderately workman-like job.

The bulk of the book is spread over chapters seven to 11, which take almost 100 pages to describe medical privacy laws and issues in 51 countries. I am not aware of any previous survey encompassing this scope. However, the entries for countries with whose medical privacy issues I am familiar fall short of the mark.

The coverage of UK issues appears to have been culled uncritically from the Department of Health’s website. The coverage of Iceland is even less convincing; it describes the law that granted Decode its franchise without mentioning the controversy it generated, or the fact that 11% of the population opted out. Turkey is described in terms that suggest that it is a paragon of legal protection for medical privacy, while even a casual web search throws up masses of material on the persecution of doctors who provide confidential treatment for victims of torture, an issue with which the BMA has long been involved.

The coverage of the US, and the HIPAA (Health Insurance Portability and Accountability Act) regulations, is extensive, but manages to miss critical debates such as the definition of anonymous data. Is a medical record anonymous (and thus exempt from privacy protection) if it contains zip code, sex, occupation and date of birth, or must it be scrubbed down to year of birth? In other words, will the law protect the medical privacy of 20% of Americans, or 80% of them?

To sum up, this book appears to be an undigested compilation from a large number of sources, with a bias towards government PR. The editing is also appalling—there are many typos and grammatical errors, there is no index, and the last five paragraphs of chapter nine (from page 140) seem to have been displaced; they follow logically from the second to last paragraph of page 66.

I will not be throwing my review copy in the bin; rather, I’ll treat it as an annotated bibliography, but one in which both the selection of material and the annotations are deeply suspect. If I need to find out what medical privacy might mean in Latvia or Brazil, this is one of the sources I’ll consult—but not the only one.

Ross Anderson reader in security engineering, Cambridge University Computer Laboratory rja14@cl.cam.ac.uk

The BMJ Bookshop will endeavour to obtain any books reviewed here. To order contact the BMJ Bookshop, BMA House, Tavistock Square, London WC1H 9JR.
Tel: 020 7383 6244, Fax: 020 7383 6455
email: orders@bmjbookshop.com
Online: bmjbookshop.com
(Prices and availability subject to change by publishers.)

NETLINES

- The US based National Center for Infectious Diseases has produced a treasure trove of publications and resources that will be of great help to travellers and their healthcare providers (www.cdc.gov/travel/reference.htm). From details about cholera infected countries to a database of the sanitation inspections of international cruise ships (including a list of ships with unsatisfactory scores), there is a mass of information here. This is an amazing collection that should be a core reference point for global travel medical advice.

- From the Scottish Intercollegiate Guidelines Network (www.sign.ac.uk/guidelines/published/index.html) comes a well designed site with downloadable documents on a range of subjects, from day case cataract surgery to the control of pain in people with cancer. Helpfully the guidelines are grouped by specialty, and some are available directly to view within the browser, while virtually all are available as PDF files. This site is a model of how to distribute guidelines online.

- Clinical signs may not always be easy to interpret, but if you want help on nystagmus there is a useful site available (www.mrcophth.com/nystagmus/nystagmuscases.html). The information is clearly set out, with a link to a diagnostic flow chart. This site is an excellent clinical and educational aid.

- Sometimes it is educational as well as moving to read online diaries produced by patients or their families reflecting the ups and downs of their illness. At www.acor.org/ped-onc/homepages.html there are numerous personal stories of children with cancer, all organised by tumour type and broad age group. This is a stimulating way to share experiences and knowledge. It is also possibly therapeutic for the authors. Certainly for doctors it is an illuminating read.

- For a useful compendium of sites relating to evidence based practice and systematic review, have a look at www.cardiacrehabilitation.org.uk/Links/research_resources.htm. Many of the sites mentioned are well known already but it is useful to be able to access them all from one page. Helpfully each link is accompanied by a description and, although the host site looks at cardiac rehabilitation (worth a look in its own right), the resources on this page are of a general nature.

Harry Brown general practitioner, Leeds
DrHarry@dial.pipex.com

We welcome suggestions for websites to be included in future Netlines. Readers should contact Harry Brown at the above email address

Dots and dashes; zeros and ones

The Once and Future Web: Worlds Woven by the Telegraph and Internet

An exhibition at the National Library of Medicine, Bethesda, Maryland, until 30 July

The full exhibition is also available at www.nlm.nih.gov/onceandfutureweb

Rating ★★★

It allowed people to communicate almost instantly across great distances. It revolutionised business practice, gave rise to new forms of crime, and inundated its users with a deluge of information. Secret codes were devised by some users and cracked by others. The benefits of the network were relentlessly hyped by its advocates and dismissed by the sceptics. Governments and regulators tried and failed to control the new medium.

It was the telegraph, as described by Tom Standage in *The Victorian Internet* (Orion Paperbacks, 1999).

In "The Once and Future Web: Worlds Woven by the Telegraph and Internet" the US National Library of Medicine has mounted a compare and contrast exhibition, in which the similarities predominate. As well as filling the exhibition space in Bethesda, the complete exhibition is accessible from the library's website.

The route travelled by Samuel Morse's inaugural telegraphic message in 1844, "WHAT HATH GOD WROUGHT," passed only a few miles from the library's door. Within a few decades telegraph wires had crisscrossed the world, speeding up everything they reached: news gathering, commerce, manufacturing, war. The telegraph became a symbol of innovation and the quickening tempo of life, which is why the *Daily Telegraph* seemed such a smart choice for a newspaper title in 1855.

The telegraph's arrival sparked off waves of enthusiasm. As Anonymous wrote in *The Ladies' Repository* of 1848: "I conjured up . . . a vision of telegraphs . . . the whole land . . . covered by a perfect web of them . . . I saw our science, and philosophy, and arts, and religion, passing into the barbarous countries with the speed of lightning. The thrones of all tyrants tumbled down."

Patients, physicians, insurers, and drug manufacturers all made use of the telegraph for medical purposes, although it had only a limited range of applications. Unlike the internet, it required trained operators and was not directly accessible by the public. Sending or storing large amounts of information was beyond it. Nevertheless, the telegraph played an important part in transmitting messages that served the public health, conveyed important personal information, and sometimes even saved lives.

Probably the most famous example was the deliverance of an icebound Nome, Alaska, from the risk of an outbreak of diphtheria. The telegraph was used to alert the outside world and then to track a dog team's mercy dash with life saving serum. The episode was recycled in vaudeville acts, Hollywood films, and comic books.



How they brought the serum from Anchorage to Nome

Further up the cultural hierarchy, the world of the telegraph provided a rich source of metaphors. Physiologists compared the nerves to cables, the brain to a telegraph office, nerve endings to transmitters, thoughts to telegraphic messages, and the entire nervous system to a telegraph network. The metaphor also worked in reverse: writers often described the telegraph network as the nervous system of the nation or the world.

Login

Nobody thought to ask what God hath wrought when Arpanet, the world's first large scale computer network, went live in 1969. Its inaugural message was "login."

Medical applications mostly had to await the arrival of the world wide web in the early

1990s. Although the hype now surrounding the internet is reminiscent of that surrounding the early telegraph, the medical applications at the exhibition failed to live up to the hype.

Asthma and diabetes monitoring systems that allow doctors to access real time patient data don't sound like great clinical leaps forward. Similarly, relaying information from ambulances to the emergency room at the Maryland Brain Attack Center is undoubtedly clever, but what is this information that can't be more easily communicated by mobile phone?

There's a very unweb-like glorification of the centre at the expense of the periphery. The exhibition predicts that "one of the internet's most important medical uses will be to let physicians in remote locations consult with specialists at major medical centers," with online consultation and collaboration bringing "the expertise of leading specialists to distant locales." Examples include radiation treatment planning and paediatric echocardiogram reporting at a distance from the patient. No doubt these initiatives are being rigorously assessed by controlled trials and economic evaluations, using end points that matter to patients rather than to the electronic toys for the boys brigade.

A better place to look for how the internet might affect the future of medicine is a video clip of an interview with Mario Morino, who studies the internet and social change. Morino believes that tapping into the collective intelligence of thousands of people using the web could provide a new model for problem solving.

"The power of bringing together the right minds around a subject in an online dialogue, well facilitated, well deliberated, has enormous potential to help us get through issues that we've never solved before. You see this embodied in the open source model for software creation. But that same model could apply to policy issues, social issues, educational issues."

Initially, I saw the exhibition in Bethesda, but to make sense of my more illegible notes I accessed the exhibition from the library's website. The ability to check the exhibits, days later, from thousands of miles away, is a great plus, although there's nothing quite like seeing a real Copyleft T shirt, with the code for cracking DVD encryption printed on its back.

The heyday of the telegraph lasted less than 50 years. For most of this time it was inconceivable that anything better could come along.

Tony Delamothe *web editor, bmj.com*
tdelamothe@bmj.com

PERSONAL VIEW

A day in the life of a stalker's victim

I expect that under everyone's serene exterior lie untold secrets. Mine relate to my stalker. Superficially, the humdrum of life continues, with routine largely unruffled. Underneath, however, even though my stalker interferes far less in a physical sense than in previous years, the problem never goes away.

It is now more than four years since I realised that a patient had begun to follow me. While on my list, the patient led me a merry dance of lies and bizarre behaviour. When I finally realised that this saga was all a fabrication and removed the patient from my list, the stalking began. This is where my sense of control left me. How do you apply rational thought to something illogical and unpredictable? Such is mental illness. I can only understand it in the following terms: the stalker had made such an emotional investment in this fantasy world of which I had become a part, that it was too great to be abandoned.

The questions began early on. What constitutes stalking? Being followed in a car sounds straightforward enough, or was it coincidence? I've given up on the idea of coincidence with this person, but when I have reported the behaviour to the police, frightening episodes have suddenly sounded incredibly mundane and ordinary—hardly a threat and quite possibly coincidence.

"Keep a log," I was told. My log now reads like the obsessive diary of a sad intro-spective.

"Was walking outside my house."

"Was walking by the traffic lights on the school-run route."

"Was standing at the end of my childminder's road."

The childminding bit is the one that got me. Dabble with me if you must, but you can leave my kids out of it. This is where anger really crept in and why I remain anxious. The police were very helpful at this stage—there's nothing like a child protection issue to generate an initial response. But police action can be remarkably slow—weeks for an arrest, while my mind was in turmoil.

At this stage, when activity from the stalker was frequent, and I felt goaded into some sort of action and could no longer ignore it, I found myself dipping into the realms of paranoia. I examined every car, studied every number plate, my stomach lurching if I glimpsed an abnormal loping gait. I remembered the phrase "Just because

you're paranoid doesn't mean they're not out to get you." Often my anxious gaze would find not reassuring strangers, but that face again.

I tried a helpline. I wanted a good kick up the behind, I thought; pull myself together, put things back in perspective. After all, the stalker wasn't even particularly threatening—just notes, silent phone calls, frequent followings, and sightings. Not the stuff of Hollywood. The helpline was laughable. The paranoia from the other end of the line certainly put my anxieties in order—the counsellor was a victim who had suffered considerably more than I had. It was questionable who needed the counselling.

I came away confused but relieved. To interpret the messages I had received as death threats—as the helpline had suggested—would have been absurd. Yet in an odd way, the helpline did give me support. It raised two choices in my mind. I could fall in love with the glamour and intrigue of having a stalker, or I could try much harder to gain perspective, assess the actual risk posed to me and my family (which is probably pretty low), and take control of the endless ruminations in my head.

Practical help was still variable. An injunction would have cost me over £1000 and make little difference. All attempts to get psychiatric help to the patient failed. Although the police were supportive and the Harassment Act of 1997 gives some scope for a legal response, the police were reluctant to take the stalker to court, saying that there was insufficient evidence. However, being arrested modified the stalker's behaviour to some extent. In fact for a few months I even thought the stalking had ended.

But therein lies the problem. It is just as with people with cancer who hope that surgery has cured them—they cannot know for sure. Just as their physical scars remind them of the trauma of surgery, pain in the operation site brings back fear of the disease, and follow up appointments reawaken their and their families' anxieties, so my "ailment" is frequently at the front of my mind. That car! There are cars like that everywhere, and so my number plate checking continues. I feel guilty if I need to visit patients near the stalker's address—am I secretly asking for more trouble? I hesitate to stick to old routines.

Looking back, is there a sense of winning or losing? Perhaps winning, in as far as my faith in patients has not really altered. Bizarre stories (common in my line of work) do not make me assume the patient is mad or manipulative. I realise that uncertainty is here to stay—should I ignore the current low key intrusions or should I come down on them like a ton of bricks? I just don't know and so do nothing.

I feel guilty if I need to visit patients near the stalker's address

SOUNDINGS

The basics

Once, a long time ago, I was buttonholed quite politely in the hospital dining room by a young anaesthetist I vaguely knew. He asked me to come and see an old man in intensive care who was very frail and very ill: but for where he was, he would have been dead already. No doubt there are excellent protocols now, and these things are well ordered within clinical governance, but what my young colleague needed then was someone already labelled consultant to say enough was enough. We agreed what was needed: comfort, dignity, and peace at the last.

More recently, in a ward where my responsibilities are far better defined, a frail and muddled elderly lady became quite unwell. A neurosurgical problem was suspected, though not by me. Some ambitious investigations were being planned in a hospital an uncomfortable ambulance journey away. The diagnosis was unclear but infection seemed more probable. We investigated lightly and treated vigorously. She did well.

Our trainees come to us highly skilled in diagnosis and intervention. For some, the most difficult lessons of the first few months are those of restraint: when not to do all the wonderful things they have spent the last three or four years honing to perfection. It takes time, but the dawning of compassionate realism is wonderful to watch.

Each month our students are asked to identify from their various attachments cases for discussion that demonstrate social and ethical issues arising in relation to the care of the elderly. From time to time the debate focuses on activism towards the end of life. Yes, even the frailest patients can benefit from the most sophisticated investigations and interventions; but occasionally our students seem to suspect that zeal goes untempered by judgment. In discussion both hawks and doves fly free. So we revert to the basic principles: beneficence, non-maleficence, autonomy, justice. Sometimes they help. Difficult cases remain difficult.

But only up to a point. Once, a long time ago and as a distinctly underdone registrar, I was left with unusual responsibilities when the unit's two consultants headed for a specialty meeting on the other side of Scotland. As they set off, the senior man wound down his window. "Colin, my boy," he said—for that is how juniors were addressed in those days. "Heal the sick... Comfort the dying..." His blue eyes narrowed a little as the car drew away. "And don't get them mixed up."

Colin Douglas doctor and novelist, Edinburgh

If you would like to submit a personal view please send no more than 850 words to the Editor, BMJ, BMA House, Tavistock Square, London WC1H 9JR or email editor@bmj.com